ALL ABOUT PREMATURE BABIES
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CHAPTER FIVE

1. HOW BREAST MILK HELPS PREMATURE BABIES? ......................... 96
2. EXPRESSING BREAST MILK FOR THE BABY – ALL THE ANSWERS TO YOUR QUESTIONS .................................................. 99
3. MY BREAST MILK SUPPLY HAS SUDDENLY DECREASED – WHAT TO DO? .......................................................... 109
4. I HAVE A SLOW BREAST MILK FLOW AND IT IS NOT INCREASING – WHY? .......................................................... 111
5. HYGIENE AND STORING BREAST MILK FOR PREMATURE OR SICK BABIES .......................................................... 113
6. BREASTFEEDING A PREMATURE BABY – HOW TO BEGIN, WHAT TO EXPECT, HOW TO DEAL WITH THE PROBLEMS YOU EXPERIENCE? .................................................. 115

CHAPTER SIX

1. FINALLY AT HOME! THE DISCHARGE – EVERYBODY HAS THE RIGHT TO HOLIDAY! .................................................. 127
2. WHO CAN HELP YOU WHEN THE BABY IS ALREADY AT HOME? ........................................................................... 130
3. IF YOUR BABY IS NOT FEELING WELL? .......................................................... 132
4. WEANING OF THE PREMATURE CHILD .......................................................... 140
5. LOCOMOTOR DEVELOPMENT OF THE NEWBORN BABY AND PECULIARITIES OF PREMATURE INFANTS ........................................ 144
6. PROPHYLACTIC EXAMINATIONS .......................................................... 152

CONCLUSION ....................................................................................................................... 158

ORGANISATIONS THAT CAN BE OF USE .......................................................... 160

WHO ARE WE AND HOW YOU CAN SUPPORT US .................................................. 161
~ INTRODUCTION ~

Expecting our baby – this is an incomparable experience we, the mothers, are endowed with. To feel the new life coming into existence in the womb is a moving, exciting and touching feeling, which makes you dream and see the world in pink. In her consciousness, every mother imagines her beautiful, healthy and cuddly baby – the first happy moments together, the first touch, the first hug. However, things not always happen the way you have planned them. Sometimes the baby is born much earlier than expected.

‘Your baby is premature! The first 48 hours are critical. At this stage we cannot give a prognosis.’

Usually these are the first words you hear after a baby is born prematurely. Thousands of questions rush into your consciousness – ‘Did he/she cry? Does he/she breathe? What can I expect? Will he/she live? What is the meaning of these complex terms used to describe our baby’s condition? Why did all this happen? What are the chances of the baby to survive and be healthy?’ Thousands of questions the answers of which you are desperately trying to find. You are overwhelmed with helplessness, fear of the unknown, feeling of guilt, sadness, even with anger… a whirl of emotions, which leave you helpless and tighten your heart every minute, while the most precious thing in your life – your child – is somewhere there, alone, tied up in wires, hoses and complex medical apparatuses.

When I gave birth to my daughter in the 31st gestation week and her weight was only 1440 grams, my whole world collapsed. I was completely unprepared and did not know what to expect. There was nobody to answer my questions, I was feeling all alone and everything seemed hopeless to me. Today my child is a proof of the fact that there is nothing impossible in this world – she made me believe in wonders and showed me that despite their helpless appearance, premature babies are extremely resilient and strong.

You are faced with difficult times full of ups and downs, hope and despair, successes and failures. However, you should never stop believing that everything will develop in the best possible way. Our premature children have unexpected will to live and you yourselves will get convinced that the youngest ones are the greatest heroes.
In the pages below, we try to answer most of the questions you might be asking yourself and we hope that this will make you more informed, calmer and more confident. A part of the information might frighten you, but we believe that it is in the interest of our children that we are informed about and prepared for what awaits us so that we are able to do what is best for them.

All of us from the Foundation ‘Our Premature Children’ are parents who have been faced with this test. It is namely the experience we have gained that motivates us to help other families like ours. We hope to be useful. Do not hesitate to connect us if you need additional information or just support.

Respectfully yours,
Nadya Drenska
Foundation ‘Our Premature Children’
~ CHAPTER ONE ~

1. Why was my baby born earlier?  
   Reasons for the premature birth
2. Why does my baby need special care?  
3. Medical terminology: prematurity and birth weight
4. Resuscitation
5. Transportation to another hospital or special care unit
1. Why was my baby born earlier? Reasons for the premature birth

The normal duration of pregnancy is about 40 weeks. It is not until then that the newly born child is completely ready for life outside the womb. However, sometimes the baby happens to be born earlier than expected. This might pose many risks, but the good news is that nowadays medical science has reached such a high level that it is possible to save earlier and earlier born babies.

The more advanced the week in which a baby is born, the more mature their organism is and the greater the chances for them to cope with life outside the mother’s womb are. Nevertheless, premature babies need special care, qualified medical specialists and modern equipment that can provide them with the best development. Some babies stay in a hospital for months, until they reach the growth and development that is necessary to allow them to get home without the need for medical care.

As parents, we are never prepared for such a situation. Perhaps you are not either. You are facing a huge challenge, which makes you confront a painful reality, where you start counting every minute, every gram of weight gained and every small victory won by your child, instead of being overwhelmed with joyous euphoria caused by the birth of your child. In addition, you are eagerly waiting for the cherished moment when all of you can get home together.

Do not lose heart and do not stop believing, even for an instant, that everything is going to be all right. The dozens of stories on the website of the Foundation ‘Our Premature Children’ (www.premature-bg.com) will convince you how willing to live and ready to fight these little heroes are.
Main Reasons for Premature Birth

**Vaginal infections**
One of the most common causes of premature birth are the vaginal infections such as chlamydia, trichomoniasis, mycoplasma, toxoplasmosis, bacterial vaginosis, etc. Normally, the uterus is sterile, but every inflammation makes its walls dysfunctional, so pregnancy continues until the walls of the uterus can be stretched, with the body trying to get rid of the foetus after that.

**Viral infections**
Rubella, cytomegalovirus, herpes, influenza, adenovirus infection.

**Non-typical attachment of the placenta**
The so-called placenta praevia.

**Multiple pregnancies**
They pose a risk of premature birth, although there are cases of post term of twins. The birth of a premature baby can occur in 75% of women who become mothers for the first time and in 45% of those women who had given birth before. This is due to the fact that, as it is stretched more than usual, the uterus contracts more easily. Examinations should be made every 15 days, and the pregnant woman should rest as much as possible upon entry into the seventh month.

**Age factor**
Pregnancy is considered risky in young women at 14 to 18 years of age, as well as in patients over 35 years of age.

**Chronic diseases**
Both good prenatal care and strict follow-up by a specialist are required in case the pregnant woman has got any disease such as hypertension, cardiovascular diseases, anemia, diseases of the lungs or liver, etc.

Particular caution should be paid by women who have chronic and acute inflammation of the uterus; endometrium; those who have had abortions and those who have had a miscarriage. A present inflammatory process should be cured immediately.

**Shock, trauma, excessive exercise**
These are also factors that can contribute to premature birth.
Cervical insufficiency
The second most common cause of premature birth is the cervical insufficiency (CI). CI is an anatomical abnormality of the muscles of the cervix in the region of its internal opening.

CI can be congenital (very rare) and acquired. Its development can be caused by a trauma to the cervix during previous abortion as a result of the use of metal tools. It may also be due to ruptures of the cervix in previous births (with large foetus or when using obstetric tools), and coarse extension of the channel during examination of the uterus. Often, CI occurs with increased levels of testosterone in the blood. In congenital conditions, the main reason for the occurrence of CI is a defect in the muscle tissue.

As a result, the internal opening of the cervix cannot endure the growing foetus during pregnancy, the cervix opens and miscarriage or premature birth occur.

Pre-eclampsia
Pre-eclampsia is characterized with high blood pressure (hypertension), swelling and intumescence of the hands, ankles and face, rapid gain of weight (1.5-2 kg per week) and sleep disorders. In fact, these are only the visible signs that there is something wrong in the woman’s body. The increased level of proteins (albumin) secreted by the kidneys into the urine and severe headache are typical of pre-eclampsia. Known also as „toxemia“ (presence of toxic substances in the blood), pre-eclampsia typically occurs in the last trimester of pregnancy and is developing very quickly.

Kidney function is impaired, and the proteins of the blood are carried into the urine. With deterioration of the condition, several other vital organs are affected, including liver, lungs, heart, and blood clotting. Dangerous complications occur, such as eclampsia (convulsions), brain hemorrhage, pulmonary oedema (due to fluid in the lungs as a result of abnormal heartbeat), liver damage and blood dilution. Fortunately, these complications are rare.

In preeclampsia, the blood supply to the placenta may be compromised. This is dangerous, since if the placenta does not get enough blood, the baby does not receive enough oxygen and nutrients. This may be the reason for a lower weight at birth (hypotrophy) and other problems for the baby. Caesarean section should be undertaken in serious adverse intra-
uterine conditions. Taking such a decision is hard, the situation must be assessed calmly and the following questions should be answered:

1. What is the status of the mother?
2. What are the risks for her if the pregnancy continues?
3. What are the chances of the baby to survive?

**Gestational diabetes**

Gestational diabetes is one of the most common metabolic diseases, which occur during pregnancy. It is caused by elevated blood sugar levels and can have serious short-term and long-term adverse effects on the mother and the baby. Most of the pregnant women with this disorder deliver healthy, full-term children. Adverse effects can be reduced through appropriate care – timely diagnosis and proper treatment, dietary regime and physical activity, as well as proper behavior during and after birth. Poorly controlled blood sugar levels can lead to serious consequences.

In some situations, giving birth is induced earlier to save the life of the mother and the baby. The reasons for this can be chronic diseases of the mother, pre-eclampsia, placental detachment and others.
There are many different reasons why babies should be admitted in intensive care unit, but the most common cause is premature birth.

Nature has provided for 40 weeks, during which the baby to develop, feed and grow in the womb. Earlier born babies are too small and their bodies are too immature to survive independently without being subjected to special care. The reasons for this are, that babies are often born with very low weight, almost no subcutaneous fat, which is why their thermoregulation is extremely immature and they alone can not maintain normal body temperature. Often, the lungs are unfolded, so that premature babies can not breathe on their own and require additional oxygen supply. Premature babies do not yet have sucking and swallowing reflex, which requires them to be fed parenterally – via injecting of nutrients in the form of solutions directly into the blood.

Sometimes, even full-term infants need to spend some time in the intensive care unit of the neonatal wards. This handbook is aimed primarily at premature babies, but it can help you even if your baby was born full-term, but is in hospital because of a serious illness or medical condition.

Many babies born at term, who require special care or need surgery, will spend some time in the intensive care sector. The main reasons are:

**Jaundice**
Some babies need phototherapy (light therapy) for jaundice. It is usual even in otherwise healthy infants.

**Breathing problems (Respiratory Distress Syndrome)**
This condition most commonly affects premature babies, but can also affect full-term infants. For example, maternal diabetes during pregnancy
and birth by cesarean section are two risk factors associated with respiratory distress syndrome.

**Problems diagnosed with ultrasound during pregnancy**

Sometimes ultrasound examinations during pregnancy show physical problems that are treatable with surgery only after the baby has been born. Such examples are the incomplete development of the esophagus and the trachea.

**Questions that you may ask:**

1. Why was my baby born so early?
2. How serious is the condition of my baby?
3. What tests and treatments does my baby need?
4. Should the baby be transported to a specialized hospital for treatment, surgery or intensive care?
5. How soon will my baby feel better?
6. Will my baby need intensive care after the date of the term?
7. What outcome can I expect for my baby?
8. When will my baby come home?

**Our baby is not such we expected?!**

Many parents say they are ambivalent in their first meeting with their child. Depending on how early your baby is born, as well as on how serious its condition is, you are likely to be shocked when you see it for the first time. Premature babies are usually quite tiny and with almost no subcutaneous fat. They look much different than most full-term babies who you might have seen. This is due to the fact that your baby is in a different phase of its development as it is born early. The difference comes from the fact that you see your baby in a phase of development, during which, in normal circumstances, it should still be in your womb.

**What does the premature baby look like?**

Some premature babies are so tiny that they can fit in your palm, and their hands and feet can pass through a wedding ring. Many premature babies are covered with fine hair called lanugo. This hair is normal.
It is stimulated by maternal hormones while a baby is in the womb. It will disappear soon.

At the beginning, the skin of your baby may look like wax. Probably it is also transparent, as the baby has almost no subcutaneous fat. Therefore, it is possible to see the fine network of its blood vessels. Due to the lack of fat tissue, which has the function of maintaining the heat, these infants are unable to maintain their body temperature.

Cheek bones and bones of the head of premature babies are very soft. The ears are sometimes flat, curved or sagging, since the cartilage, which gives them their form, is not yet formed.

It is possible that the head of your baby could be deformed if standing too long on a flat surface in the incubator. The team that takes care of your baby changes the position of his body and puts it in the correct position to avoid such deformity. The moment your baby is mature enough to go home, these bones are strengthened and thus will be healthier and with
greater firmness. Foundation “Our premature children” has provided some neonatal intensive care units (NICUs) in the country with anatomical seats for premature infants. They can prevent such deformity, and many other adverse effects from the long stay in an incubator.

Sexual characteristics usually are not fully developed – it is possible that the testicles have not descended, there might be a lack of areola around the nipples, etc. It is also possible, that many normal reflexes (grasping, sucking, swallowing, etc.) are still missing, since the development of muscles and the nervous system is not complete. Usually, premature babies do not cry at all or do that very little at the beginning.

Nevertheless, all this is temporary. When your baby reaches the date of the eventual birth term, it would probably look almost like term newborns with similar to its weight.

“She was so fine, so incredibly tiny... I could not hold her properly in the first two weeks. I was shocked when I saw her for the first time,. I could not believe it was possible for a baby to look that way. It both frightened me and made me feel sweet. I remember well, that the first time they let me hold her, I was overwhelmed with amazing sensations. I had the feeling that she was made of porcelain and will break any moment. It was amazing when I held her properly for the first time. I thought it was impossible ever to deal with it.”

L.M., mother of Laura, who was born at week 26
According to “Neonatology” medical standard: “A premature newborn child is born at gestation term less than 37 gestation weeks (less than 259 days).” A week during pregnancy is called a gestation week. There is no difference between gestation week and calendar week.

<table>
<thead>
<tr>
<th>Lunar Month</th>
<th>Gestation Week Range</th>
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</thead>
<tbody>
<tr>
<td>1 lunar month</td>
<td>from 1 to 4 gestation week</td>
</tr>
<tr>
<td>2 lunar month</td>
<td>from 5 to 8 gestation week</td>
</tr>
<tr>
<td>3 lunar month</td>
<td>from 9 to 12 gestation week</td>
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<tr>
<td>4 lunar month</td>
<td>from 13 to 16 gestation week</td>
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<tr>
<td>5 lunar month</td>
<td>from 17 to 20 gestation week</td>
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<tr>
<td>6 lunar month</td>
<td>from 21 to 24 gestation week</td>
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<tr>
<td>7 lunar month</td>
<td>from 25 to 28 gestation week</td>
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<tr>
<td>8 lunar month</td>
<td>from 29 to 32 gestation week</td>
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<tr>
<td>9 lunar month</td>
<td>from 33 to 36 gestation week</td>
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<tr>
<td>10 lunar month</td>
<td>from 37 to 40 gestation week</td>
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<tr>
<td>First trimester</td>
<td>from 1 to 12 gestation week</td>
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<tr>
<td>Second trimester</td>
<td>from 13 to 28 gestation week</td>
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<tr>
<td>Third trimester</td>
<td>from 29 to 40 gestation week</td>
</tr>
</tbody>
</table>
According to the weight at birth, premature babies are divided into three groups:

<table>
<thead>
<tr>
<th>Weight Category</th>
<th>Weight Range</th>
</tr>
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<tbody>
<tr>
<td>low weight</td>
<td>up to and including 2499 grams</td>
</tr>
<tr>
<td>very low weight</td>
<td>up to and including 1499 grams</td>
</tr>
<tr>
<td>extremely low weight</td>
<td>up to and including 499 grams</td>
</tr>
</tbody>
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The state of prematurity can prompt us what to expect with regard to adaptation of the newborn and possible problems later, but also determines the behavior of doctors in their treatment and the extent of resuscitation.

In recent years, we have seen a continuous improvement in the care for children with very low weight, and those below 1000 g. Very good results have already been achieved, following the experience gained in the preservation of the life of newborns with extremely low weight.

Any premature baby has a chance to survive, heal, grow and develop normally. Each of them brings its individuality and uniqueness. The cases, where newborns with very low, even extremely low weight at birth, adapt and overcome the neonatal period without serious deviations and complications, are not rare. In other cases, in more mature and of higher gestational age infants, some severe diseases are observed and there is a need for regular follow-up and eventual treatment.

Not only normal physical and neuro-psychological development, but even geniality can be achieved with adequate care for these children. One should not forget that Darwin, Newton, Jean Jacques Rousseau and Volter were all born with low weight.
High quality neonatal resuscitation plays a key role for saving premature babies and reducing the risk of disabilities. Resuscitation is not necessary in the majority of the newborns – they adapt to life outside the womb without substantial additional support.

Unlike full-term babies, the premature newborns (about 6% of all and 80% of those born weighing less than 1500g) require different volume of primary resuscitation in the delivery room. It is carried out by a team including: a neonatologist (if necessary, a second doctor is included), an obstetrician, a midwife, and a nurse.

In Bulgaria, according to the Neonatology standard, all rooms are equipped with facilities for primary resuscitation of newborns. Resuscitation in the delivery room is done following unified protocols, mandatory for all involved in this process.

**Preparation before birth.** It includes heating the reanimation table, an aspiration system, and the provision of oxygen.

**Steps of neonatal resuscitation – „The Golden Minute“:**

- Patent airways
- Effective breathing
- Heart rate, circulation
- Medications
- Review and assessment

**Immediately after birth**, the premature child is taken away and dried with a warm blanket. It is placed of resuscitation table with a direct heating source. The nose, the mouth and the stomach are aspirated (cleaned) with
a small suction catheter. A sensor is attached to the hand or the leg, by which the cardiac function and oxygen saturation in the blood in the first minutes after birth are being followed. The neonatologist evaluates further treatment, depending on the condition of the premature baby, as the most important indicators are **breathing and cardiac function**. Premature babies, and especially those born weighing less than 1500 g and before gestation week 32, are usually not able to show effective spontaneous breathing.

Depending on the child’s condition, the neonatologist takes the following actions:

1. **Mechanical stimulation**: smoothing movements with fingers along the spine, on both sides of the breasts, massaging the feet.
2. **Oxygen delivery**.
3. **Ventilation with oxygen mixture via balloon (Ambutype) through a facial mask**. It fits tightly to the face, covering the nose and mouth of the child. If the child is breathing independently but should be supported, shorter tubes called nasal cannulas can be put in place. They fit tightly to the nostrils and a heated air mixture, enriched with oxygen, is delivered to the child through them.

Another way to assist the breathing of a premature baby (especially with a weight of less than 1500 g) is **intubation** – a tube is introduced via the nose, less frequently orally, into the trachea, which is then linked to a pulmotor. In this way, the breathing of the baby is done by the machine, which supplies warm air-oxygen mixture and ensures unfolding of the lungs.

The second important indicator that the neonatologist tracks is **the cardiac function** of the baby. Usually, providing optimal breathing leads to a normalization of the heart rate. If it does not happen and the heart rate remains below 60 / min. or between 60-80 / min. the following shall apply:

A second doctor or resuscitator starts performing **external cardiac massage** of the baby following a strict protocol. Based on the achieved result, the **administration of medicines** during the primary resuscitation in the delivery room is being considered. An intravenous route for their application is provided.

**After initial stabilization** of the basic vital signs of the baby, it is transferred into **Intensive Care Unit or a Special care sector for newborns**, in a pre-warmed incubator without interrupting respiratory support and reporting of
heart rate and saturation of blood oxygen (via monitor). There, the newborn is placed in a prepared personal incubator. Maximum sparing treatment and diagnostic procedures are performed there after the normalization of body temperature.

**Who will inform you about the condition of your newborn baby and when?**
The resuscitation of your baby is carried in the delivery room. According to your condition, you may see who is taking care of the child, how it looked after birth, what type of care is undertaken, etc. When birth was done via surgery (by Caesarean section) or you have been applied anesthesia immediately after birth, the fear of the unknown is even stronger.
The neonatologist will come to you once they had finished performing urgent care for your baby and its admittance in the department. You will get from them the following information about the child: gender, weight and height at birth, in what state it was born, what type of care and resuscitation measures had to be done, how is the baby now, where it has been admitted, what is to follow - treatment, tests, what to expect and what is the approximate timeframe. It is better if this information is given in the presence of both parents. If the condition of the mother does not allow it, the first report about the baby is given to the father.

It is a common practice to allow the father to see his child, should he wishes so. It is necessary, that he had been previously prepared in brief for the technical characteristics of the atmosphere in the intensive care sector (light and sound signals, equipment, personnel, etc.), as well as for the look of the child. In this way, he will be able to describe it and tell the mother about the baby. Once the mother is stable, she is allowed as early as possible to see her baby, to touch it and caress it. The neonatologist will give you information about its current state, what treatment was applied, what tests have been done and their results, as well as what the future actions are. You should ask your questions, what is not clear, get yourself informed on the internal order in the department, relating to access to information and to the baby.
The best means of transportation for the premature child is “in utero”, i.e. directing and transporting the pregnant woman to a specialized neonatal delivery department. Unfortunately, this it is not always possible. Transportation of a newborn premature baby is a very responsible activity.

**Who organizes and carries out the transport of the premature child?**

The neonatologist / pediatrician, who was present during birth, takes the first care and resuscitation of premature child. They assess the need for transporting the child, based on the regulations in accordance with the requirements for transferring preterm infants (according to the Medical standard of Neonatology). Depending on the condition of the infant, this can happen in emergency or to be planned for an appropriate time. The doctor organizes the transportation of the baby, contacts the respective hospital and hospital ward, presents the case and agrees approximate time of arrival of the child. During transportation, which is accomplished with fully equipped ambulance, care and monitoring of the baby is a responsibility of a doctor. When necessary, e.g. twins, a nurse / midwife can be added as a second member of the team.

**Why should my child be transported?**

Neonatal wards in our country are organized into three levels of competence according to number of births, medical equipment availability, personnel, and the history of already performed medical activities. Transportation of the premature baby is necessary when it needs a higher level of neonatal care - assisted ventilation, surfactant treatment, prolonged intensive care, tests, monitoring and others. Your healthcare professional will explain what
requires the transfer of your baby.

**Why is it so important when and how it will be transported?**
Depending on the condition of the baby, in some cases, the transfer must be done as quickly as possible. This is vital when the baby has hindered vital functions or deterioration of the condition. The doctor provides optimal preparation for transport – assisted ventilation and/or oxygen if necessary, optimum body temperature, venous access, stable cardiac activity and others. Timely, and in a stabilized condition, transfer of the baby is important for the favourable influence on its condition and for the prevention of possible later negative consequences.

**Can I see my child before transportation?**
Yes, depending on the condition of the mother after birth. When she is incapable of seeing it, the father and/or close relatives have the right to see the child. After receiving information about the baby, the reasons necessitating transfer, and get awareness of the risks of transport, parents/guardians sign an informed consent form for the transport.

**Who will take care of the baby during transport?**
Transport and monitoring of the newborn is always carried out by qualified personnel – a doctor with or without a nurse. Skin colour, breathing, cardiac activity and other indicators are monitored during transportation. The required equipment set that is specifically designed for the transport of newborns is available for this purpose.

**Who and where will admit the baby?**
Parents are carefully and fully informed about the hospital, the department, and the clinic where the baby will be transported. They are also informed about the name of the doctor who is familiar with and prepared to meet their baby. It is helpful if this information is given in a written form – an address, a ward, a doctor, a telephone contact number and time in which they can receive information about their child. The doctor who has transported the baby gives feedback to the parents about how the child has tolerated transportation and where it has been admitted.

**Who will inform me and will I be able to see my child after my discharge?**
In line with the established internal regulation of the respective department, the parents receive daily details of the child. After the mother has been discharged from the maternity ward, she could see her child during visit
times. In emergency admittance from another hospital, regardless of the time during the day, the parents (usually the father) are given information by the doctor who has admitted the baby. It is necessary that you show understanding and patience for some time, which is required of the medical team to admit and take care of your baby. Sometimes, it is necessary to carry out urgent tests, procedures and activities in connection with the life and health of your baby. Once the doctor has taken the necessary urgent measures, he will inform you about the child’s condition. The practice in most departments is allowing the father to see the baby. That is how he will get an idea where it is placed, how it looks, etc.

**Is there any danger to the health and life of the baby during transportation?**

Depending on the child’s condition and the degree of immaturity (birth weight, gestation weeks, etc.), there is danger to the life and health of the child. Other important factors are: the remoteness of the hospital in which the baby will be transferred, degree of the child’s condition stability (basic life functions – breathing, heart rate, body temperature, etc.), available and working equipment for the transport of newborns, delays in transportation due to objective circumstances and so on. That is why, transporting the baby is done only if absolutely necessary and following the assessment of the treating physician.

**When to transfer a child in the special care unit?**

A “special care structure” is a separate unit in neonatology. It treats premature infants who have received intensive care, preterms who require an extended period of special care, and who are without pathological conditions until reaching discharge weight. It may be within the NICU. In these cases, when your baby is ready to be taken care for at home, it will be discharged by the NICU. In some cities of the country, there are separate special care units or medico-social care homes for children.

After stabilizing the child’s condition and the absence of a direct threat to the life of your baby, it can be transferred in such a department. Care, treatment, nutrition, tests, monitoring and others are continued there. A qualified medical staff of doctors and nurses / midwives is taking care for the child. Information, visits and parent education are being carried out according to the established internal regulations of the unit / home.

Decision making, organization, implementation and quality of neonatal transportation are essential to protect the lives and health of premature
babies, as well as to minimize the possible late consequences for the child. It is carried out by qualified medical personnel, according to the standard for neonatology in our country. This document regulates exactly: the basic requirements for the implementation of intra-hospital and inter-hospital neonatal transport, the indications for transfer, the organization and the equipment.
~ CHAPTER TWO ~

1. Equipment in the NICU: what does what?
2. Medical staff: who is who?
3. The established order in the NICU
4. Common medical procedures
5. Family focused care
1. EQUIPMENT IN THE NICU: WHAT DOES WHAT?

You may feel shocked initially, seeing all the medical equipment, which they treat your baby with. Noises, beeps, clicks, alarms and flashing lights from the machines seem strange at first, but over time, you will become familiar with the equipment and learn how each device helps your baby.

There are many different types of technology devices in the intensive care sector of a NICU, including various types of ventilators, monitors and life support devices. Below you will read some more detailed information that can help you identify the types of equipment in the NICU.
**Scales / E-scales**
The scales may not be one of the most modern equipment in the NICU, but is one of the most important. Each meal, either intravenous or medication one is pre-calculated, based on the weight of your baby. That is why it is vital that the weight is accurate, timely, and accessible at any time of day. Measuring the weight of your baby is one of the main morning tasks in the NICU, the child is measured at the same time and in the same way every day. Then the weight is recorded in its health card. The net weight is consistent with the weight of the diaper as well as any medical equipment attached to your baby. Usually, it is recorded in grams and is calculated with accuracy of up to +/- 5 grams.

**Cardiorespiratory monitor**
This is a device which recognizes the cardiac and respiratory activity. Sometimes, it is called cardiac activity monitor. Adhesive patches, connected by cables, are put / stuck to the breasts, abdomen, arm or leg of the baby. The cables are connected to a device that records cardiac activity of the baby, heart strokes per minute and the number of breaths. If the heart rate or breathing of your baby are too fast or too slow, the machine will notify a staff member via an alarm.

**Equipment, assisting baby’s breathing**

> When a baby is born too early, the lungs are often not developed enough to be able to breathe independently. Some premature babies have a need for additional assisted ventilation for a few days, some babies need the most modern ventilators for weeks, and there are such babies who need those even for a few months.
**Oxygen and oxygen mask**
Oxygen can be provided directly in the incubator of the premature baby or through an oxygen mask and is often used when the child can breathe independently, but still needs supplemental oxygen.

**Nasal cannula**
This is a plastic tube which passes behind the ears and ends with two nozzles, which are inserted into the nostrils of the child. The nasal cannula is attached to the oxygen cylinder or to a portable oxygen generator, or to one that is attached to the wall in the hospital, via a tube, in which oxygen flows through the two tubes delivering supplemental oxygen to the premature baby. Low-flow oxygenation –this is a method for supplying oxygen to the baby via a thin, soft, plastic tube placed in the nostrils. The tubing is attached to the baby’s nostrils and oxygen is delivered through small holes that are placed just under the nose of the baby.

**Moisturizer**
When the premature baby needs additional intake of oxygen, often both the air and the oxygen go through a moisturizer first. It helps through moisturizing and warming oxygen.

**CPAP**
Continuous positive airway pressure. Many premature babies need help with breathing. One or two plastic tubes are placed in the baby’s nostrils and oxygen is provided under pressure in small quantities. Providing oxygen under pressure helps the lungs remain expanded and reduces the efforts.
that are necessary for your baby to breathe. To ensure that the pressure / oxygen enters the respiratory tract of the baby, it is important that the mouth is closed. Sometimes, this is achieved with the use of a small leather strap. It keeps the airway open during sleep and prevents breathing pauses in infants with apnoea and other breathing problems. The mask does not breathe instead of your baby, the air flow is under such a pressure that is necessary for your baby’s breathing.

**Ventilator**

If the CPAP is not sufficient to support your baby’s breathing, a small plastic tube (ETT – an endotracheal tube) is inserted through the nose or mouth of the baby into the trachea. The airway tube enters the lungs of the baby and allows the flow of oxygen or air under pressure directly into the lungs. The endotracheal tube is connected with a ventilator (or respirator) – a machine that provides warm and humid air in the lungs of the baby. It can breathe entirely instead of your baby, or just assist his breathing. The amount of oxygen, the pressure and the number of breaths per minute can be adjusted so that they are best suited for your baby’s needs. Sometimes, a ventilator that can sway the chest of the baby is used (high-frequency ventilator). It provides a lower pressure, but much faster. Both ventilators will be explained in detail by the specialists in the NICU.

**Oxygen tent**

Serves to increase the oxygen concentration around the baby.

**Nasal or oral feeding tube**

The gastrointestinal tract of preterm babies is immature, which means that these babies often have difficulties in digestion. It is important that premature babies receive good sources of food to help them develop and grow.

Any premature baby has specific nutritional needs that will be determined by the physician who cares for the baby. Premature babies cannot be fed orally at the beginning. That is why, it is necessary they receive important nutrients via blood vessels (parenteral nutrition – nutrition, which is done through infusion of nutrients in the form of solutions directly into the
blood). When the baby is stabilized, it can start receiving breast milk or infant formula. The time may vary, depending on the condition of the baby. Since premature babies are unable to be fed directly from the breast or a bottle until gestation week 32-34, they can be fed through a thin, flexible tube (probe). Feeding by a tube is done through the nose or mouth directly into the stomach (nasal and oral gavage). The nasal tube is inserted through the baby’s nose and the oral one in his mouth and throat to the stomach. Feeding can begin in small portions to prepare the gastrointestinal tract to digest. Mothers of premature babies can express their breast milk and their babies could be fed with it through a tube. Although there are specially developed formulas, breast milk remains the ideal source of nutrition for prematures and babies born at term.

The intake of breast milk reduces the risk of:

1. Nosocomial infections
2. Necrotizing enterocolitis (NEC)
3. Chronic lung disease

Umbilical venous and arterial catheters
When a baby is in the womb, it is fed through the umbilical cord. After birth, the navel can be used to insert a small catheter, through which nutrients, in the form of a solution or medications, are inserted, the blood pressure can be measured or blood samples could be taken from.

Incubator
Premature babies are usually cared for in an incubator, where their temperature is regulated and they receive intravenous fluids safely in a stable environment. Incubators have small holes that allow doctors and nurses to perform manipulations, and you to touch your baby. The incubator preserves the warmth of the baby through humid air that is fed into it, which is important, because the hot, dry air from the outside can harm premature babies who are vulnerable and their skin is delicate. Premature babies have difficulty controlling their own temperature and can lose a lot of water through the skin. Incubators prevent this from happening. They also protect your baby from the noise in the NICU, infections and unnecessary contact.
**Oxygen analyzer of the air in the incubator**
This is a device inside the incubator, which monitors the amount of oxygen in the air inside.

**Thermal bed**
A bed, which is maintained warm and allows for easy access to the baby at any time during his stay in the NICU. This is an open bed that has special heaters. Some sick babies are placed in such beds instead of being in an incubator, if they often need to be hugged / drawn out, or if they are too large to be placed in an incubator, but are still in need of intensive care.

**Phototherapy**
Phototherapy is used for the treatment of neonatal jaundice. The neonatal jaundice is characterized with an excess of bilirubin in the blood, which causes the skin and sclera (white of the eye) to become yellowish. The baby is exposed to special blue light which reduces the level of bilirubin in the body. The eyes are covered with a mask to prevent injury. Ultraviolet light treatment can increase the risk of moles in childhood. Since the increase of the mole is associated with an increased risk of skin cancer, ultraviolet light is not used for the treatment of neonatal jaundice. Instead, blue light having a specific wavelength is used, which does not bear any risks. Treatment can be in the form of phototherapy and / or with blanket for phototherapy.

**Biliblanket**
This is a portable device for phototherapy to treat neonatal jaundice. The name (Biliblanket) is a combination of bilirubin and blanket. Other names used are a system for home phototherapy, a bilirubin blanket or a blanket for phototherapy. Phototherapy is done by a lamp that emits blue light on the baby’s skin. This technology uses fiber optics that emit bright light to treat jaundice in babies. The blanket is placed directly on the baby’s
skin and fiber optics are used to transport the light sources to it. Light absorption leads to bilirubin reduction.

**Phototherapy lamp**

It shines with bright blue light. The lights are placed over the baby’s incubators or bed and the baby is usually dressed only in diapers and wears a blindfold. Jaundice usually disappears in the third week after birth. Jaundice is common (in about 70% of babies).

**Intravenous catheter**

The intravenous catheter is a thin, flexible tube inserted in one of the major veins of the baby. It can be placed in the arm, the leg, the head or the umbilical cord. Most babies in the NICU have an intravenous catheter for insertion of fluids, nutrients and medications. Instead of injecting your baby every few hours, the systems allow certain medications to be introduced continuously. Doctors may use these medications to control heart function, blood pressure, or pain for relief. Sometimes, an intravenous catheter is required for a longer period of time and / or to deliver larger volumes of fluids and medicines, and for this purpose they use a central catheter. It is placed in the larger and central veins of the chest, neck or groin. This type of catheter lasts longer and requires less frequent replacement, which means less discomfort for your baby.

**Infusion pump / syringe pump**

A syringe pump is used for neonatal infusion therapy. The syringe pump is a device which permits a slow and dosed introduction of the medications, electrolyte solutions and fluids for parenteral nutrition.

Dose adjustment of the inserted medication can be
carried out during the process of work. There is a possibility for simultaneous application of several medications. Infusion pumps go together with a syringe and extension cords that connect with an abocath. It is necessary that the nurse has provided in advance a lasting venous pathway, which is checked for patency. After the syringe pumps connected to the patient, the nurse sets the speed and time for the substance introduction. It has an alarm system and a fault or the completion of the medication insertion starts an alarm that notifies the staff.

**Urinary catheter**

If your baby needs to measure the amount of its urine or take a urine sample, sometimes a catheter might be inserted. It is soft and is being removed as soon as necessary.

**Monitor for following vital parameters**

Monitor wires are attached to sensor pads placed on the baby. This gives important information on how the major operating systems in the body of the baby work. Information from several different types of monitors is often combined into one device that emits via a TV monitor type.

**Pulse-oximeter**

It indicates the amount of oxygen in the blood to your baby using an infrared light sensor. It is usually attached to the hand or the leg of the baby. It is very important because too much or too little oxygen could cause health problems in the long term.
2. MEDICAL STAFF. WHO IS WHO?

**Neonatology** is a clinical specialty dealing specifically with newborns. Its main objective is to provide optimum adaptation of newborns after birth, and adequate treatment of health problems in the neonatal period - from birth to the 28th day after birth.

**The staff** consists of doctors, nurses or midwives, and non-medical personnel (sanitarians). Doctors, nurses and other people working in the NICU work in a team. In the beginning, it is likely to be difficult to understand who is who and who is responsible for what. This summary will show you who you will meet in the unit:

**Doctors:**

- Doctors coordinate the medical treatment of your baby;
- You can contact them with questions related to the therapy, the current status and the progress of your baby;
- You can also ask them for a second opinion, especially if you feel insecure in making important medical decisions;
- Pediatricians and neonatologists take care for the health of newborns in the NICUs;
- Surgeons work in a separate team, but if your baby needs surgery, surgeons will work together with pediatricians and neonatologists.

**Pediatric nurses:**

- Pediatric nurses take care for sick babies in the NICU under the supervision and with the help of nurses from the department. Furthermore, they also have a number of non-medical tasks. They help take care of the baby as if it were in a family environment as they communicate with babies and follow their needs and wants. They perform daily hygiene toilet, skincare, care of the navel, eyes, nose, etc., daily weighing of the baby, gastric tube or bottle feeding, status and basic vital signs of baby monitoring, give the medications prescribed by the physician, assist the physician in a number of specific manipulation of the baby and so on.
- They work with members of the neonatal teams;
- They often work together and with the teams that prepare babies and parents to return home.
Sanitation:
• Non-medical staff in the NICU. They do the cleaning, washing and disinfection of incubators and other medical equipment. Preserving hygiene in the department is consistent with the disinfection policy of this type of department.

Psychologists:
• Some departments have such specialists, although in Bulgaria it is not common practice. Psychologists might help you understand your emotions and deal with them.

Other specialists:
• Ophthalmologists check eyesight of babies.
• ENT (ear, nose and throat) specialists check their ability to hear.
• If your baby needs radiography, it will be made by the radiologist. Ultrasound examinations are also conducted by specialist in radiology or by neonatologists.

You can also meet with graduate students and trainees at the hospital. If you do not want them to monitor your baby, you can deny their access.

If necessary, the doctor discusses with the parents and organize emergency and planned advice on site / by phone with:
• republican / national consultant in neonatology,
• pediatric surgeon,
• pediatric neurosurgeon,
• pediatric cardiologist,
• pediatric neurologist,
• pediatric ophthalmologist
• physiotherapist and others.

Should rehabilitation is needed, a profile special rehabilitator performs the rehabilitation.

Access to information

Daily, in a given time for the respective department, parents receive detailed information about the baby, test results, procedures, consultations, further
aspects of treatment are discussed together, counselling, rehabilitation, prevention and others. After preliminary preparation and awareness of the baby and the specifics of the neonatology intensive care unit, parents should be allowed to see their child, to touch it, embrace it and interact with it. After stabilizing the child’s condition, visits in a designated room can be organized, where possible. Guidelines and instructions on breastfeeding / feeding of the baby and maternal care after discharge are provided.
3. THE ESTABLISHED ORDER IN THE NICU

The neonatal intensive care unit (NICU) is a closed unit in terms of staff, patients and relatives and is a territory with restricted access. It will be useful to ask one of the nurses to show you the unit and to inform you of internal order in it to know what to expect. Each unit works differently, but there are some standard practices that are respected everywhere.

Answers to premature baby parents’ frequently asked questions

**How is my baby, what information do I get and from whom?**
The neonatologist provides information to the mother and / or father as soon as possible after birth, and after the baby receives care according to the first condition. It is better if this happens in the presence of both parents. The information includes: weight and height of the baby, morphological maturity (gestational weeks), how was it born, baby’s first cry, what resuscitation measures were applied, where it is placed (intensive care sector, special care sector), incubator, application of assisted ventilation, oxygen treatment, and so on. The neonatologist evaluates the child’s condition, outlines what the possibilities are and the appropriate behavior.

If there are test results, he communicates them and explains them, and outlines what the treatment plan is, according to the disease and the condition of the premature baby.

**When can I see my child?**
If the condition of the mother allows it (natural birth without anesthesia), she can see child as early as possible. In surgical delivery – after stabilizing her condition. In most NICUs, the father could see the child after birth.

**To whom can I ask questions?**
Your questions and all your worries should be addressed to the treating neonatologist, the doctor who replaces him or the doctor on duty.
How often and for how long can I see my child?
The neonatology team takes entire care for your premature baby in the early days and according to the severity of his condition. You can see your baby according to the regulated by the department time span. In some wards it is once a day, in others - three times a day, or for 15 minutes every three hours. After stabilizing the condition, feeding should be started and you can take care of nutrition. Nurses / midwives help you and guide you in the preparation and technique of breastfeeding or bottle-feeding. They teach you how to prepare for breastfeeding or bottle-feeding, how to access to the child when it is in an incubator, what you need to watch while feeding and after that, how to hold the baby, about swallowing, belching, placing after meals, etc.

Can I touch it?
Of course! You can and should do. Babies need contact with their parents. Your doctor or nurse will show you how to make this contact.

What rules must be respected in terms of hygiene and prevention from infections?
You must be wearing overshoes with insulation wrap (isolated front of the body), well washed and disinfected hands, gloves if there is damaged skin of the hands (wounds), and place a mask in cases of fever, cough, herpes labialis, etc. Touching the little baby is an incomparable emotional experience for parents.

What if the mother is sick or the family members who come to visit are sick?
Direct contact with a premature baby is not recommended when the mother is sick (fever, sneezing, coughing, malaise, etc.). A short duration visit without opening the incubator is possible when abiding by the above hygienic measures. Information on the condition of the baby is given additionally on neutral territory (in the room of the mother, if not yet discharged, or in a special room for this purpose). The decision to visit in such cases will be taken by your neonatologist. In severe illness of the mother, the doctor gives detailed information about the baby at the mother’s bed. This happens twice a day: before noon (by the treating neonatologist) and in the evening (from the neonatologist on duty). The father is offered to see the baby and then the parents are left alone. The nurse shows the baby to the mother. If its condition allows, it may be removed briefly from the incubator. It is not recommended that sick family members visit the mother and the premature baby.
**What happens if the child should be transported to another hospital?**
Transporting premature baby is carried out according to the medical standard of neonatology, the regulated levels of competence and the inter-hospital transport indications. The neonatologist who was present at birth informs as soon as possible the mother and / or the father and other relatives of the child’s condition and the need for transportation to another hospital. He explains what has been done so far, what treatment, tests and other manipulations are needed and that the hospital, where baby will be transported to, is equipped for the treatment and care of such children. There will be information on how it will be transported, by whom and when. The doctor explains exactly the name of the hospital, the department, the name of the doctor on duty who will admit their baby. A contact phone number is given for information. It is necessary the mother or the father to sign an informed consent for the transport.

**Can other family members visit the baby?**
Yes, they could. This can be done in the appropriate hours, after consultation with the treating neonatologist, and following the consent of the mother and the father.

**What happens after the mother has been discharged from the maternity ward - visits, getting information? How?**
All NICUs give daily information about the baby after discharge of the mother – the dynamic of its condition, occurring complications or improvements, test results, treatment, consultations done and planned, how the baby is being fed, the weight of that day, etc. Information can be obtained on site or by phone during the regulated by the unit hours. Access to the child is also according to the regulated internal order.

**When are the babies examined? What do they get – medications, devices, tests, manipulations, what to expect, etc.?**
Do not hesitate to ask the physician questions. It will be useful to consider them in advance (write them down) so that you do not miss anything at the meeting. He will answer and could determine approximate dates for certain problems, and could discuss problems of mutual decision in the near and distant future.

**From whom can you expect help in feeding, taking care etc.?**
Nurses and / or midwives working in these units have professional experience and qualifications. Some are trained lactation consultants. Ask for them. They will encourage you, help you and demonstrate techniques
of breastfeeding of your baby, how to hold it during breastfeeding, and after that bottle-feeding technique, etc.

If you need additional information, you can connect the voluntary lactation consultants in various organizations. Such are the National Association „Support for Breastfeeding“ (National Association for Breastfeeding Support) - http://www.podkrepazakarmene.com/ and La Leche League Bulgaria - http://www.lalechebg.com/.

Detailed information about breastfeeding and expressing breast milk during the time of separation from the baby, can be found in Chapter 5.

**Who takes care of the babies - feeding, bathing, etc.?**

Nurses take care for your baby around the clock - bathing, skin care, umbilical residue, navel, nose, eyes, ears, dressing, feeding, weighing, monitoring and a number of other specific manipulations for premature babies.
4. COMMON MEDICAL PROCEDURES

Any baby admitted in the NICU sector requires special treatment / procedures, regardless of whether there is a need for an incubator to keep it warm or a ventilator to help it breathe. Due to these special needs, each baby will be subjected to a number of medical procedures and tests to determine how it should be treated and how much time should its progress be monitored.

**Infusion of intravenous fluids**
These liquids pass through the veins into the blood of the baby and consist of sugars, salts, proteins, vitamins and fats (lipids), and all chemical substances, which are needed for optimal growth. These fluids are essential for the progress of your baby while it is unable to eat.

**Arterial route**
This is similar procedure for infusion, except that an artery is used instead of a vein. This is a more difficult process and takes longer to implement. This small tube is inserted to maintain continuous blood pressure measuring or blood sample taking.

**Blood tests**
This is one of the most common procedures performed in the intensive care unit. Blood can be taken from the arterial route, the umbilical vein, from the heel or vein puncture. Close monitoring of the he blood of your baby is very important and can alert medical staff for potential problems before they become more serious. Your baby may have a blood test immediately after it is admitted, to check blood gases and to see if it needs supplemental oxygen, mechanical ventilation and / or glucose, to maintain its normal level in the body.

**Blood transfusion**
It is often necessary, especially in premature babies, so that a safe level of hemoglobin is kept. An adult can donate blood in the blood bank after a test for certain viruses, including HIV, hepatitis and cytomegalovirus (CMV), and after they prove negative.

**Endotracheal intubation**
A thin tube is inserted through the nose or mouth of a baby into its airways (trachea or windpipe) to help the baby breathe. The tube is then attached
tightly to the baby’s face, to ensure that it will not be removed. If this tube is occluded (or if the baby is pulling it), it might be needed to be replaced. When the tube is in place, the baby does not produce any sounds, even when it seems like crying.

**Examination of the eyes**
The eyes of very small premature babies are exposed to risks. For this reason, periodic examinations by an ophthalmologist must be made. Drops will be put in the eyes of the baby before the examination, in order to enable the physician to see the retina (the back of the eye) and to determine whether it develops normally.

**Transfontanelle ultrasound – TFU**
Premature infants are at risk of brain hemorrhage, and this may be detected by ultrasound scans of the brain of the baby. Transfontanelle ultrasonography (TFU) is an ultrasound examination, which is non-invasive and completely safe, which means that it can be done regularly. This exam provides neonatologists with important information about the status of the child’s brain. The method can be used to the moment of closure of the large fontanel of the head. Early diagnosis is crucial for timely and adequate treatment. Transfontanelle ultrasonography (TFU) is a tremendous advantage over the computed axial tomography – CAT (scan), the nuclear magnetic resonance, and the ordinary X-ray, which are associated with radiation. Transfontanelle ultrasonography (TFU) gives information about the status of brain folds, the cortex, the cerebral ventricles, the movement of cerebrospinal fluid; the development of the brain; for postoperative brain condition; the presence or absence of: brain edema, brain hemorrhage, brain abnormalities, brain tumors, prenatal abnormalities and so on.

**Hearing exam**
Your baby will have a hearing exam whether before leaving the hospital or shortly thereafter. It is important not to skip this exam, because premature
babies or very sick babies are at risk of hearing loss. The test will be carried out by a specialized professional and might be repeated over time, if your baby has problems with one or both ears.

**Checking for infections and antibiotics**

If your baby is not well, and if there is an infection, a test / examination, which may include blood tests, urine test for possible infections, a lumbar puncture or an image / x-ray examination might be done. While waiting for the results, often a preventive antibiotic treatment is started, and if it turns out that there is no infection, the treatment is stopped.

**Intercostal drainage**

Some premature babies can develop pneumothorax. It is life-threatening for the baby and is generally a dangerous medical condition caused by the release of small bubbles / air sacs of the lungs of the baby to his chest. Small, flexible plastic tube may be inserted into the baby’s chest to remove the collected air or fluid to help the lungs to unfold. In principle, this tube is removed after a few days.

**Intravenous route / infusion**

This means placing a thin needle (cannula) into a vein. It can become very difficult and can take some time. It is usually inserted into a vein in the arm or the leg of the baby, or on the head. If your baby is big enough, painkillers could be given during this procedure.

**Lumbar puncture**

Meningitis is very dangerous for babies and can only be diagnosed by a lumbar puncture. A needle is used, through which a small amount of cerebrospinal fluid (CSF) is taken from the lower part of the spine and the sample is sent for testing.

**Magnetic Resonance Imaging (MRI)**

This is a test which gives a picture of the tissue that can not be seen in X-ray or ultrasound exam. MRI is a modern, non-X-ray method to display all layers of different organs, parts and structures in the body. This diagnostic method may be applied for obtaining detailed images of the nervous system, the brain, the spinal cord, the soft tissues (which are enclosed or surrounded by bone), the skeleton, the muscles, the joints, the cardiovascular system, the organs in the pelvis, the breasts, the fat tissue and others.
**Mechanical ventilation**
The ventilator is a machine that delivers a predetermined quantity of oxygen and pressurized air through a tube inserted into the trachea / throat of the baby. It can completely replace the breathing of your baby or assist his breathing (depending on the% of oxygen). The amount of oxygen, air pressure and respirations per minute can be adjusted according to the needs of your baby.

**Newborn Screening Test**
A blood test is done for the detection of hypothyroidism, phenylketonuria and congenital adrenal hyperplasia. This test can help to provide early diagnosis of over 30 different congenital metabolic disorders.

**Other ultrasound examinations**
Other organs besides the brain (e.g. heart and kidney) may be checked by ultrasound. The ultrasound examination of the heart is called echocardiography.

**Phototherapy**
When the baby has jaundice, it is placed under a special lamp that helps him overcome it faster. The eyes are usually protected with a bandage and your baby can be put into an incubator for the duration of phototherapy.

**Feeding through a tube**
This is a way of feeding, in which a small plastic tube is placed through the mouth or nose into the stomach of the baby. Milk and medicines are delivered directly into the baby’s stomach through it.

**Umbilical vein route**
A small tube is inserted into a vessel through the navel of the baby. This can be used instead of an intravenous system in the first days of the life of the baby.

**Urine test**
As well as the blood test, the urine test can tell a lot about the health of your baby. The test can show how its kidneys work and whether the baby has an infection. It can be collected by cotton balls placed in a diaper, a small plastic bag / collector which is attached to the genitals of the child, or through a catheter that is removed immediately after the urine is withdrawn.
**Weighing**
Your baby’s weight will be measured shortly after birth and then regularly while in the NICU. It is quite possible that your baby could lose some weight during the first weeks after birth, it is normal for most babies, especially very small ones.

**X-ray exam**
An X-ray examination of the lungs of the baby is needed if your baby is on a ventilator / intubation or having troubles breathing. Some babies need more than one X-ray exam, depending on their condition. An X-ray exam can also be used for viewing the baby’s tummy, the bone structure and to see if the tubes and intravenous systems are installed properly.
5. FAMILY FOCUSED CARE

From the moment your baby is born, he/she becomes part of your family. Your other children (if you have such), the baby’s grandmothers and grandfathers, and in general all your relatives are excited about and interested in the new family member. Everything that happens to the baby has an impact in one or another way on them, too. At this stage, while your baby is still in the hospital, the linking unit between him/her and the remaining part of your family is you, the parents. In these circumstances, getting into the mood of being a parent might be difficult.

You will need a huge dose of patience and understanding. The focus of doctors and the whole medical team, especially during the first days after the birth, will be on your baby’s health and life. Sometimes the parents’ feelings and emotions may recede into the background. The positive attitude and relationship between you and the medical team is of extreme importance. Remember that you and the doctors have a common goal – your baby’s health. At the same time, you should not forget that you have every right to be by your child as often as it is possible and to participate in the care for him/her.

While taking care of the baby, the doctors and nurses will work with the whole family. They are aware that you know the baby better than anybody else and will support you in your care for him/her and in making informed decisions.

Family focused care means:

- To take into consideration your family’s emotional and social needs
- To provide clear information
- This kind of care requires from the staff to be sure that you understand
the treatment of your baby and take into account your opinion of it
• You are shown how to take care of the baby and are encouraged.

This kind of care can help you build and strengthen your relationship with your baby. It is possible that this type of care shorten your baby’s stay in the healthcare institution.

Talks with the doctors and nurses are really important so that you are aware of your child’s condition and of what you could expect in the future. Talks with other parents who have premature children could be useful as well.
~ CHAPTER THREE ~

1. How to deal with the challenge
2. How can you help your child?
3. Your rights as parents
4. First contact with the baby. Feelings and emotions.
Kangaroo Care
Premature birth is the reason for complex and contradictory emotions. Many parents share emotions of shock, sadness and anger because their child is in a serious health condition, which poses a number of risks. They are unable to experience fully the sadness because the child is alive. The parents do not know how to share and accept their sadness as they are expected to celebrate the birth of their child, but they do not feel like celebrating at all. The congratulations on the arrival of the newborn baby sound absurd and distant, and it is as if somebody else has been congratulated, not them. They feel devastated by the feeling of fear – whether their child would survive and if yes, what future is in store for him/her. This condition is called ‘indefinite loss’ and it leads to an overall conflict between joy and sadness.

Let us understand our feelings!

The preterm birth of a baby might provoke a whirl of emotions in the parents. You might experience guilt, sadness, anger and helplessness. Premature babies’ parents experience a nearly universal feeling of a lack of connection to their baby. There is no way to be prepared for the huge feeling of helplessness that overwhelms you at the sight of your fragile newborn surrounded by apparatuses and tubes connected to the baby’s body. Your discharge from the hospital without your baby may aggravate even more your negative experiences and your feeling of having failed as a parent.

Most of the premature babies need hospital treatment, at least until the baby’s estimated due date (when the baby was expected to be born), and some babies even longer. Your routine related to going to the hospital, other commitments, the breast-milk pumping and combating the sometimes all-engulfing fear and sadness, may be completely exhaustive. At the same time, the atmosphere in the neonatal unit makes you feel even more stressed.
During the first days, you may have the feeling of chaos and confusion. You need security, but can only have possibilities. To live without knowing what happens next is a rather difficult task.

Because of your impaired health status, you may have not been able to think firstly about your baby. This may stir up a feeling of shame (What kind of mother am I?). You may have a gnawing feeling of guilt inside of you. You keep thinking about what had gone wrong during the course of pregnancy, which caused the premature birth, and how it could have been avoided.

You might feel deceived and robbed. Every expectant mother dreams of normal pregnancy, birth and intimacy with the baby after the birth. Instead of this, you have been faced with the probability of death or impairments.

Things may not get back to normal. You yourself may feel alienated from the other people, frustrated by the impossibility to communicate. At the same time, you may feel that the others do not understand the depth of your experiences. You may also have the long-lasting feeling of fragility and limitations of your body.

The unresolved trauma may hinder your attempts to get back to your life from before birth. It may manifest itself in bursts of tears and in impossibility to cope or feel as emotionally stable as you were before. On the other hand, your attempts to cope well may be so excessive that they can prevent you from experiencing what is happening.

**Take care of yourself!**

Take care of yourself. This might be the last thing you feel like doing; you might not have the time and strength to do it, but the act of taking care of yourself is beneficial for everybody.

Sticking to a daily routing is of use, too. The performance of certain activities at one and the same time helps to build it. Structuring things in all this chaos and confusion can be comforting.

**Emotional support – where to get help?**

Check if a psychologist is available in the hospital where you gave birth or in the ward where your child/children (if different) are being taken care of. A
psychologist can help you both in the emotional crisis you are in after the birth and in the contact with your baby.

**Support and mutual assistance group**

You are experiencing something that is similar to what a small part of the population only are experiencing. Joining a support and mutual assistance group, you will find it easier to express the depth of your experiences and feel understood. Empathising with others may help you reduce or overcome your feeling of isolation.

The Foundation “Our Premature Children” works actively towards providing support for premature children’s parents and organising groups for emotional support and mutual assistance. The groups are meant both for premature children’s parents and for parents of children in a very bad health condition.

**The groups’ main objectives are:**

- To support parents in their coping with the stress and the flow of emotions they are overwhelmed with at the birth of their preterm baby/babies (or baby/babies in a bad health condition).
- To provide parents with the possibility to share their emotions and experience with other parents in a similar situation so that they can feel better understood and less isolated and lonely in their experiences.
- To support the contact between parents and their children, and reduce the risk of abandoning prematurely born babies or children in a grave health condition.

*For more information about the support and mutual assistance group in your town, visit the Foundation website [www.premature-bg.com](http://www.premature-bg.com) or write at our e-mail address info@premature-bg.com*
Online consultation with a psychologist

What does online psychological consultation mean?

Many of the women who have experienced premature birth, as well as their partners and relatives, often do not find the strength to speak openly about this, especially during the first weeks or months, and tend to seek indirect support, using often the Internet.

This consultation method has many advantages:

- It is not necessary to visit a special place or adjust your schedule, but find a comfortable nook in your home and in your heart, and pour your heart out, pour your thoughts on the screen.
- It is suitable for both the mothers and fathers, even for the family friends.
- It is suitable for people who live in distant areas and do not have the possibility to use the services of a psychologist.
- It is suitable in cases, when you do not feel comfortable to seek psychological consultation in a formal setting and prefer the privacy of your home.
- It is suitable for people who feel confused to speak openly, ‘face to face’ about their feelings.
- Online consultations provide conditions for sharing of thoughts in a safe and anonymous environment, and at the same time, they offer directly a quality consultation service.

The Internet is a part of our everyday life and you have long known the pleasant feeling of anonymity it can offer you. People often do not look for psychological consultations because of feeling embarrassed about what the others would think about them, whether they would not be censured or looked at with an evil eye, or whether the intimate things they are sharing would be heard by a third party. Every psychologist is obliged to respect your right to anonymity and treat you with absolute consideration and respect. If you need this additional sense of anonymity, the online
consultation offers you this easily and accessibly. In addition, in the online consultations you are aware that you communicate with a trained and experienced specialist who works according to established professional standards.

Think whether online consultations are the best variant for you in the following cases:

- You find it difficult to use a computer or the Internet.
- You feel awkward to talk about your personal experiences on the Internet. Some people would rather have a live contact with a psychologist.
- Your condition requires psychological or psychiatric support with greater involvement. If you are going through a serious emotional crisis or have self-harm thoughts, you had better seek a direct help from a specialist and we will refer you to one.
- You have questions referring more to your medical state.
- A psychologist can offer you support and consultation, but he/she is not a medical person

You can use the online consultation service completely free of charge by visiting the Foundation website: www.premature-bg.com or by writing at info@premature-bg.com

**Fathers of premature children**

Attention can be focused on the baby and the mother to such an extent, that the father’s anguish and despair might remain unnoticed. Fathers are supposed to be strong and independent. They often feel lost in their wandering from one place to another (home, hospital, work) and do not have a sense of control, safety and satisfaction.
Parents often notice that they react much more differently to a premature birth: while mothers experience everything about the event very emotionally, fathers often look more serious, silent and somehow distanced from what is happening. It is good to bear in mind that men and women differ a lot in a number of aspects and if you are a mother of a premature child, do not rush to blame your husband for not caring for what has happened.

Not infrequently have men been taught since childhood that it is unacceptable to show freely their emotions. They need to feel helpful by being absorbed in practical activities like looking for information on the topic, talking to the medical staff or accomplishing a number of other tasks, which seem illogical to the mother, but they help them regain their sense of control over the situation and their feeling of security and safety. Although being staunch on the surface, men experience the event strongly, too. It is just that they do not express it in words.

As with all unexpected traumatic experiences, fathers are unprepared to cope with the premature arrival of their child. Having expected one situation and role, they suddenly end up in another. Instead of experiencing the luxury of abundant, mixed and ambivalent feelings following the pregnancy, the premature birth brings them a touch of urgency, concern about health and even about the survival of the mother and the baby. Fathers take upon themselves the whole anxiety and fear for their partner and the child.

**Siblings**

What do I tell my other children? It is best to be honest with them. Provide them with the information they seek, but give them the amount and detail that is appropriate for their age. Very young children ask simple questions and need simple answers. Talk about the baby, referring to him/her by his/her first name, in the way you talk about any other member of the family.

What are the most common reactions of young children to having a baby in the neonatal unit? Even very small children can feel you are upset and sad and their lives will certainly change because of your emotional state and the time you need to be with your new baby. These common reactions usually include the following:

- They think that they caused the premature birth of the baby. Magical thinking is very common in children at the age of 2 – 6. This is the child’s
certainty that their thoughts and wishes can make things happen.

- The child will not be happy about sharing his/her parents with a new sibling, although the idea of this makes him/her feel excited. They may have wished for the baby not to be born or they may have accidentally kicked your tummy and think that is why the baby is early or sick.

- They think they made you sad or upset by something they did or said. Confirm that you are sad and unhappy, but assure them that it is not because of something they did or said, but because the new baby is so small or sick.

- Their family environment and their usual routine are different and they can sense that the people around them are emotionally unsteady. This makes them feel insecure. They express this by acting out their internal conflicts, which is the only way they know to get more attention. Try to find someone they know and like (grandmother, grandfather, close friend, favourite babysitter) who can give them extra attention, not only when you are not at home, but also when you are in. Also, stick to their usual routine (such as time for meals, time to sleep and other activities) as much as possible. If they go to a nursery or school, let their teacher know what is happening so that she/he can give them more attention and understanding.

- You feel insecure, abandoned or lonely – try the above approaches. Assure your child that you still love him/her as much as before the baby came.

- They think they are sick, too. They complain more often of stomachache or other indispositions or hurts. Try the above approaches for increasing attention to them.

- They fear that they will catch the baby’s illness – most children know that they usually get ill after being in contact with someone who is ill. Assure them that neither they nor you can get the baby’s illness.
• They wonder who will care for them when the baby comes home. Show them that they are very important to you and to the family. Talk to them about ways that can make the baby part of the family. Show them you are proud of the things they can do for themselves, which babies cannot do.

• They regress – when children experience emotional stress, they often regress, i.e. they return to a kind of behaviour they had when they were younger. For example, they may begin to wet themselves more often than usual. They may stop using newly learnt words or refuse to dress themselves. They may start sucking their thumb again, use a pacifier more often, want a feeding bottle or return to their transitional object (usually a plush toy or a small mirror, which they used when they went to sleep and helped them part more easily from mum). Do not scold, punish or talk negatively to them about these kinds of behaviour. They are the child’s way of telling you that he/she needs more of your attention and love. When the child feels secure again, he/she will return to their former level of development.

If possible (if the hospital policy allows this), take your children to the neonatal unit to visit the baby. Encourage them to do something for the baby, which can help them feel him/her as their brother or sister and as part of the family, for example, let them draw their family together with the baby. Pay attention to your children’s comments and to their emotional reactions, and help them understand the things that make them feel worried.

Positive thinking and negative attitudes

Parents’ experiences at the birth of their child vary widely. They are often differentiated not only as mother and father’s reactions, but also as a type of emotion. In some cases, the early birth can require a general anaesthesia or may be so surprising and unpleasant to the mother, that she may not remember clearly what happened. It such cases, the ‘texture of the memory’ should be duly filled with the
missing moments and the mother should be told about what happened in an appropriate way, without hiding the truth from her, and she should be supported to see her baby. According to many psychology specialists working with people who have experienced negative events, this is of primary importance because it can facilitate the process of recovery for both the mother and the child.

During the stay in the hospital and after it, many parents try to charge themselves with positive wishes, which can prevent them from causing a negative event magically, just by thinking about it. However, instead of helping them, this extremely positive way of thinking may be completely exhaustive for the parents or may deprive them of the possibility to meet steadily the reality, especially when things do not develop in the best possible way.

Every extreme poses risks. Thus, for example, if we are permanent pessimists and are fully armed with stormy expectations, we can fall under the so-called ‘nocebo effect’ known by science as the alternative of the placebo effect.

The placebo effect (from Latin ‘placebo’ – to please, to improve) makes people feel a positive effect of a given treatment or medicine only on the strength of their beliefs and expectations. On the other hand, the nocebo effect leads to real symptoms caused by the patient’s negative expectations or by the negative prognosis given by the doctors in charge of their treatment, even when there is no physical cause for illness. In this sense, the words you use to describe the events that are happening and the way you perceive reality are important. Nocebo can find expression in increasing the stress and anxiety about what can go wrong during the birth or after it. The way the medical staff communicates and provides current information to the parents is important, too, because the course of recovery may depend on it. The golden balance between the unrealistic positive and extreme negative attitudes lies in the creation of a clear and true picture of the event with all its pros and cons, because life is what it is and what depends on you is to live it in the most fulfilling way possible.

Of course these processes are much more complex and they need to be taken into account in a detailed conversation with an experienced specialist (psychologist or psychotherapist), when necessary.
Mum’s diary: before, during and after the premature birth

While the baby is still in the hospital, the rhythm of life of the two parents, and often of a wider circle of relatives and friends, is entirely subject to the hospital regime, diet and care. The parents are inundated with complex medical terminology related to the baby’s coming to light and they have to learn fast how to ‘swim’ in the medical slang. During the child’s stay in the intensive care unit the parents’ days and weeks are completely filled with visits, worries and hopes.

Quite often, preoccupied with care for their baby, the parents cannot have a rest and deep down, they have the feeling that they do not have the right to rest until their baby is stabilised. The truth is that there is no way to expect that you will not worry, this is impossible. However, you can help yourself if you know that the care for yourself is of prime importance for your abilities to go through these difficult times.

One of the supportive techniques you can come across as parents of a premature baby is the keeping of a diary, because meeting with your thoughts and experiences, you have the possibility to structure yourselves at moments of insecurity, to express everything you have on your minds and look at yourselves from aside. Many mothers describe the birth of their premature baby as a barrier that seems to divide life in two: ‘before’ and ‘after’. In the wide river of life, you are always yourself, although enriched or changed by certain events. The stories we tell about ourselves are often the basis on which our lives go.

The story as a life guideline is considered important from as early as the moment of your birth, when it is still believed that you cannot talk. However, more and more modern researches show the newborns’ ability to recognise and respond to human speech, especially to their parent’s voices (even to shades of meaning of the words and their emotional charge). It is not accidental that folk traditions and world mythology speak about the Weird Sisters who foretell our future with their words. The words we pronounce on meeting the child for the first time may become their ‘personal myth’ they begin to live with.

According to some studies, mothers of prematurely born children have different stories or ‘personal narrative’ about the moment of birth. Cases in which, despite the uniqueness of what is happening, the mother manages to experience the rich palette of emotions associated with the birth, are considered to lead to easier psychological recovery. On the other hand, experiences like frustration, disappointment and passiveness at birth, when the mother finds it hard to feel
completely the reality of what is happening, often lead to slower and more
difficult recovery. Not rare are the cases of 'reactions deferred in time, when
the parents feel intensive emotions associated with the event weeks, months
and sometimes years later. It is appropriate that they discuss these cases with
a psychologist or another mental health and wellbeing specialist, who can help
for the family recovery in this period.

Many mothers find it difficult to recollect their premature birth experiences
and often do this with reluctance. As any traumatic event, it is not easy
to get back or keep long to yourself the pain and fear. The deliberate
suppression of certain memories and emotions however leads to negative
effects. The awareness and acceptance of events does not make them
less painful or real, but it brings more peace of mind and gives you the
possibility to think about other things in your life and to keep moving
forward. Nobody can stand being engulfed by one single emotion for a long
time – by anxiety or sadness.

Today it is increasingly spoken about the importance of telling the baby his/
her true story, even when he/she are still in the hospital, although it may
seem to you that it is too early for them to understand speech, even more
at the time when they are growing up and start asking how they were born.
Anyway, children often feel a lot of what is happening around them and
adults’ words can vest the little fellow’s experiences with understandable
sense. One of the parent’s most important roles is to ‘translate’ the world
and events in a language that is understandable to the child, helping him/her
to grow up and be themselves.

A lot of mothers say that it is useful to keep some photos or objects from
the child’s stay in the hospital, which will later become a symbol of this
period and help create a whole ‘Tale of My Birth’ or a home-made album.
The child may look through such a hand-made booklet or mini-diary with
interest and the former can tell him/her the details of their story in a gentle
and understandable way. To tell your baby how he/she saw the light of day
does not mean to tell them a made up or rosy story, in which everything is
wonderful and nearly incredibly positive. Children need to hear the truth,
but a truth they could understand, because it is the basis on which they
will build up their personal ‘autobiographical novel’ and will learn from it how
to accept both good and hard moments in life.
2. HOW CAN YOU HELP YOUR CHILD

Go to the baby as often as possible and try to establish and maintain the closest possible contact with them both physical, by fondling them, and psychological, by talking and singing of songs. Talk to the baby. He/she may not understand the language in the way a man who has already mastered it does, but they certainly recognise your voice, your body odour and the taste of your milk. The baby feels your presence.

The power of words

If you can, tell him/her the story of his/her birth. Talk to him/her about his/her brothers and sisters (if any). Fransoise Dolto, a children’s psychoanalyst, says that a wound can be cured or rather overcome through true words said by somebody who has been approved by the child’s mother or father, and the child knows this, and who talks to him/her about the ordeal they have gone through... Only the word can make the child regain symbolically his/her internal harmony... It may be amazing, but children, babies, newborns understand the words said to them, although we do not know how, intended to tell them the truth which concerns them; words that tell what somebody knows about facts without evaluating them.

Miriam Sager, a children’s psychoanalyst, working in a neonatal unit in France, advises parents to observe when the baby will open his/her eyes and seek contact. When the baby shows that he/she is tired, the parents stand by the (neonatal) incubator without bothering him/her. In Bulgaria, it is not a practice to accept the baby as a person and subject from his/her very birth, but this demonstrably helps for the faster recovery of the baby, as well as for his/her further psychomotor development.

How can you help your baby?

Your basic parental instincts make you protect and keep the newborn baby. When your baby is in the hospital, it is possible to have the feeling that your relationship with your child has been broken and that it is impossible to fulfil your parental obligations.

Many of the parents feel separated from their children and upset. The feeling of being separated may torment you even when you are standing by the incubator.
One of your big responsibilities as a parent is to make important decisions about the treatment of, and necessary care for your child. It will be best for your child if you have the possibility to work together with the doctors and nurses in charge of his/her treatment.

Insist on being informed, do not hesitate to ask questions, ask for a second opinion and express your opinion on matters related to your child’s treatment.

**What can you do?**

You can do many things to ensure the comfort of and good care for your baby:

- Provide assurance to your baby by touching and talking to him/her, and by letting him/her feel your body odour.
- Provide breast milk to your baby. In the beginning, express your breast milk. Put the baby to the breast as soon as possible.
- Participate in the care for your baby. Change his/her diapers, wash him/her, do everything that is within your power and what you are allowed to do.
- Learn ways of promoting your child’s physical development.
- Get the baby familiar with his/her siblings, grandmothers and grandfathers.

**Privacy, peace and quiet**

Your baby needs peace and quiet in order to rest and start growing up. Quiet helps the baby relax and not to be afraid so much.

Unfortunately, in reality hospitals are not very quiet places. Hospital staff and visitors come and go, different tests, medical examinations and procedures are carried out; the sound of monitors and alarms does not stop at all. Some neonatal units are packed with incubators placed one next to the other and there is not enough space for the parents.

Neonatal units could maintain a favourable and peaceful environment for the baby in the following manner:

- Reduce the light intensity at night and protect the children from bright light as much as possible. In a number of neonatal units, factory covers
are put on the incubators, which protect from the light. The covers are always placed in a way that will not stop the nurses from watching your baby.

- Protect the babies from the loud and continuous sound of apparatuses.
- Keep the level of human voice noise low in the wards.
- Plan quiet hours for the babies and their parents.

Neonatal units could respect the needs of the babies and their families by doing the following:

- Provide privacy at certain meal times, cuddle the baby and perform medical procedures. A good variant for this purpose is a separate room or provision of private space through curtains in case your baby needs constant supervision.
- The staff in the ward may require parents not to peep into the incubators of other babies who have no relatives with them.
- Provide a secluded place, where you can discuss your baby's condition and their therapy with the medical staff.

**Synchronise with the baby**

It is important that your baby come to know you with all his/her senses, remember your smell, your voice and your tender touch. This allows the baby to know when you are around.

However, there will be days when your baby is very tired and you had better limit your contacts with him/her to the minimum. The more your baby's condition improves, the more rarely this will happen. There might be days when you would not even be able to hold your baby's hand. Perhaps he/she feels better when he/she feels your smell. Try to hold a soft toy or a piece of cloth close to your skin for some time and ask the nurses if you can place it in the incubator with the baby. Ask them if it is possible to sit and talk to the baby.

Sometimes the whole equipment in the ward may be extremely annoying. Yet try to disregard it. Focus on your baby as much as possible. Remember that the nurses' job involves constant checking of the monitors and you can feel free to devote your whole time to care for the baby and to the process of getting to know each other. Thus, you will learn how to recognise your baby's needs and guess when the baby is pleased and when he/she is not comfortable and is stressed.
Comforting touch

Even if your baby is very sick or fragile, you can provide tenderness and comfort to him/her. Ask the nurses to show you how to recognise the signs showing you when the baby is calm and feels comfortable, and when he/she is tense, hypersensitive or when he/she feels uncomfortable.

The comforting touch is one of the numerous ways of allowing you and the baby to get to know each other. It allows you to feel tenderness and love on touching the baby even if he/she is not ready to be carried in your arms.

In case it is safer for the baby to be in an incubator, it is possible, provided they think he/she is well enough, that the nurses offer you to try a comforting touch. Putting the baby to sleep with calm and motionless hands might be more comforting to him/her than caressing or massaging, because they are more stimulating.

The comforting touch can:

- Calm your baby during unpleasant procedures;
- Calm him/her when he/she is restless;
- Help your baby get to sleep again after a meal, bathing or changing diapers.

You should always talk to the nurses before you try the comforting touch. They can show you how to do it exactly.

- Before you begin, remove your watch and jewellery, roll your sleeves below the elbow and wash your hands well. This will reduce the risk of
introducing infection into the incubator.

- Always make sure that your hands are warm before you put them on the baby.
- Talk to the baby before you touch him/her. Let him/her understand that it is you before you have started.
- Put one or both your hands round the baby’s feet, head or body. Keep them still.
- The baby may like to hold some of your fingers.
- You can continue holding him/her as long as both of you can feel comfortable. Watch for signs showing that the baby is tired or wants you to stop.
- When you finish, remove your hands slowly in order not to startle him/her.

Prematurely born and sick babies go through a number of medical procedures, which may cause them discomfort. As their parents, you are the right people who could compensate their discomfort by creating a positive and encouraging bond between yourselves. Do this immediately after you feel you are ready and confident enough to create it. The positive bond is what will allow you to give your baby love and confidence, as well as to feel his/her needs. Babies can communicate. Watching and listening to your baby, you can make him/her feel protected, calm and pleased.

It is harder for the baby to communicate when he/she is exposed to so much light and noise or if he/she is in an uncomfortable body position. In this case, first check if it is possible for the surrounding environment to get a little more peaceful. In the course of time, you will come to know your baby’s reactions and will see that he/she responds more and more often and for longer periods.

“The first time I was holding Alex I got terrified of all those pipes. My husband tried to hold the baby, too. This continued for a week. I was lucky with the possibility to pump the breast milk. This really helped me feel really involved in the care for the baby.”

K.N., mother of Alex, born in 30th gestation week.
3. YOUR RIGHTS AS PARENTS

Your rights as newborns’ parents (Charter of the European Foundation for the Care of Newborn Infants EFCNI/European Foundation for the Care of Newborn Infant):

**The right to receive equal and early access to education**
All (expecting) parents have the right to receive equal and early access to evidence-based adequate education. This must include comprehensive and adequate information and counselling/advice on pre-conceptual and maternal issues, sexual and reproductive health, healthy lifestyles, healthy pregnancy, delivery, newborn care and early parenthood.

**The right to evidence-based high-quality treatment and care**
All (expecting) parents and newborns have the right to evidence-based, high-quality treatment and care as a basis for active and healthy ageing. This includes equipment, use of medication, as well as education and training of healthcare providers.

**The right to remain as a family unit**
All families have the right to be considered as a unit. Each member, and the family as a whole, has to be approached with dignity, respecting their social, cultural, developmental, emotional and clinical needs as well as their rights to privacy.

**The right to comprehensive and accurate information**
All parents have the right to be provided with comprehensive and accurate information on available techniques and procedures of diagnosis and therapies, including risks in their own wording and language. Based on this information, parents have to be included in the decision-making process to perform a chosen diagnostic and/or therapy service.

**The right to be actively involved in child care**
All parents have the right to receive appropriate education and be actively involved in their baby’s care giving in an effective manner.

**The right to complain**
All parents have the right to voice complaints and recommend changes without fear of negatively affecting or influencing a change in the quality of care of their child.
**The right to support**
All (expecting) parents and children born at risk have the right to psychological, social, and financial support.

**The right to pregnancy-, maternity/paternity- and parental leave**
All parents are entitled to pregnancy-, maternity/paternity- and parental leave.

**The right to family-centred care**
All parents and newborns have the right to family-centred care and to stay together while the child receives healthcare.

**The right to allow close family members contact with the newborn**
All parents have the right to allow close family members (i.e. grandparents, siblings or close friends) to have contact with the newborn.

**The right to receive information about services and help groups**
All parents have the right to receive adequate information about the existence and services of parents help groups and national parents organisations.

**The right to appropriate transfer and discharge procedures**
All parents and newborns have a right to appropriate and individual transfer and discharge procedures.

**The right to receive specialised aftercare services**
All parents and newborns at high-risk have the right to receive evidence-based and experience-based, coordinated, specialised and appropriate follow-up and aftercare services.

**The right to lifelong inclusion**
All newborns with adverse neurological and motoric outcome have the right to lifelong integration and/or inclusion as well as psychological, social and financial support.
4. FIRST CONTACT WITH THE BABY, FEELINGS AND EMOTIONS. KANGAROO CARE

A well-known fact is the extreme importance of the first contact between the mother and the baby. The mother is recommended to embrace her baby immediately after birth, which facilitates the newborn’s adaptation to the outside world and strengthens the bond between the two. Premature birth, however, is often accompanied by complications, which do not allow this to happen because of the importance of a number of medical procedures aimed at stabilising the physical condition of the baby and the young mother.

Many mothers who are aware of the importance of the first contact due to the ample information on the Internet and the tons of specialised literature in the country, or just feel intuitively that they have to cuddle their baby immediately after birth, feel strong frustration, anger or disappointment that they cannot do it because of the baby’s earlier arrival. In time, these emotions may often develop into accusations against the hospital staff or into sense of guilt for not having been able to do things in the best possible way. These experiences are often enhanced because of the strict hospital requirements for care for the baby’s life, which do not allow daily or lasting contact between the mother and the baby, when the latter is in the NICU.

In Bulgaria, there is an Ordinance of the Ministry of Health (Ordinance No 16 of 1996, Section VI. Patients’ Rights and Obligations), which allows the parents of a child up to the age of 14 to accompany him/her during his/her hospital stay, but this appears difficult to achieve in practice. It is important to know however that the Law on Health stipulates those young mothers and their newborn infants have the right to ‘optimal living environment’ in the physical, psychological and social aspects, and have the right to be informed and to make decisions on every aspect of the care given to their children.
It is good to know that although very important, the difficult first contact in case of premature birth is not as fatal as it may seem to you now and what is most important is that it can be restored with time. The so-called Kangaroo Care helps a lot in this. The Kangaroo Care appeared in Columbia in the 70s of the 20th century and it involves a facilitated skin-to-skin contact between the mother or another family member and the baby. At times, this method is called ‘womb outside the body’.

In Bulgaria, Kangaroo Care is increasingly opted for in neonatal unit. However, it is a pity that this method is not a common practice yet and its application is rather an exception. Nevertheless, do not give up and ask for information about whether it is practiced in the ward where you are.

Before you try the skin-to-skin contact, consult with the medical staff if the baby is well enough. If everything is all right, make a joint plan for the time and place where to do it. If the baby still has breathing problems, in some cases it is possible to apply Kangaroo Care with careful planning and only with the medical staff’s assistance in order to be completely safe. If possible, they will help you by holding the apparatuses while you are cuddling the baby.

Kangaroo Care can be performed by both of the parents and it is a way of creating a bond between the father and the baby.

**Here are some facts about Kangaroo Care:**

- Babies who have had the chance of benefiting from Kangaroo Care stabilise faster than those who have only been cared for in incubator. This certainly does not mean that if they have only been taken care of in incubator, they do not have a chance to survive, just the opposite – modern and quality technology is their greatest chance.
- Kangaroo Care helps babies stabilise and improve their breathing due to the mother’s stable breathing.
- The baby’s heart rate stabilises (the mother’s heart regulates the baby’s heart).
- The baby’s temperature is regulated the best on the mother’s breasts. Through the
skin-to-skin contact the mother automatically warms up the premature baby who cannot regulate his/her body temperature yet and does not have enough subcutaneous fat that can preserve it.

- Kangaroo Care often leads to reducing the length of stay in the hospital and the need for expensive health services, increasing the parent’s participation and possibilities for education and better use of the funds for health care.
- Kangaroo Care is recommended by the World Health Organisation.
- Skin-to-skin contact can be practised after the baby’s discharge from the hospital, at home – this practice has a number of beneficial effects in terms of the bond between the parents and the baby, as well as many other benefits with regard to breastfeeding.

During the first days after the birth, the parents often ask themselves questions like “Why did this happen to us? What can we do? Is our child well and does he/she receive the best care? Who is to blame for this?”.

When the baby spends days and at times even months in the neonatal unit, the worries intensify. Although being fully understandable and normal, worries help too little for the parents’ mental recovery. They often tend to compare themselves to other parents, to take the lack of security as deliberate misinformation. In addition, they are engulfed by sadness or anger.

**Seeing the child for the first time – “Is this my child?”**

The child’s prolonged stay in the intensive care unit often prevents the mother and father from seeing him/her immediately after birth and when this happens, it can cause a wide range of reactions in the parents. Some mothers immediately start feeling tenderness and love for the tiny creature. On the other hand, others experience various and more complex feelings on meeting their premature baby for the first time, which, although confusing, are completely normal.

The child’s earlier birth is an unexpected event and many parents find it unnatural to feel attachment to a child who was so much in a hurry to appear. Others realise that the fragile baby in the incubator, who looks unrealistically small and nearly lost in the diaper, and who is often attached to medical equipment facilitating his/her breathing, eating and physiological functions, does not look at all like the plump rosy babies they have seen previously. They may feel confused and frightened, and may find it difficult
to accept the child. To still others, the very birth may have been a very traumatic event and they even do not want to see the baby or they seem not to feel any emotions at all at the sight of him/her. All these and many other reactions are completely real and possible, and if you are a premature baby’s parent, it is important to know that it is normal to feel like this. Do not blame yourself for having ‘dark thoughts’. It is better to be aware of yourself better instead, and know that it is human to suffer and feel confused.
~ CHAPTER FOUR ~

1. Awareness and decision-making
2. Relieving the pain
3. Complications and risks of complications
4. Disease prevention
5. How long will my baby stay in the hospital?
1. AWARENESS AND DECISION-MAKING

Due to the advance in medicine, premature children can be saved and develop as healthy ones. Parents are rarely ready for the shock and stress they experience at the birth of the premature child and his/her prolonged stay in the neonatal intensive care unit. This may change dramatically the transition to parenthood and lead to long-term effects for both the child and the parents. In these circumstances, it is extremely important to have timely and adequate information.

What does the first information about your baby contain?

The doctor informs you about the time your baby was born, his/her sex, birth weight and height. Then an evaluation of his/her condition at birth follows (if the baby cried out, can he/she breathe independently, is he/she rosy etc.); what resuscitative actions have been performed in the delivery room; where was he/she placed after leaving the delivery room; what procedural actions have been performed; the child’s condition at the moment. The doctor reports the results of the tests made, informs about the tests that are to be made and the treatment given to the baby. Short-term perspectives of the baby’s condition are outlined at the first opportunity, as well as the expected problems with the child. If you have questions or have failed to understand some part of this, the doctor will answer and clarify things. The mother/father has the right to see their child, touch him/her and have contact with him/her for as long as the doctor in charge decides for each individual case. Preparation is needed to accept the child’s appearance and the specifics of the unit (incubators, monitors, ventilation apparatuses, alarms), as well as the medical staff’s actions.

How can I receive regular information about the child?

Ask your doctor and he/she will let you know. Information is provided daily at a time specified in the neonatal unit’s internal regulations. There is also a practise of putting a sign at an accessible and visible place, which should contain at least the following information: the time range for providing information and a valid telephone number of the unit. Information about the child’s condition can also be received on the phone at designated times. The parents have the right to receive information on the phone. Information can be given to another person only with the parents’ consent. Only the doctor in charge or on duty gives information about the child’s
condition. The nurse can give information only to the amount determined by the Head of the NICU.

**Information you will receive before your baby’s discharge**

1. How often to feed your baby and what amount of food he/she needs.
2. Condition of the child upon discharge. Organising follow-up checks of the child’s psychomotor development, eyesight and hearing – where, when and with what medical specialists.
3. Follow-up treatment – for example, prevention of rachitis, late anaemia in infants etc.
4. Terms for conducting immunisations and need for additional immunisation.

Upon the child’s discharge, the parents receive an epicrises containing the above information. In most neonatal units, it is a practice for a mother to be hospitalised before her baby’s discharge. She participates in the care for her child – bathing, breastfeeding techniques, ways of holding the baby during and after breastfeeding, techniques of feeding with a nursing bottle, etc. This makes her useful and more confident and prepared for parenting her baby at home. It is useful for parents to receive information about the existing services and mutual assistance groups, as well as about national parents’ organisations. If you do not receive such information, do not hesitate to ask for it.

**Decision-making**

The most important part of being a parent is to seek to do the best for your baby. In the situation you are in, the best thing for your baby is your being well informed about what you are faced with and your being able to make a choice about medical care, if necessary. The doctors and nurses want the best for your baby, too. During your baby’s stay in the hospital, doctors and parents should be a team because their aim is the same – ensure the best possible care to the child.

The doctor provides the necessary amount of accurate information that is acceptable for the parents, which includes their child’s health status, methods of treatment, including alternative ones.

**Doctors are professionally responsible to:**

- explain everything that happens to your baby;
to make sure that you understand the different situations;
• to make joint decisions about the care for the baby.

Following these steps and your approval are called ‘informed consent’. As parent representing the patient (your baby), you have the right to participate in the decision-making about the performance of diagnostic procedures, therapeutic manipulations, consultations, transporting the baby to another hospital and others. It is your right to refuse or want changes in your child’s treatment without being afraid of negative attitude and negative effect on the childcare quality.

Many routine procedures like blood tests carry a low risk for the baby. They do not require consent. In case of newborn children who are in condition threatening directly the child’s health and life, the doctor has the right to perform resuscitative actions without the parents’ consent. In this situation, doctors have to explain what has happened at the first opportunity.

Questions you can ask when the doctor informs you about the need for a certain kind of treatment, manipulation, operation or medicine:

1. How fast should a decision be made?
2. What are the benefits for the baby?
3. What are the risks for the baby?
4. What do the tests show and what is possible to do in this situation?
5. Will the baby feel pain? How can the pain be controlled?
6. What are the risks if nothing is undertaken?
7. Where can I find more information or details?

The decision-making shared between doctors, medical staff and parents is the best thing for your baby. Do not hesitate to ask about everything related to your child’s treatment – tests, procedures, medicines, etc. If you feel uncertain or if a difficult decision should be made, seek a second opinion.

After the birth, the doctor or the nurse will present you a document: ‘Informed consent of the newborn child’s parent/guardian for intensive
treatment or special care’. Read it carefully, get yourself familiar with the information concerning your baby and if you have questions, call on the neonatologist for explanation.

2. RELIEVING THE PAIN

As a parent, you do not want to see your child to suffer in whatever way. This is probably one of your greatest worries. That is why this section explains some of the ways of controlling the pain and reducing the stress for the baby.

During the time of special care, babies need different medical tests and procedures, which can often be painful for the baby. This refers to children subject to intensive treatment due to different kinds of diseases. The procedures are performed unless they are absolutely necessary.

The newborn baby must be protected from any painful procedure, which is not absolutely necessary for his/her health – extract from a Draft Law on the Rights of the Newborn Baby.

Any medical manipulation brings both risks and benefits, but the use of analgesics is not obligatory. If a procedure has to be applied to the child, who is more painful and unpleasant than the average, a medicine can be given to relieve the pain. The dose is based on the baby’s weight. If the baby needs an operation, a full anaesthesia is applied.

The neonatal unit should follow a policy of relieving the pain. Always signal if you think the baby feels a pain and needs help.

Over the recent 10-15 years, the attention of the medical staffs has been focused on the pain suffered by the youngest patients. Achievements in this area outside Bulgaria are already available and are applied in practice. However, in this country the problem is not discussed enough yet and is even neglected.
Yearlong research in this area has proved the necessity of the so-called family centres for intensive care for premature babies or babies with health problems. It has been proved that care in such centres reduces stress and pain, and guarantees parents’ support. According to the American Academy of Paediatrics (AAP), this helps:

- preserve the baby’s emotional state;
- ensure physical and social bond between the parents and the newborn;
- the pain and stress of the treatment is reduced.

All this has a favourable effect on the baby’s state, including on his/her weight, the need for supporting breathing and tube-feeding, as well as on reducing the length of his/her hospital stay.

Despite the lack of such family centres in Bulgaria, some simple steps could help a lot. For example, research shows that familiar smells like that of breast milk or the parent’s skin could have a calming effect on a baby at blood sampling. This applies fully to premature babies as well.

Other non-pharmacological methods that can help control the baby’s pain are:

- **Breastfeeding the baby during the time of the test or manipulation.** Breastfeeding has an analgesic effect and it is applicable to full term infants in stable condition. It is inapplicable to babies below 34-36 gestation weeks because of lack of a sucking reflex, as well as in cases when their condition does not allow it.

- **Putting a little breast milk or sweet solution (glucose) on the baby’s tongue.** It does not cause side effects. The analgesic effect is related to release of β-endorphin in the brain.

- **‘Kangaroo’ care.** Rey and Martinez first applied it in 1983. ‘Kangaroo’ care helps reduce the pain based on the mother’s touch and the ‘skin-to-skin contact’. At the same time, it leads to stabilising the newborn infant’s condition and temperature, and reduces the time of crying.
It lowers heart-rate variability and oxygen saturation resulting from the pain. It facilitates breastfeeding and is favourable to the child’s later development.

- **Music therapy.** While still in the womb, the baby can perceive sounds (after the 29th gestation week). After the birth, the mother’s voice has a calming effect on the baby. Music reduces the cortisol levels and improves the premature baby’s physiological stability. ‘The Mozart effect’ – Mozart’s music has a special emotional charge and it significantly excels in its healing power the works of other composers like Beethoven, Schumann, Ferentz List and others. The ‘Mozart effect’ helps recover the energy balance, which is commonly referred to as health. Apart from this, it creates harmony in the organism and has a favourable effect on the brain activity.

Of course, besides all these methods it is always possible to resort to medicamentous anaesthesia (analgesia). The doctor decides when it is necessary. Watch your baby for signs of stress and alarm the nurse and the doctors if the baby needs pain relief.

Other factors influencing the stress and pain in the baby are the mother’s voice, the contact, the embrace, the skin-to-skin contact, etc. Ask your neonatologist to let you touch your baby to fondle and cuddle him/her or to play music for them. Ask the doctor about the pain your child feels and how you can help reduce it. Doctors’ efforts to reduce stress in premature babies are aimed at providing quiet, darkened and peaceful environment for their treatment and growth. This is achieved by limiting the volume of sound alarms and signals in the intensive care unit. Another stress factor for babies is the twenty-four hour luminescent lighting in intensive care units. For this purpose, special covers are put on incubators. This makes the environment closer to the mother’s womb. The attending medical staff takes care and performs manipulations to the premature infants as gently as possible, according to the feeding and sleep schedule, etc.
Future research in this area is focused on studying, prevention and reduction to complete elimination of pain in the neonatal period. This is an additional precondition for achievement of the most important goal – saving the baby’s health, later development and quality of life.

3. COMPLICATIONS AND RISKS FROM COMPlications

Premature children encounter too many challenges in the first minutes of their lives. The reason is the immaturity of all organs and systems, leading to the inability of the baby to adapt alone to life outside the womb. It requires special care. The good news is, that in recent years, medicine has undergone significant development. Thanks to this progress, preterm children who previously could not survive, can now be saved and develop as healthy children. The biggest challenge for doctors is treating newborns with a birth weight below 1500 g, and especially under 1000 g. Even if your child is born with such weight, you can be sure that doctors will do everything in their power to make it survive and grow a healthy child.

Premature children have to overcome difficulties associated with breathing, maintaining body temperature, feeding, frequent infections and others. Here comes the role of the medical team of the Department of Neonatology. A „welcome“ preparation is done before each premature baby is born – a warm incubator, oxygen or ventilation device, monitor reporting oxygen saturation and heart rate and so on. This is of utmost importance and aims at maximizing the support of vital functions of the baby (breathing, heartbeat) from the first minutes after birth. The primary resuscitation in the delivery room, carried out on unified protocol, is a significant reserve to reduce late complications. Some premature babies (more mature and weighing around and above 2000 g) do well alone and do not require intensive care, prolonged treatment and special care.

Early complications

They occur shortly after birth, in terms of conducted intensive
treatment during their stay in the department. Possible complications are: pneumothorax (collapse of the lungs due to air entering the pleura), pneumonia, anemia, brain hemorrhages, severe forms of infections and others. These conditions of the baby require additional treatment, prolonge the stay of the child in the ward, and increase the risk of late damage. If they occur in your baby the neonatologist will explain what changes have occurred in the child’s condition, is there any danger to life and its later development, what measures have been taken and in what approximate time limits an improvement could be expected. More often such complications occur in premature infants weighing less than 1500 g and 1000 g. We will focus a little more in detail on some of them, but if you have any questions about your child’s condition, do not hesitate to ask your neonatologist.

Lung problems
During pregnancy, the baby develops and matures progressively until it reaches ability to cope with the life outside the womb. The drastic transition from the „water“ to „oxygen“ life is an impressive challenge requiring immediate adaptation, involving breathing, circulation, thermoregulation, metabolic balance, renal and digestive functions.

Of all organs that have to adapt to life out of the womb, the lung is undoubtedly one where the start of functioning is most impressive, but also the richest of consequences, due to its effect on the function of other organs. This very efficient respiratory system is achieved through the unity of the factors responsible for the correct anatomical and functional maturation.

- **Insufficient synthesis of surfactant substance – hyaline membrane disease.** The synthesis of surfactant increases after week 24. That is why, premature babies suffer from the lack of it, and this leads to the development of respiratory insufficiency in the first hours and days after birth. The artificial synthesis of surfactant and the therapy with
it are considered as a revolution in neonatology. The product is given to infants, who need it through a tube which penetrates into the throat and slowly releases the substance in the lungs.

- **Apnoea of the premature birth.** Premature babies often show breathing patterns, in which short breaks occur. Sometimes, these breaks can be longer and the babies should be „reminded“ to breath with gentle stimulation. Some medications can be used to stabilize the baby's breathing. Sometimes these breaks can be severe enough so that your baby needs a little help in breathing, but in most cases this problem will improve. If your baby is no longer on assisted ventilation, it will be attached to the monitor, which includes an alarm when the pause in breathing prolongs too much.

- **Pneumothorax.** Sometimes, air may be leaking from damaged air sacs in the lungs, especially if your baby is breathing with the help of assisted ventilation device. Air bubbles may form in the tissues of the lung or around the lungs and cause collapse of the lungs (pneumothorax). Large air pockets can press the lungs and make breathing difficult. In this case, the doctor can insert a tiny tube in the baby’s chest to be able to get the air out of there. Local anesthesia is administered during the procedure. Often, a drainage tube is placed in an emergency, so doctors and nurses may not have time to discuss the procedure with you.

- **Chronic pulmonary disease.** Babies, who have been on assisted ventilation for a long time, may develop chronic pulmonary disease (known as broncho-pulmonary dysplasia or CPD). We will discuss CPD in more detail a little later.

- **Meconium aspiration syndrome.** One of the reasons babies may need help breathing is the so-called meconium aspiration syndrome. During birth, some babies often inhale a mixture of meconium and amniotic fluid. Meconium is the first feces of the baby, that is thick, sticky and dark green. If your baby has the meconium aspiration syndrome, it may show signs of fatigue, weakness, lethargy and have a slow heartbeat. The trachea of the baby is cleaned from the most of the meconium. This is done by inserting a tube into the trachea of the baby (through the mouth or nose) and the meconium is sucked into it during the extraction. The doctor will continue until clean fluid comes out of the tube without signs of meconium. This can be a serious condition that requires complex and intensive medical care. However, most babies recover within a few days or weeks, depending on how much meconium they have inhaled. Usually there is no permanent damage to the lungs.
Other problems faced by the premature babies are related to:

- **Inability to maintain their own body temperature**: these children are kept in an incubator, which provides them with optimal ambient temperature and humidity. In infants under 1500 g and especially under 1000 g, the time of the incubator stay is longer – weeks, even months.

- **Immaturity and easy vulnerability of the brain structures**: the reason for the more frequent cerebral lesions in premature infants weighing less than 1000-1500 g. The most common neurological complications are brain haemorrhage and the formation of cysts. We will discuss this issue in detail later.

- **Incomplete development of the retina**: retinal maturation continues in unusual conditions (lack of complete darkness, air), and the developing structures are exposed to higher concentrations of oxygen, assisted ventilation, etc.

- **Immaturity of the immune system**: the immune system of premature babies is immature and this is the reason for more frequent and more severe forms of infection. Complications in premature infants were observed more frequently in those born **before weeks 32-34 / weighing below 1500 g**. Their frequency significantly increases in premature babies **under week 30 and weighing under 1000 g**. The existence of aggravating factors during pregnancy, birth and after that also affect the condition of the newborn after birth, the morbidity and the late complications.

**Major risk factors for the occurrence of complications in premature infants:**

1. Abnormal pregnancy.
2. Birth weight and gestational age – the lower the weight and gestational age, the greater the risk for damages.
3. Incomplete development and immaturity of all organs and systems of the premature baby - lungs, brain, gastrointestinal tract, kidneys, retina, etc. Their further development and maturation continues in a totally different environment and under conditions of intensive methods of resuscitation and complex treatment.

Late complications

**Bronchopulmonary dysplasia (BPD)**

Chronic pulmonary disease - develops in part of the preterm children. The incidence of the disease higher at gestational age under 30 weeks and weight less than 1500 g. Children weighing less than 1000 g are with the biggest.

- **What factors predispose to the development of this disease?** There are many circumstances that can affect and cause the development of bronchopulmonary dysplasia. Among the main reasons are: pulmonary immaturity (due to premature birth), presence of lung disease (hyaline membrane disease), which is more severe and requires longer and more intensive assisted ventilation of the child. The action of the oxygen, which is necessary for the treatment can cause specific changes in the lung. The premature baby has immaturity and low levels of protective enzymes. Therefore, it is more vulnerable to oxygen. A number of other factors also have an impact and meaning: infection during the birth of the child or developed later, feeding the sick child prematurely and many others. While presented with all these factors, not all at-risk children develop BPD.

- **What is the disease like?** Babies are diagnosed with bronchopulmonary dysplasia, if they are constantly on oxygen after reaching 36 gestation weeks (4 weeks before term), and chest X-ray confirms that there are changes in the lungs typical of this type of disease. They have rapid and difficult breathing, expend energy for the respiratory movements, eat harder and their weight gain is less than optimal.

- **What can be done to reduce and / or prevent the development of BPD?** Prevention of premature birth, effective primary resuscitation in the delivery room, treatment with surfactant, using the lowest possible concentrations of oxygen and so on. The main rule is to conduct an effective complex intensive care, maximum sparing for the child.

- **How should I care for the child and who will do the follow-up?** Besides the information during treatment, parents receive guidance on nutrition and child care at discharge. The disease, the treatment, the condition at discharge are described in the medical history. This information is
important for the GP of the baby. Follow-up and treatment of children with BPD is carried out by a team—a GP (general practitioner), a pediatric pulmonologist, a neonatologist, a pediatric cardiologist. The family is also part of the team. They carry out specific and continuous home treatment. Parents are informed of the need to ensure a non-smoking environment and timeliness of mandatory immunizations. In recent years, a specific prevention of RSV infections carried out for these children. You will be informed about it by your neonatologist, who will carry out this prevention in the autumn-winter season together with the GP. In the majority of cases, the result is a gradual improvement of clinical symptoms and lung function is normalized the age of 2. In some cases, an asthma may develop later on.

**Cerebral complications**

**Brain hemorrhages** (you will hear them also called intraventricular, ICH, or bleeding in the brain ventricles). The developing brain of the baby has plenty of blood vessels. Sometimes, these blood vessels rupture, causing bleeding in the brain. Short bleeding does not cause long term problems. Bleeding in the brain is classified according to its severity. First and second degree are mild and moderate bleeding - their prognosis is good. The third and fourth stages are the most serious – the late prognosis for them is the better, the sooner the haemorrhage if found out, the better it has been followed up and the timely the treatment was initiated. The increased bleeding can restrict the flow of blood to other parts of the brain, which means that they will not get enough oxygen.

**Risk factors**

Premature birth is an independent risk factor, especially if it is caused by conditions during pregnancy, leading to fetal distress. Preterm infants (especially with weight below 1500 g and 1000 g) are characterized with immaturity of the brain and brain vessels. Under an ongoing intensive treatment, the brain of premature babies is very vulnerable due to incomplete development. This creates conditions mostly for intraventricular haemorrhage – unilaterally or bilaterally. Their diagnosis and monitoring begins in the department. At discharge, you will receive information about the condition and the need for check-ups, tests and consultations. The follow-up is clinical and neurological, and with ultrasound examination – TFU (transfontanelle ultrasound). It is performed by a neonatologist and/or a pediatric neurologist.

**Formation of brain cysts** (the medical term for this problem is a periventricular leukomalacia or PVL). Sometimes, examinations show that parts of the brain
had not received enough oxygen. If these parts die, a pocket full of fluid, called a cyst, is formed in the place of brain tissue. How this will affect the baby depends on how many the cysts are, how big they grow, what areas of the brain are affected. This is a specific damage to the central nervous system, typical of premature babies, especially those born before week 31. It occurs in 10-15% of children under week 31 and only in 1% of those over 33 weeks. These changes in the brain may occur before birth, during birth and after it, or later due to various diseases of the child. Again, the main prerequisite for the occurrence of these changes is the immaturity of the brain. The child’s condition is monitored by transfontanelleultrasound (TFU). Long-term prognosis depends on the severity of the cysts. In the most severe forms, deviations in the locomotor and/or mental development are expected. This is the most common cause of development of CP (Cerebral Palsy). Follow-up, treatment and rehabilitation in these children is carried out by a team of specialists: a neonatologist, a pediatric neurologist, a physiotherapist, a therapist, eventually a psychologist. Early start of physical rehabilitation is important to prevent delays in motor development.

The terminology can be confusing. Do not hesitate to ask your doctor to explain the situation in a more simple and comprehensible language.

Hydrocephalus is more often a consequence of heavy bleeding. Hydrocephalus is an increase in the amount of CSF (cerebrospinal fluid) and the expansion of the ventricular system (brain ventricles). The leakage may be progressive, i.e. rapid growth of head circumference and progressive enlargement of the ventricular system. In these cases, after consultation with the neurosurgeon, a surgical treatment is carried out. In other cases, the follow-up shows retention or slow increase in time of the ventricular dilatation, which is more favorable.

A neurological consultation is required for all premature babies under 2000 g, after 2 months corrected age, for early and timely rehabilitation.
or other treatment. The purpose is to prevent and / or reduce the possible delay in early motor development of a child. Individual rehabilitation to stimulate motor development is recommended.

Eye problems in premature children

More common in premature children are: impaired visual function, reduced visual acuity, strabismus, retinopathy of the premature baby.

Retinopathy of the premature baby

It is a violation of the development of the blood supply of the immature retina. The degree of immaturity is essential for the emergence of retinopathy - gestational age and the weight at birth, taking into account the role of other factors such as oxygen, anemia, infections and others. The disease may go with mild and reversible damage to the retina, but in other cases it could be heavy and requiring treatment. There are five different stages, according to the severity of the disease. Prompt and specific treatment is needed in cases of III-rd to the V-th stage of the disease.

Which premature babies undergo mandatory eye exam?

- premature infants born weighing less than 1500 g or of gestational age below 32 weeks.
- children of mechanical ventilation longer than 72 hours or oxygen treatment more than 30 days.

When, by whom and how is the examination performed?

- First check up at the age of 4-6 weeks by a pediatric ophthalmologist.
- The frequency of subsequent examinations is determined by the ophthalmologist.

How is the examination carried out?

- With indirect ophthalmoscopy after pupil dilatation. It is performed by a pediatric ophthalmologist. The examination is short and painless.
- The examination with digital retinal camera (RetCam) is gaining more importance as the primary method in premature babies. Before the examination, local anesthesia and eye drops to dilate the pupils are administered.
Basic methods of treatment in the more severe forms of retinopathy are cryotherapy, laser therapy, and surgical treatment. Preventing retinopathy is limited to prevention of prematurity. The most important tool in this disease is the effective screening of premature infants and the early and adequate treatment. The universally conducted eye screening for designated categories of premature newborns is a fact in our country.

**Damage to hearing in extremely preterm infants**

It is more often in premature infants born weighing less than 1500 g. Deviations in hearing can be identified by the treating neonatologist or an ENT specialist. The examination is painless and within 5-10 minutes with the respective device. Thanks to the „Bulgarian Christmas 2014“ initiative, most NICUs are equipped with specialized devices to examine the hearing of the newborn. This allows for early detection of abnormal hearing and timely treatment.

**Anemia of the premature child**

It occurs more frequently in babies born before week 32. This is late anemia. It develops at the end of the first month after birth. The peak of the hemoglobin fall is at postnatal week 3-12. It is found with a blood sample requested by a pediatrician or a neonatologist. Prophylaxis and/or treatment with iron preparations, or vitamins is carried out, eventually transfusion, performed in a hospital.

**Growth and development**

The growth and development in premature children are important indicators to be monitored after discharge of the child. They are assessed against the corrected age (to be read on the day of the term rather than from the actual date of birth).

**Untill when to use corrected age?**

1. up to the age of 24 months for children born weighing under 1500 g
2. up to 12 months in children born weighing between 1500 g and 2000 g
Monthly assessment of the weight, height, head circumference, fontanelles, in accordance with the growth curves for premature infants. Healthy premature babies go through a period of accelerated growth in the first months. They quickly reach their peers. Children, born weighing less than 1500g, and especially those under 1000 g, can not catch up with their peers in growth until the third year. Follow-up is done by your pediatrician. You have the right to an examination and consultation with a neonatologist either as you wish or a referral by a GP.

**Herniations**

They are more common in premature babies.

**Umbilical herniation**
It rarely requires surgery. It is usually corrected with dressing and subsequent development of the muscles of the anterior abdominal wall.

**Inguinal herniations**
The incomplete descent of testicles in boys facilitates their emergence. They are often bilateral and quite large, but rarely lead to incarceration (entrapment). Most modern authors recommend early correction of the defect, i.e. an early consultation and follow-up by a pediatric surgeon is mandatory. Your pediatrician or neonatologist will refer you to a pediatric surgeon for check up.

**Conclusion**

Today, in the conditions of modern neonatology, there are opportunities for timely and effective response of the majority of the identified deviations of premature children. A good collaboration of many specialists: a pediatrician (general pediatric care and prevention), a neonatologist, a pediatric neurologist, a pediatric pulmonologist, an ophthalmologist, an ENT specialist, a psychologist, and so on is needed to carry out the best possible and efficient follow-up of premature children.
4. DISEASE PREVENTION

Disease prevention in premature infants includes a set of different measures. Many people are involved and responsible for their implementation, improvement and modernization: the state, the healthcare institutions, physicians, nursing staff, medical professionals, NGOs.

Prevention of the most common diseases of the premature infants and the possible late consequences are the basis of the treatment and care for these children. Today we witness the survival and growth of children under 1000 g. This is due to the contemporary and modern neonatal therapy. Recent years are characterized by extremely rapid development and introduction of new methods of intensive care therapy, prevention and follow-up of premature infants.

Some of them are: a routine application of surfactant treatment in hyaline membrane disease (HMB) in premature infants. This led to significant reduction of mortality from HMB and improved survival. Introduction of new methods for artificial ventilation, dosed and strictly controlled oxygen treatment, improved housing conditions, timely diagnosis and treatment of early neonatal and nosocomial infections, and of the complications, etc.

Examinations that are performed at the NICU

1. “Eye screening of premature infants” for the early detection and treatment of retinopathy of the premature baby.
2. Ultrasound examination of the central nervous system in premature for the early diagnosis of intraventricular hemorrhage, the periventricular leukomalacia, etc.. This allows for rapid focusing the parents of these children to the need for early motor rehabilitation.
Further to these facts and priorities, we should also mention the improved equipment in most NICUs in the country. It includes modern incubators for growing premature infants, newer generations ventilation equipment, with improved capabilities and gentle to the immature child, personal continuous monitoring for each baby, and rapid diagnosis equipment (transfontanelle ultrasound equipment in the department, and mobile X-ray machines, etc.).

The medical staff with their skills, experience and attitude towards the child and his parents plays an important role in the whole process.

After being discharged from the department, the care for the baby is taken on by the parents along with doctors from different specialties. These children are grown, checked up and monitored more often and with more caution. The care for them post discharge contains many components.

**Frequently asked questions and concerns after discharge**

1. **How and what to feed the baby with?**
   Upon discharge from the department, your neonatologist will inform you on how to continue feeding at home. The common practice in most NICUs is that the mother to be next to the baby before discharge. She takes part in caring for it - bathing, breastfeeding techniques, how to hold it during breastfeeding and then, the technique of bottle-feeding and others. Breast milk is the ideal food for your baby. In the beginning, the baby may get tired quickly when breastfeeding. In such cases, squeeze and supplement with this breast milk. When difficulties or doubts whether the deal with breastfeeding, breastfeeding consultants in your city may be useful for you when in difficulty or in doubt whether you do well with breastfeeding. Look for them. If you feed the baby with infant formula, the neonatologist will help you with the choice of milk (a special type for premature babies), the optimum amount for the age and condition, the number of feedings, and medication supplements: vitamin E, iron formulations and others, targeted at prevention or treatment.

2. **If your child is diagnosed with bronchopulmonary dysplasia (BPD)**
   Your neonatologist will inform you about the disease, both during hospitalization as well as the state of the baby at discharge. He will direct your attention to the feeding peculiarities, what to watch on the baby, what is normal and when to seek medical attention. The GP will refer
you in the first month after discharge to a consultation with a pediatric pulmonologist. He will follow up the pulmonary disease of your baby, the appointed tests, treatment and checkups.

3. **When to seek medical help?**

If the child refuses to eat (in three or more consecutive refusal of food), if breathing is difficult, fast or slow, the color of the skin becomes pale, and the area around the lips and the hands appear of bluish color. You should seek for a doctor immediately regardless of the time of day.

4. **If your child is diagnosed with intraventricular hemorrhage (IVH) or periventricular leukomalacia (PVL)**

Diagnosis and monitoring of the evolution of the IVH / PVL start at the department. At discharge, the child will receive information about his condition at the time and the need for check-ups, exams, and consultation. Your GP or neonatologist will refer you for a consultation with a pediatric neurologist.

Your pediatric neurologist will inform you for any further examinations, testing and treatment. Following up the evolution of the IVH / PVL is done by examining the neurological status, reflexes, etc., in accordance with age, as well as by periodic ultrasound examinations. It is important to note that the ultrasound evaluation is completely harmless to the child and thus can be repeated without side effects. This is a major advantage over all existing modern methods of examination.

Children are very suitable patients for ultrasound, due to the reduced subcutaneous fat in newborns and open anterior and posterior fontanelles, allowing for the visualization of brain structures in detail. Screening of the central nervous system makes it possible to determine the potential risk of a serious disease and to take the necessary measures to prevent it. It is performed by a neonatologist and / or a pediatric neurologist.

**In children with PVL,** the follow-up, the treatment and the rehabilitation are carried out by a team of specialists: a neonatologist, a pediatric neurologist,
a physiotherapist, a therapist, and eventually a psychologist. Early start of 

motor rehabilitation is important to prevent delays in motor development.

**What signs in the baby should I pay attention to?**

Some symptoms in children with increased risk are useful in reporting 

the opportunities for development of cerebral palsy (CP). 

Such symptoms can be:

1. increased sleepiness,
2. restlessness or excitement,
3. high cerebral crying,
4. weak sucking reflex,
5. inability of the child to hold the head in line with the body (tilts forward or backward)
6. profuse salivation,
7. reduced interest towards environment
8. asymmetry in motion
9. twitching – short or long,
10. staring eye, etc.

If you notice these or other symptoms, which are of your concern, you should call and talk to your GP, your neonatologist or neurologist.

**5. Premature baby retinopathy**

Premature baby retinopathy is a significant health problem. The first exam of the eyes, and if necessary, the initial treatment of retinopathy is also done in the NICU. Your neonatologist will inform you of the characteristics of the disease, at what stage it is with your child, what the treatment is, etc. At discharge, both in medical history and orally, you will be explained when and where to perform the follow-up of the child. Your GP will refer you to a pediatric ophthalmologist. You have the right to choose the ophthalmologist for your baby. Your treating ophthalmologist will set the schedule for follow-up, treatment and exam frequency. Basic methods of treatment in severe forms of retinopathy are the cryotherapy, the laser therapy, and the surgical treatment.
Retinopathy prevention is limited to prevention of prematurity. The most important for this disease is the effective screening of premature infants and the early adequate treatment. A universally conducted eye screening for designated categories of premature newborns is a fact in our country.

Conclusion

Children need a special policy to guarantee them their natural right of a life, good health, full training and development. They should be a priority of the state policy. The state has exclusive options to create the most favourable conditions for the development of our children and to provide special care for vulnerable groups, including our preterm children. Today, the country is in debt to the children. In this regard, a certain compensatory role is played by the NGOs, the various foundations and associations. Associations of families with children suffering from certain chronic diseases are particularly important because of their mutual support in solving the complex medical and social problems of these children.

5. HOW LONG WILL MY BABY STAY IN THE HOSPITAL?

Perhaps one of the main questions you keep asking yourself is: ‘When can we take our baby home?’ The answer depends on your baby’s needs. It might be several days to weeks and sometimes even months. Many premature babies get home about the date of their expected day of delivery. If nobody tells you how long the baby’s stay can be, do not hesitate to ask the doctors or the nurses.
You can always ask about everything you are interested in because as a parent you have the right to know.

Although there is no single answer to this question, to be able to get an idea of the time a premature baby stays in the hospital, depending on when it is born, we present you a study of Foundation ‘Miracle Babies’ made among families with premature babies. The answers of 625 families participating in the study have been compiled and the medium length has been calculated.

It is important to specify that this is rough statistics, because we should not forget that every child is unique. That is why their stay in the intensive care unit is different.

<table>
<thead>
<tr>
<th>Birth in gestation week</th>
<th>Average stay in the hospital</th>
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<tbody>
<tr>
<td>24th week</td>
<td>133 days (19 weeks)</td>
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<tr>
<td>25th week</td>
<td>108 days (15 weeks + 3 days)</td>
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<tr>
<td>26th week</td>
<td>101 days (14 weeks + 3 days)</td>
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<td>27th week</td>
<td>80 days (11 weeks + 3 days)</td>
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<td>28th week</td>
<td>76 days (10 weeks + 6 days)</td>
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<td>29th week</td>
<td>75 days (10 weeks + 5 days)</td>
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<td>30th week</td>
<td>50 days (7 weeks + 1 day)</td>
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<td>49 days (7 weeks)</td>
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<tr>
<td>32nd week</td>
<td>36 days (5 weeks + 1 day)</td>
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<tr>
<td>33rd week</td>
<td>27 days (3 weeks + 6 days)</td>
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<td>34th week</td>
<td>21 days (3 weeks)</td>
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<tr>
<td>35th week</td>
<td>16 days (2 weeks + 2 days)</td>
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<tr>
<td>36th week</td>
<td>11 days (1 week + 4 days)</td>
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~ CHAPTER FIVE ~

1. How breast milk helps premature babies?
2. Expressing breast milk for the baby – all the answers to your questions
3. My breast milk supply has suddenly decreased – what to do?
4. I have a slow breast milk flow and it is not increasing – why?
5. Hygiene and storing breast milk for premature or sick babies
6. Breastfeeding a premature baby – how to begin, what to expect, how to deal with the problems you experience?
1. HOW BREAST MILK HELPS PREMATURE BABIES?

Your body knows that the baby was born much earlier than normal and begins to take care of ensuring his/her survival. Since premature babies require a higher amount of protein, fat, calcium, phosphorus, zinc, magnesium and other trace elements, in the first 2-4 weeks after birth your body tends to produce milk, which contains more of those.

In the last three months of pregnancy, large protein molecules – immunoglobulins – pass through the placenta and accumulate in the baby’s body. As their name suggests, they provide immunity against various infections once the baby is born. Your baby was born earlier and failed to accumulate enough protective factors for life outside the womb. Therefore, your body starts to concentrate immunoglobulins in the milk in order to transfer them to the baby and continue to protect the baby.

During breastfeeding, part of these protective factors “pad” the lining of the digestive system and help it mature faster. This reduces the incidence of all types of infections in premature babies. It is also one of the mechanisms through which your milk significantly reduces the risk for your baby to develop one of the extremely dangerous conditions in premature babies – necrotizing enterocolitis (a serious inflammation of the bowel requiring surgery).
Not only the baby’s body, but also the baby’s brain develops rapidly in the weeks before the term. In the last months of pregnancy, the brain doubles its size and weight – and therefore needs the special development ingredients contained in breast milk. **According to research, premature babies fed breast milk have a better chance of developing a full intellectual potential.**

The maturation of the brain helps for the quicker development of the baby’s feeding reflexes. Breastfeeding – direct breastfeeding! – from the moment it is physically possible, is less stressful to the baby than bottle feeding. At the breast, the baby can control the milk flow and stop when necessary. This way the oxygenation stabilises, the cardiac rhythm remains steady and your body helps to maintain the baby’s body temperature.

Last but not least, babies who are fed breast milk only or whose diet consists of mainly breast milk, leave the intensive care unit on average 1-2 weeks sooner! Your milk helps your baby go home sooner!

**How breastfeeding and expressing breast milk for your premature baby helps you**

Expressing milk for your baby will help you feel you are doing something specific and extremely important. Sensing your full breasts is a way to feel a constant physical relationship with your baby, even if he/she is far away.

Each bottle of breast milk reminds you that you are helping your baby return more quickly to you and you are guarding and defending your baby all the time.

Through breast milk, you give your baby a feeling of you, your scent and the taste of the food you eat – and this will help you “recognise” each other more easily when you finally cuddle your baby.

The moment your baby is able to attempt to suck, breastfeeding automatically provides you with time for cuddling your baby. You know
how valuable, how brief and frustratingly insufficient this contact is while your baby is in hospital – breastfeeding is the ideal strategy to ensure maximum physical contact, cuddling and feeling the baby while he/she is still in intensive care.

Last but not least, the skin-to-skin contact helps both you and your baby. Cuddling your baby gives you a feeling of peace and hope and helps you express breast milk more easily. The physical contact is a proven way to increase the amount of breast milk!

The time spent in your hands gives the baby invaluable sensory stimulation. You provide movement, smell, heat, your voice (which sounds especially for your baby!) and the taste of your milk changing from feeding to feeding. These experiences may seem small but in the womb, they are natural and typical, whereas in intensive care you and your baby are almost completely devoid of them if the infant is not breastfeeding and is not getting your breast milk. Perhaps the better brain development that occurs in breast-fed immature babies is partially due to the stimulation of all the senses through the contact with Mom!
2. EXPRESSING BREAST MILK FOR THE BABY – ALL THE ANSWERS TO YOUR QUESTIONS

Your goal

- 600-700 ml of breast milk on the 14th day after the birth of a baby
- 900-1000 ml of breast milk on the 14th day after the birth of twins

How and when do I start expressing breast milk for my baby?

Start expressing as soon as you can – best in the first few hours after delivery!

Your situation is very different from that in which a baby is born at term and healthy. The baby is not with you and you cannot rely on his/her sucking to trigger and maintain the production of breast milk.

For your body, however, things are no different. The baby was born, the placenta separated, the hormonal start of breastfeeding occurred. Your breasts expect to receive stimulation just as often as if your baby was born at term.

Breastfeeding depends entirely on you – you need to create a good organisation and technique of expression to allow milk to start on time and to achieve the required amount.

When do I start expressing?

Ideally, irrespective of when the baby was born, the stimulation of the breasts should begin during the first several hours after delivery.
With all the stress about the premature birth, you probably will not have a breast pump. Expressing milk by hand, however, is an affordable and easy way for stimulating the breasts during this time. Colostrum is thicker and in a small amount so it is often considerably easier to express it by hand than with a pump. You can ask the midwives to show you how to express milk by hand and begin to drain both breasts every 2-2.5 hours during the day and about 4 hours during the night.

The first day you will hardly be able to express breast milk more than 3-5 times. This is normal – but it is important for the breasts to receive a signal that the milk will be necessary! The next day you will feel much better physically, so then it is important to achieve at least eight expressions in 24 hours.

At first, the amounts of colostrum you express will be very small.

**It is normal to obtain only drops of breast milk during the first expressions.**

During the first 2-3 days, the amount increases to 2-5 ml (half a teaspoon to one teaspoon).
The amount of breast milk starts increasing significantly after 4-5 days, depending on when you began to express frequently and regularly. The sooner you start after delivery, the faster the breast milk will increase!

The hospital will not probably have the proper conditions for storing colostrum. It is possible that your baby will not be able to receive anything through the mouth in the first 1-2 days. In our hospitals, there is still no practice of rubbing drops of colostrum on the lining of the baby’s mouth as a hygienic measure and a first step towards parenteral nutrition. However, you can discuss this option with your baby’s doctor.

The loss of colostrum probably makes you sad but think ahead. It is important that you, through frequent expressing, build a good milk supply for when your baby will be able to take it. Therefore, even if you cannot store colostrum and it does not reach your baby, it is still important to continue to express frequently and regularly, not less than 8 times in 24 hours.

**How often should I express breast milk?**

**Why should I express frequently?** In the beginning, your baby is very tiny and his/her needs are very small. Often premature babies begin with 1-2 ml per feeding. At first, you will be able to cover your baby’s needs with only one expression per day. If you express only 2-3 times a day, however, the amount of your breast milk will not increase but will soon start to decrease.

The first days after delivery are the “marketing phase” in breast milk production. Stimulation in these first days dictates how much breast milk you will be able to produce. The frequency of emptying the breasts determines whether you will build a large factory with a lot of milk or a limited dairy farm with small production.
The mammary gland contains multiple cells, whose function is to produce breast milk. In the first days after delivery, your body releases hormones that activate these cells. That is why after 3-4 days the amount of breast milk expressed starts increasing sharply. However, if the breasts are not stimulated constantly and frequently through complete emptying, most of these cells go into “sleep mode” and stop producing. The few remaining cells will produce as much as is set by the frequency of expressing. If for several weeks you set approximately 100-200 ml per day, because that is how much the baby needs, your breasts will gradually adapt to produce such an amount.

However, a premature baby needs 700-800 ml of breast milk per day the end of the first month. When you need more breast milk, it will be very difficult to awake the “sleeping” cells. Increasing breast milk supply in such a situation requires a lot of work and effort and is associated with many concerns and fight. Therefore, in situations like yours – when a long period of separation from the baby can be expected, in the first weeks it is extremely important to maintain a frequency of expressing corresponding to the frequency of feeding a term baby – at least 8 times in 24 hours. The aim is to strive to achieve and maintain that amount until your baby becomes stronger.

Expressing and maintaining plenty of breast milk is important for several reasons:

Even the best breast pump available on the market does not have the same effect on your body as your baby. The cold plastic is quite different from the feeling of a warm hungry baby in your arms. That is why the body does not secrete hormones in exactly the same way. However, it is important to know that breast milk can be maintained only through pump expressions in the course of many months.

This, however, requires more effort and more attention on your part. When maintaining breast milk only through expressing it, the amount of milk usually decreases slightly after the first 3-4 weeks. Therefore, the initial quantities of breast milk should exceed the needs of a term baby. Thus, the expected reduction will not be of particular importance and will still cover the needs of your baby, even when he/she is big enough and close to the term.

The abundancy of breast milk has another very important aspect – when there is a lot of milk and it flows easily, it is significantly easier for the baby to feed at the breast and he/she learns to suck much more quickly.
How should I organise the expressing of breast milk? I should still be able to rest and visit my baby at the hospital...

Clearly, it is almost impossible to express breast milk every three hours around the clock – it is impossible to do it for weeks or months. It is therefore necessary to find a way to combine the eight expressions with at least one longer break for sleep.

The longest possible period in a day without expressing breast milk is 5-6 hours. It is a good idea to use it for a night’s sleep, which will allow you to relax and be in a good shape. I.e. assuming the last expression for the day occurs around midnight, you need to wake up around 5-5.30 am for the first expression of the new day (your breasts will probably signal you before the alarm because they will begin to overfill).

Since you did not express breast milk in those 5-6 hours, you have 18-19 hours remaining to do the eight expressions. Apparently, there is no way to do the eight expressions at 3-hour intervals, so it is wise to try expressing every 2 hours. And because at some point you will surely need to go to the hospital to see your baby, where you will probably spend some time, the pace will be broken.

It is almost impossible to achieve equal intervals between the expressions of breast milk – fortunately, this is not necessary. Contrary to what you hear and what you see as a pattern of feeding at the hospital, babies do not feed at regular intervals either. At times they feed more frequently and at other times they take longer breaks. Therefore, you should seek to express breast milk every 2 hours during the day when you are at home. If you need a longer break, you can express several times at shorter intervals – every hour or so. It is very typical of babies to suck every half an hour or every hour for a few hours in the evening, so it is not a strange rhythm to your body.

If at the beginning you express breast milk at larger intervals and then start to express more frequently, it may seem that you express much less. The feeling of filling the breasts will also confuse you. It is important to watch the amount expressed for a total of 24 hours and not per session. In fact, eight expressions of 30 ml is the same amount as six expressions of 40 ml or four expressions of 60 ml. The difference is in the frequency of breastfeeding – and hence in its effect on the amount you produce. Expressing 30 ml 8 times will result in an increased amount of breast milk
after a few days because the breasts are stimulated frequently, whereas expressing 60 ml 4 times can lead to a gradual reduction after a week or two (or even faster).

The larger number of expressions, even if they are shorter, has a better effect on the amount of breast milk than long sessions at large intervals.

How should I express breast milk?

It is important to choose the way that is most convenient for you and gives the best result. You can either use a breast pump or express by hand. You need to try to see what will be most appropriate for you.

How long and how much should I express?

With a little practice, you will quickly learn to understand when your breasts are fully emptied. At first, while still building a routine, you can follow these steps:

- Wash your hands thoroughly with soap and water
- Wash your breasts according to the instructions given to you at the hospital.
- If you want, you can apply a warm moist compress for several minutes
- Massage, caress and stimulate the breast for a few minutes
- Start draining the first breast
- When the milk flow decreases to drop, start draining the second breast
- Once again, massage, caress and stimulate the nipples
- Go back to the first breast – milk should flow again, though less and for a short time
- Drain the second breast in the same way
- If necessary, repeat the whole procedure
- If you need to increase the amount of milk, continue to drain each breast for another 2-3 minutes although you get only drops.

After a good expression, the breasts feel relieved and softened. There are no painful lumps or hard areas sensitive to pressure (on the side of the breast the mammary gland expands most rapidly so there are always
tough and hard patches which, however, are not painful when the breast is emptied).

In the beginning, while your breasts are not yet used to responding to the pump and while you are looking for the best technique, expressing will probably take a long time – about 45-60 minutes. After building a routine, for most women the whole procedure of draining both breasts by hand or by a single pump takes about 30 minutes. An electric pump, which allows you to drain both breasts at the same time, can reduce the time needed to about 15-20 minutes per session and generally stimulates breast milk production to a greater extent due to the simultaneous stimulations of the breasts.

When using a manual or a single electric pump your goal is to spend at least 240 minutes expressing breast milk per 24 hours.

The important thing in the first month is to express breast milk at least 8 times per day, always until both breasts are fully emptied. Ideally, your goal 10-14 days after delivery is to produce 600-700 ml of breast milk (900-1000 ml if you have twins) per 24 h.

When you reach this amount and keep it steady for about a week, you can try to see if you can maintain it with 6-7 expressions a day – it is usually
possible for most mothers. Depending on how early the baby was born and what his/her condition is, the baby may be home by this time and help you maintain your breast milk supply through sucking.

Expressing breast milk is difficult and takes an awful lot of time – how to do it easily and efficiently?

Expressing breast milk is not an easy job and despite your strong motivation and desire, it quickly becomes tedious and difficult. Therefore, it is important to find a way to do it in the most efficient way. This will help shorten the duration of the sessions.

Your breasts are programmed to release milk in response to the various sensations caused by the baby’s touch, wet mouth and sucking movements, as well as the rush of hormones, which occurs in your body when you simply take your baby in your hands. All this is infinitely different from the cold plastic of the pump, the stress connected with the need to express and the concerns how much you will be able to express. Therefore, it is quite normal that your body may not respond to the pump very enthusiastically at first.

Expressing breast milk is not in your nature – it is a skill, which along with a purely physical dexterity and understanding of the operation of the pump, requires the creation of a certain emotional attitude and habits concerning the facilitation of the release of breast milk in order to make the pumping successful.

The following can facilitate the expression of breast milk:

**Physically:**
- A warm moist compress on the breasts 10-15 minutes before expressing
- Breast massage
- Nipple stimulation
- A glass of fluid (especially a warm soothing tea, e.g. linden or chamomile)

**Mentally:**
- Meditation
- Relaxation techniques
- Breathing techniques (yes, the same you learned when preparing for delivery)
- Visualisation (imagine certain things, especially running water, a river, a
waterfall)
• A photo of your baby
• Baby’s clothes that smell of him/her
• A record of your baby’s cooing and crying (on your phone)

The creation of a routine in the preparation for expressing breast milk will help you immensely. The hormone oxytocin, which is needed to trigger the milk flow and to empty the breasts properly, can be stimulated successfully with physical as well as with mental and emotional stimuli.

If you regularly do the things that are most successful specifically for you, especially when done in the same sequence, this will create not only a physical, but also a mental attitude. It will allow you to trigger the oxytocin easily and release the breast milk. This requires time and patience – but usually in about a week your body will begin to respond automatically to these stimuli.

Do not be discouraged if at first you only express 10-15 ml and it seems like that is all. The vacuum of the pump sucks only the milk that is located directly behind the areola. For the full draining of the breast, it is necessary to excite the reflex ejecting the milk located in the upper parts of the breast.

**Stimulating the let-down reflex**

It is no coincident that oxytocin is called the love hormone – it is stimulated by a variety of physical interactions (e.g. a hug, a touch), as well as by stimulating the nipples.

Breast massage and the gentle teasing of the nipples will cause oxytocin release and will facilitate pumping.

**Breast massage**
• Place your fingers on the upper part of the breast.
• Press toward the chest so that you can feel the pressure – but not pain!
• Massage gently in a circular motion round the breast

**Caressing**
Try the different options to decide which of them feels best for you

• Using your fingers caress your breast from the top toward the nipple
• Gently move your fingertips from the top of the breast to the nipple
• Bend your hand into a fist and using you knuckles caress toward the nipple

**Nipple stimulation**
• Hold the nipple at its base with the thumb and forefinger
• Rhythmically squeeze between the fingers several times, making sure to do it gently and tenderly
• Tease the nipple by gently pulling it forward (particularly useful with poorly shaped nipples)

*Remember – your goal is to encourage your breasts to release the milk and not to mistreat them! After the massage, the skin of the breast should have a normal colour and not be irritated or chafed.*

The duration of the massage, caressing and nipple stimulation usually takes 2-3 minutes for both breasts.
3. MY BREAST MILK SUPPLY HAS SUDDENLY DECREASED – WHAT TO DO?

Reduction in the breast milk supply can occur for many reasons – and it often happens even to mothers who nurse directly at the breast. You express breast milk and see what you produce – it brings more stress and concerns about the normally occurring fluctuations in the amount that otherwise you would not have noticed.

The amount of expressed milk can fluctuate from day to day for a number of reasons:
- **Less frequent expressions** (this is the most common and serious cause with the most dramatic effect on the quantity!)
- **Stress** – e.g. if the baby’s condition has deteriorated or you got seriously upset at the hospital
- **Tiredness**
- **Insufficient fluid intake**

The reduction in the breast milk supply can be avoided! Just do as mothers whose babies suck at the breast do – if the amount is decreasing or if there is a need to increase the amount it is necessary to empty the breasts quite frequently (sometimes even twice as often as compared to the current routine).

- For 2-3 days try to do 2-3 additional expressions.
- Try a “super” schedule for draining the breasts – put the pump in a place where you feel comfortable and where you most often sit. Every time you sit there pump each breast for a few minutes.
- Apply breast compression during pumping
- After pumping, try expressing by hand for 2-3 minutes. Do this additional expression by hand after at least five of the pumpings for the day.
- If possible, attempt to spend more time making skin-to-skin contact with your baby during your visits – it favours the production of breast milk and calms you.
- Try to rest more – a short nap can help you feel fresh and rested. You may notice that afterwards you are able to express more breast milk.
• Do not neglect drinking fluids in the panic – try to drink a glass of water, lactogenic tea or your preferred drink before each pumping.

If the reduction in the breast milk supply is substantial and is not affected by the appropriate measures within a week, or if 14 days after delivery the amount of expressed milk with a good frequency of draining remains below 500 ml per 24 hours, contact your baby’s doctor or nursing consultant. You can discuss additional ways to stimulate the breast milk with them.
4. I HAVE A SLOW BREAST MILK FLOW AND IT IS NOT INCREASING – WHY?

With premature childbirth, your body has not yet fully completed the cycle of pregnancy. Breasts are not ready either to start producing milk as at term. If because of the stress and anxiety in the first days, you have not begun to express soon enough after delivery and often enough, the delay in the increase of breast milk is not surprising. The most common reason for the delayed and difficult increase in the breast milk supply is exactly this – a late start (3-4 days after delivery) and an insufficient frequency (3-4 times a day instead of 9-10 times). Fortunately, this problem can easily be overcome if dealt with during the first week.

According to research, for only a quarter of the mothers whose babies are born earlier breast milk starts to flow about the same time as when the baby is born at term (48-72 hours after delivery). For most women it takes about a week to observe a steady increase in the breast milk supply.

If, with an early start and a good organisation of pumping, at the end of the first week you are able to express only drops or 10-15 ml of breast milk, it is important to contact a nursing consultant immediately and try to identify the reasons.

- **Is the reason related to the pump?** An unsuitable pump (e.g. a syringe-type pump or one with a bubble for squeezing) may be the reason why you are not able to drain the breasts well. Pump connectors have different sizes as nipples differ in size and diameter. If the connector is too small or too large for your nipples, pumping may not be possible. Changing the connector (or the pump if the one you are using cannot be fitted with the proper size) can quickly resolve the issue. The improper
use of the pump can also lead to difficulties. Carefully read the instructions in order to be aware of the different buttons controlling your pump. Begin to pump at lower vacuum power and when you can feel the milk start descending or see the first streams, increase the power to the maximum possible level that is comfortable for you (on the border between OK and signs of discomfort).

- **Is the reason related to your breasts?** If you have had breast corrections (implants, reduction, lifting) or other types of breast surgery, this may have interrupted the ducts and be the reason why your breasts cannot produce much. Have you ever worried about the appearance of your breasts? A “strange” shape and/or a serious difference in the size of both breasts can suggest a poor development of the glandular tissue. Try not to make a diagnosis yourself but contact a consultant to discuss what exactly is going on and if the appearance of your breasts is a sign of possible problems.

- **Is the reason related to the hormones?** If you suffer from a hormone disorder (such as, not exhausting all the possibilities, thyroid problems, diabetes, hyperprolactinemia, etc.), this can have a significant impact on the descent of milk and the increase of its quantity. Fertility issues caused by hormonal and immune problems are also a risk factor for you. The retention of placental parts in the uterus after delivery also confuses hormones and often creates problems with breastfeeding, as progesterone levels do not fall as they should. This prevents the normal increase of prolactin and therefore breast milk does not increase as expected either.

- **Is the reason related to medication?** Corticosteroids, which are done with a threatening preterm delivery, are extremely important in helping the baby’s lungs mature so that the baby has less breathing problems after birth. Unfortunately, however, in some cases (e.g. when done 7-10 days prior to delivery) they affect breastfeeding hormones and for a certain period may prevent the increase of breast milk supply. If for controlling hyperprolactinemia during the pregnancy you have taken Bromocriptine or Dostinex for a long time (these two are also used for suppressing breast milk production!), this can also prevent breast milk from increasing in proper terms. Sometimes pills for suppressing breast milk production are prescribed in rather preterm delivery even without your knowledge with the idea to spare you the labour to express for months. It is therefore very important to ask every time what medicine you are given and why. There is no reason to stop breast milk production only because your baby was born earlier – the maintenance of breast milk is possible. And the provision of breast milk will really help your baby immensely!
The doctors and your nursing consultant will help you overcome all the problems you may encounter in increasing and maintaining your breast milk supply. Do not despair even if nothing goes according to plan. Normally, you have weeks to work hard on eliminating problems. Nursing consultants have the knowledge and skills to identify the obstacles and to support you on the way to overcoming them. Your doctors can prescribe medication and help control the conditions that interfere with breastfeeding. Together you will succeed!

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5. HYGIENE AND STORING BREAST MILK FOR PREMATURE OR SICK BABIES

Since your baby is immature and extremely vulnerable, it is very important to follow strictly and precisely the instructions given to you at the hospital for expressing and storing breast milk. The various hospitals have different rules concerning access to babies and breastfeeding according to the baby’s age and condition, so it is important to ask for instructions on how to proceed specifically. If no other information is given to you, you can follow these general rules:

- Wash hands thoroughly with soap and water before each expression
- At Bulgarian hospitals you are also usually required to wash your breasts with warm water and neutral soap before expressing
- Wash and sterilise the parts of the pump after each use!
- Put the expressed milk in a sterile container for breast milk and place it in the refrigerator immediately after expressing it if you are not giving it to your baby within the next hour. If the milk is not going to be used in the next 12-24 hours, freeze it as soon as possible after expressing it. (In many hospitals in the country, frozen breast milk is not accepted; the mother is required to express breast milk in the neonatal unit using her own pre-sterilised pump and the baby is given fresh breast milk).
- Do not mix breast milk from different expressions – any additional transfer of milk increases the risk of bacterial contamination.
• It is a good idea to freeze breast milk in small portions – 50-60 ml is a good amount to freeze separately. If big portions are frozen, some of the milk may not be used in time and will have to be discarded.
• Label each container with the date of pumping. When you start feeding your baby breast milk, bring milk in order of expression, starting with the earliest date. The composition of breast milk changes considerably in the first days, so it is good for your baby to receive the earliest milk first.
• Bring the frozen breast milk to the hospital in a quality cooler to avoid even minimal thawing.
• Take a little more with you than you were told. For various reasons milk can be spilled or the baby can suddenly show that he/she needs a little more.

Sometimes the breastfeeding mother may fall ill while the baby is still at the hospital. Phone the neonatologists and ask for instructions on how to proceed with the breast milk. Most likely, you will be asked not to bring milk while you are ill – but the father can bring milk expressed in the days prior to the illness.

Label the breast milk as expressed during illness and do not bring it while the infant is at the hospital. It can be given at a later time when the baby is bigger and at home.

In case you need to take medicines, you will probably be also asked not to store breast milk. Consult your doctor, pharmacist and nursing consultant at what point after the end of the treatment you can again start bringing your baby expressed breast milk. The various medicines take different time to be absorbed by the body, so it is necessary to discuss each medication separately.

The use of herbal supplements should also be discussed with your baby’s doctors! Despite being natural remedies, some herbs have a strong effect and are not suitable for use by the mother when the baby is very little or has jaundice.

If your baby develops a yeast infection (thrush) in the mouth and it is passed on to your breasts, the milk expressed during the treatment should be discarded. Freezing does not destroy fungal spores and therefore the milk cannot be stored.
6. BREASTFEEDING A PREMATURE BABY – HOW TO BEGIN, WHAT TO EXPECT, HOW TO DEAL WITH THE PROBLEMS YOU EXPERIENCE?

The baby appeared in a period in which his/her development is not yet completed. The volume of the brain of a baby who is born in the 34th-35th week of gestation is only 65% of that of a healthy term infant. In the 36th week, the volume of the brain reaches 80% of that of term infants. Therefore, it is normal for the baby’s reflexes and abilities to be immature and not sufficiently prominent or synchronised. This immaturity affects the control of breathing, the periods of sleep and wakefulness, as well as the strength and coordination required for feeding.

The earlier the baby is born, the more immature his/her reflexes and skills are. In the womb, the baby is feeding through the umbilical cord and his/her digestive system is not involved in the absorption of nutrients. The situation is similar with his/her oral abilities and reflexes. After 24-25 weeks of gestation, the baby in the womb can swallow amniotic fluid and the thumb sucking is observed as early as the 14th-15th week. However, this happens in the womb, where the conditions are quite different. The baby swims in an aquatic environment, which requires much less muscular effort. There is no air and no coordination between swallowing and breathing is needed. Therefore, the underdeveloped skills in the womb will not be applicable to life on earth for a long time.

Around the world, placing the baby at the breast depending on his/her condition begins after 32 weeks of gestation. However, at this stage feeding at the breast is not expected at all. The baby rather stays at the breast and feels it – he/she still can neither hold the nipple at will, nor suck.

Here comes the kangaroo care. It allows the baby to spend as much time as possible on your body, i.e. you hold him/her in skin-to-skin contact for
at least a few hours a day. Besides maintaining body temperature, it gives your infant a “womb substitute” and the interactions your baby would have with you if he/she were still in your belly. Touching the skin of the breast continuously stimulates the feeling of the breast; the smell and taste of milk are next to the baby’s face and this triggers his/her instincts and ability to breastfeed. Infants held like this breastfeed more often and in a better way – and thus grow and mature faster.

Around the 34th week of gestation the baby has already developed the root reflex and can hold the breast in his/her mouth, make several non-nutritive sucks (sucking without getting milk) for a short period of time and lick or swallow the spontaneous flowing breast milk.

However, with most infants a good coordination of sucking and swallowing is observed after 35 weeks of gestation. More efficient breastfeeding is expected sometime after 36 weeks of gestation.

Therefore, unlike with a term baby, the objectives regarding breastfeeding of premature babies are in the reverse order.

<table>
<thead>
<tr>
<th>Term baby</th>
<th>Premature baby</th>
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| **Latching and sucking** that provide stimulation of the breasts and at the same time **enough calories** for the baby’s growth | **1. Enough calories** for growth and development (in the most appropriate way)  
**2. Stimulation of the breasts** – expressing to maintain a sufficient quantity of milk  
**3. Latching and sucking** – these come at a later time and evolve gradually |

With term babies, latching is the most important because it will provide a good stimulation of the breasts and the baby will get enough calories. With premature babies, first and foremost we are careful to provide enough calories (with means that complement the breastfeeding), for which purpose there has to be a good stimulation of the breasts, expressing breast milk to maintain a sufficient quantity. Latching and sucking come later, developing gradually in the process of maturation and strengthening of the baby.
Maintaining the milk supply is more complicated and more difficult when the baby cannot help. If the amount is insufficient and the milk flow is slower and harder to get, it troubles the infant and slows the process of his/her getting accustomed to active nutritive (nourishing) sucking at the breast. It is very important for you to achieve and maintain plenty of milk (over 600 ml per 24 hours on the 14th day after delivery) until the time when your baby will be able to make his/her first attempts at sucking. The easily flowing milk will allow him/her to feed with a minimum of effort. This way you will be able to switch to feeding only at breast faster.

**What to expect when feeding a premature baby?**

Depending on the gestational age, the baby’s weight and condition at birth, the differences in the feeding skills and their progression can be enormous. The approach described here is the most common approach applied at Bulgarian hospitals (although it does not correspond entirely to the best recommendations and practices to promote breastfeeding according to medicine based on evidence) for a baby that is born approximately in the 34th week of gestation.

During the first day or two your baby may not receive anything through the mouth – and then he/she will be gradually given small amounts of milk by gavage, most often only 1-5 ml for the first feedings.

**From the moment the baby is able to receive food the best for him/her is to be breastfed!**
Although the composition of infant formula reflects the specific needs of premature infants, it lacks all living protective ingredients of breast milk, which support the maturation of the digestive system and protect the baby from infections. This is a well-known fact and therefore the world's largest consumers of donor milk (if the mother still does not have enough) are precisely premature babies. They are the main reason for the creation of milk banks around the world – because the “liquid gold” of colostrum and breast milk quite literally saves the lives of the so vulnerable premature babies.

If your baby was born weighing less than 1500 g, he/she has specific needs. Therefore, it is possible to enrich breast milk with a special fertiliser, which increases the content of protein and various trace elements. This ensures a better growth of the baby, without his/her being deprived of breast milk.

At first, your baby will probably feed by gavage, which passes through the nose or in the corner of the mouth and reaches the stomach. Thus, the milk (breast milk, enriched milk or special milk for premature babies) is fed directly into the stomach since the baby, in most common cases, does not possess the skills to coordinate sucking, breathing and swallowing and is not strong enough to take the right amount of milk with active efforts on their side.

When the baby’s skills and reflexes mature, around the 34th week of gestation at the discretion of the neonatologists, the baby can be offered a special miniature baby pacifier for premature infants. It is given while the stomach receives milk by gavage. This starts building the connection between the act of sucking and the filling of the stomach with food.

The same can also be done at the breast when you go to feed your baby – although the infant cannot be fed at the breast yet, it is enough for him/her to be able to keep it in their mouth or even just to feel it close to their face and lips as a first step towards breastfeeding, while receiving milk by gavage.

At Bulgarian hospitals, infants are not placed at the breast before the 34th week of gestation (most often, in fact, after the 36th week and if done earlier, it is a big exception). Generally, no attention to non-nutritive sucking is paid (sucking without milk intake), while it is very important for the faster progress of the baby’s sucking skills. It is among the things that you as parents can monitor and request in dialogue with the professionals who take care of your infant.
When the neonatologist finds that the baby has developed enough coordination of sucking, breathing and swallowing, the first attempts begin to feed the baby through the mouth, not only directly in the stomach.

Although feeding at the breast requires maturity and skills on the part of your baby, research shows that it is less stressful than bottle feeding. Apnea (pauses in breathing), bradycardia (slower heart rate), lower oxygen saturation (saturation), cyanosis (bluish coloration of the skin) – all these, considered “normal” while bottle feeding, are usually caused by the rapid stream from the bottle and the control over the feeding on the part of the person giving the milk. At the breast, the baby is competent and in control – he/she can take breaks, set the rhythm on their own and adjust the flow.

In our country, however, in most cases, the bottle of milk still precedes the placing of the baby at the breast. The first bottle feedings can be supplemented with feeding through gavage, depending on the infant’s skills. At this stage infants progress rapidly and the next step is to remove the gavage and switch to bottle feeding for all meals.

At our hospitals, the first attempts at breastfeeding usually start at this stage only.

**Obstacles to feeding**

Unfortunately, in our country the parents’ access to the intensive care unit for premature babies is quite limited. The staff is small and often unable to pay sufficient attention to the mother. Their efforts are mainly aimed at ensuring the best possible care for the baby. Most of the medical staff
still thinks that the contact between the mother and the baby can have a negative impact on the infant. All this heavily hinders the early placing at the breast and is the reason why the latter often happens for the first time only at home.

The baby’s condition, too, can either stimulate or hinder the attempts at breastfeeding, and therefore it is important to watch your baby and find the appropriate time to try.

The periods of sleep and wakefulness are not regulated with premature infants. A premature baby is more languid and sleepy compared to term babies. He/she can sleep longer and not wake up often enough for feeding. Premature babies generally need to be fed more frequently at shorter intervals, since the volume of their stomach is smaller. Moreover, they easily get tired and fall asleep while feeding and this is also why they do not take enough food.

The signals for awakening and hunger are often less visible and less pronounced than in term infants. If you have no experience and do not know what to look for, you can easily miss them. This is yet another reason to keep the baby on you at every opportunity – thus you will easily feel and notice the changes in his/her movements and the first signs of hunger, even if your baby does not open his/her eyes completely and does not look “awake and ready” as you would expect.

In premature infants, the transitions between the different states are usually sharp and fast because of immaturity. For example, from obvious crying the baby can “turn off” and suddenly go to sleep or vice versa, from a condition that resembles a deep sleep he/she can suddenly start crying directly, without going through the phases of activity. It is therefore important to recognize the baby’s first signals from the start and be able to act quickly in line with them.

Another problem lies in the fact that the immature baby does not have enough muscle strength and very easily gets tired, thus not being able to take enough food.

Since the opportunities to compensate premature babies are very few, any anatomical peculiarities, which otherwise might not create a big problem or pose only a temporary inconvenience to a healthy term baby with a good weight, can seriously hinder breastfeeding immature babies
(e.g. flat nipples, non-corresponding size of the nipples to the baby’s mouth, tongue-tie, etc.).

How should I begin to breastfeed my baby?

One of the most important things in the preparation for the first breastfeeding is to sit back and ensure the best support for the infant’s body. A premature baby is not strong or capable enough to compensate. If his/her body is not well supported and he/she has to waste energy keeping their position, breastfeeding cannot happen or it will be difficult for the baby.

The breastfeeding position that is most commonly used with premature babies is the cross-cradle position. It provides a good support and control on your part of the baby’s head and latch. Depending on the individual anatomical features, the clutch position is also a suitable option providing good visibility and control.

Your baby has to be on a pillow at breast height, tightly pressed against you. Your hand supports the neck, your forearm their back, and you can easily hold them in the right position. Your baby is “soft” and easy to place in the starting position. His/her chin is resting firmly on your breast, the head is slightly bent back so that your nipple lies entirely on the baby’s lips. If you can express a few drops of milk on the nipple in advance, this will remind your baby what he/she is supposed to do.

Do not expect too much – the first attempts at sucking most often remain only attempts. The baby’s reactions can vary significantly. Some babies cry and move away or rotate their head in a disoriented manner (especially if their chin does not touch the breast!). Others simply fall asleep, drifting off in mom’s huddle, warmth and smell. It is better if the baby opens his/her mouth to lick the nipple. Some babies manage to take the nipple in their mouth, although they still do not close their lips around it and do not latch on. Others are so advanced and enthusiastic that even from the beginning they start making very determined efforts “to make this thing work”.

Whatever the first reaction of your baby to the breast, do not be discouraged. Try to analyse what happened and how to continue the next time.

- Is the baby in the right condition – awake and able to focus quietly?
- Does the baby need swaddling to feel stable and comfortable?
- Can the position be improved even more?
• Is there anything in the surroundings that disturbs him/her – e.g. the direct bright light on their face can make them keep their eyes closed and fall asleep easily.

• Is it simply the time of day when he/she responds best and feels most comfortable – this is different for the different babies and you can try observing when he/she is most active and feeds in the best possible way.

If you had the opportunity to put the baby in skin-to-skin contact several times a day, he/she already knows the feeling of the breast and will soon begin to attempt to latch on. In such a situation you can notice that he/she manages to suck with varying success.

When the baby latches on and sucks, their way of sucking is still very different from that of term infants. A premature baby makes short bursts of sucking [3-4 sucks] followed by long pauses during which they can nap.

Their sucking is not yet quite skillful, may be much slower than usual because the baby is not so strong physically, and cannot maintain sufficiently high vacuum. Therefore, swallowing is irregular and the baby quickly gets tired and easily falls asleep at the breast.

**Breast compression** is an indispensable technique for breastfeeding premature infants – it allows you to increase the flow of milk to the baby, maintains their interest for a longer time and facilitates the baby to take a larger amount of milk at each feeding than the amount the baby can get only on their own. Wrap your hand around your breast and just watch the baby. When it starts to suck, squeeze the breast between your fingers and hold it until the baby stops sucking. When he/she stops, release the pressure and wait for the next sucks to repeat the same.

During the first weeks breastfeeding usually needs to be complemented by other types of feeding in order to ensure an adequate intake of calories. The best supplement is your expressed milk (unless your doctor advises otherwise or if the quantity is insufficient).

This means that you cannot stop expressing just because the baby has latched. It will take weeks before the baby learns to suck well and his/her physical abilities grow to such an extent that he/she is able to receive all the necessary milk at the breast.
You cannot rely on the premature baby alone to stimulate your breasts and you need to continue to express breast milk. At least until you reach the term and make sure that the baby is gaining enough weight only at the breast, pumping remains a necessary and integral part of your day.

Although infants are usually released from the hospital on bottle feeding (plus breastfeeding attempts, which most often only start at home), there are other possibilities for the baby to receive the necessary calories.

According to research, cup feeding is a safe and efficient way of feeding a premature infant. The cup is also less stressful than the bottle and trains some sucking skills (the sticking of the tongue and the movements of the mandible are similar to those as the breast, although there is no vacuum creation and the movements of the tongue are not the same). This way of feeding, however, is not applied at our hospitals and parents are not shown or given the chance to practice it under supervision before they take their baby home. That is why the very idea of it usually causes stress and anxiety and consequently is not used. If you want to try, it is best if someone shows you how to cup feed your baby and you exercise at least a few times under the guidance of a skilled person. Your baby is little and vulnerable and you yourself need certainty before you can feel confident that this is your way.

Supplementation by gavage at the breast is a proper way of supplementation for premature babies. The baby must have already demonstrated that he/she can create vacuum and suck well but just gets tired easily and falls asleep quickly when the flow diminishes. On the one hand, feeding your baby by gavage is familiar to you and therefore it is not so stressful for you. On the other hand, it completely eliminates the bottle and allows your baby to feed only at the breast.

Gavage feeding is used in a slightly different way than supplementing by gavage a term and well-sucking infant. You need to actively give the milk to the baby through the syringe so that he/she does not get too tired. However, this is easily achievable and may be a preferred
and convenient way for the time when you need to supplement with expressed milk.

If your baby still has difficulty taking the breast, does not create a good vacuum or fails to keep the breast in his/her mouth, silicone nipples can be an apt transition and convenience. Studies have shown that with premature babies silicone nipples lead to taking more milk and to more successful breastfeeding. When the baby grows and starts doing well at the breast, the use of the silicone nipples gradually stops.

Silicone nipples can also be a great transition between the bottle and the breast. They create a feeling similar to that of the bottle. They are very useful in times when the baby is still not certain what to do and how to suck at the breast.

All this takes time – your baby’s maturation is slow because they grow in conditions very different from those in the womb and they have to spend considerable effort on things that are granted in the womb and do not require their participation (e.g. breathing, feeding and maintenance of body temperature). On the other hand, their condition may be further hampered by infections, serious loss of weight or medical problems related to the premature birth. Therefore, it is difficult to make predictions when the baby will be able to make their full transition to the breast. Every infant develops at their own rhythm and at a different pace, but growing and maturing are inevitable. Be patient and understand the initially limited abilities of the baby. The calm, gentle and non-pressing offering of the breast teaches babies to breastfeed. You will see for yourself that with every week that gets you closer to the term breastfeeding becomes better and better. And if during the first weeks of attempts the baby hardly took anything, around the 36th week he/she will probably manage to get about one third or even more of the required amount. Two to three weeks later more than half the milk may be taken directly at the breast. A week or two after the term you may happily find out that your baby feeds entirely at the breast. This will allow you to stop pumping gradually, which was your constant concern in the last couple of month, and you can celebrate your success.

The road you need to walk is not easy either for you or for your baby and is filled with constant changes. Things hardly ever run smoothly and in the right direction. Regress and reversion by a step or two often occur. At times you will be discouraged and it will seem to you that nothing happens and the baby will never learn. At such moments, just give yourself a chance
for a little rest – nothing bad is going to happen if for a few days you do not offer the breast at every feeding or allow yourself a day-long break from the sucking attempts at a time when things look particularly bad. Sometimes this is enough to calm both you and your baby. At the same time such a stop along the way will allow you to detach yourself from the problem a little and look at it from a different perspective and hence you will gain the strength to continue and try again and again. Do not take it as a failure – just as a break necessary for regrouping, changing the strategy and gathering strength for the way forward. The end result is what matters, not every sub-total – just keep the ultimate goal in front of your eyes and continue to fight hard. :)

* * * * * *
~ CHAPTER SIX ~

1. Finally at home! The discharge – everybody has the right to holiday!
2. Who can help you when your baby is already at home?
3. If your baby is not feeling well?
4. Weaning of the premature child
5. Locomotor development of the newborn baby and peculiarities of premature infants
6. Prophylactic examinations
Premature birth differs from any other kind of birth – this often applies also to the day of discharge of the mother and the baby. In contrast to other parents, with premature children the mother and the baby often leave the hospital at different times because of the need for prolonged hospital stay of the baby. Although this might seem insignificant at first glance, mothers often take it to heart and say that they are overwhelmed with the feeling that they have abandoned their child, and accuse themselves of this.

This can be very hard when the family is from a smaller town whereas the child remains for observation in a hospital in a bigger district centre. The difficulty of experiencing the period of separation makes some mothers very worried and the lack of a system of timely feedback and the complicated communication with the hospital staff in relation to the child’s condition is experienced very intensively. Many parents postpone in time the receiving of guests or congratulations on the appearance of the new family member, because they find it difficult to accept the event as something jolly. In some cases they even miss to mark the discharge from the hospital as something special, because they experience very mixed and different feelings with regard to what happened. This is supplemented also by some parents’ difficulty to determine the exact birthday of their children – one is the day of their premature coming into the world, the other one is the day of their planned birth. This tendency of double calculation of the age – the calendar and the corrected one – is preserved over the years and unnoticeably creates a more specific attitude to the child. Not infrequently, the parent associates his/her birthday with bad memories for many long years; it even darkens the joy of celebration.
It is important for the parents to achieve reconciliation with what happened within themselves – their child is here now and has the right to be accepted in the world as any other child, regardless of when and how he/she appeared. For this purpose, the work with a psychologist or a psychotherapist is sometimes very useful.

The baby is at home – now where to?

The baby’s discharge may also lead to actual worries in premature children’s parents – will you cope, especially in the cases of physical complications. The increased risk of rehospitalisation often leaves the parents with the feeling of frustration and failure in their role of carers of the baby and does not allow them to relax with relief for a long time that everything has finished and they can look ahead without worry.

It is important to know that each case is individual and it is difficult to foresee with perfect precision how your life will run after your child’s discharge. In this period, it is good to have somebody by your side to help you, without burdening you emotionally (all anxious grandmothers, aunts and neighbours can wait in the background until you feel more confident
in your own powers to take care of the baby). Internet groups often help with this. You can see all kinds of stories and your positive experience on the Internet, or issues related to the raising of premature children, as well as emotional support and mutual assistance groups.

However, information that is too varied and accessible is a double-edged sword for the young family. It can undermine your assurance about what is best for your child, make you have doubts about whether the doctor in charge is doing the best for you and whether, instead of helping you, often throws you in confusion. You had better find proven specialists you believe in and try to filter out the huge information flow and advice. The peace at home in this period is an irreplaceable source of supporting environment for the baby.

In their attempt to do the best for their children, some families fuss over and create a mini hospital at home, equipped with any type of equipment, measuring instruments, medicines and medical indices of growth. Although it is true that some health states and the complicated health system in this country require from parents to be aware of their children’s physical needs or to be able to perform some elementary medical procedures, this should not become an end in itself. Preoccupied with observation of whether everything about the child develops ‘by the book’; you should not forget that children would be children and need your love, a song or a story, games and fun. The difficulties associated with health are the medical specialists’ concern, whereas the parent cannot and should not be a specialist in everything at the price of the family’s emotional peace. Sometimes a rehabilitation procedure is less important than smiling at your child today. It is less important than whether you can really listen to him/her indeed. A good parent does not mean a perfect parent or a super hero, but a parent who loves his/her child and does what is within his/her powers.
Finally at home! Parents worry when the fragile and small child is discharged and they take full care and responsibility. They are faced with a number of problems, difficulties and worries. Then a completely natural question arises: who and where to ask for help in raising the child, who will monitor the baby, is there a risk for disabilities, what to do?

The general practitioner (GP) takes the main role in conducting the treatment, as well as the follow-up monitoring and immunisations of your baby. Choose a doctor with a paediatric speciality, i.e. a paediatrician. If you have another child and have already chosen a GP for him/her, who meets your criteria for care and monitoring of newborn and older children, you can make the same choice again. If this is your first child, get your bearings and find a GP while the baby is still in the hospital. After you have made your choice, contact the doctor and arrange a visit as soon as possible after the baby’s discharge. Do not miss to present an epicrisis from the neonatal unit; this document contains important information about your baby. The paediatrician should be familiar with the complete medical history of your child.

Children’s consultation is an element of the outpatient paediatric care. It is performed through monthly and more frequent examinations, at the discretion of the doctor, where the physical and neuropsychiatric development of the child is checked. It includes physical examination by the doctor, measurement of the weight and height, and the head circumference. Current problems are discussed and when necessary, consultative examinations by specialists are scheduled, the mother’s behaviour to the child for the next month is discussed (number of feedings,
quantity, bottle feeding food, etc.). It is useful to prepare in advance the questions you are to ask the specialist.

**Place and role of the neonatologist in tracking the premature baby’s development**

Parents are informed in the epicrisis and orally about their right to two follow up check-ups during the first month after the discharge. The neonatologist in charge performs these check-ups on fixed dates and during regular working hours. Do not miss them, prepare your questions, and specify everything that is not clear to you. The neonatologist also participates in the follow-up outpatient tracking of children with chronic complications together with other children’s professionals.

**Follow up tracking** is an invariable part of the health care for premature children. It begins in the neonatal intensive care units and in a few months’ time, they continue in outpatient and ambulatory settings and often finish years later. These children’s treatment requires funding, organisation and commitment of all. A general practitioner, neonatologist, paediatric neurologist, paediatric pulmonologist, ophthalmologist, paediatric otolaryngologist, kinesitherapist, and rehabilitator undertake the main commitment in this long and responsible process. More rarely specialised care is required from paediatric surgeon, paediatric orthopaedist, orthodontist, psychologist and other specialists. With these children, the role of the family is very important for the results.
3. IF YOUR BABY IS NOT FEELING WELL?

Signs and symptoms of illness: what they mean and what should be done if they occur?

The symptom usually is a manifestation of a disorder that has its cause and its localization in the body. Vomiting, constipation, pain, elevated body temperature, cough, runny nose etc. are common symptoms in infants and children. Their occurrence and development worries the parents.

How to behave, what to do, when to seek medical attention?

The pain
It is a common symptom. The smaller the child is, the more difficult it is to localize the pain. The most common causes for pain in infants are:

Colic
It occurs in most of the children, including in premature babies. It is typical for the first 3-4 months, more common in males. Usually, the pain is accompanied by crying, writhing the legs to the abdomen, reddening of the face, passing wind. The restlessness is more commonly increased in the afternoon and evening hours.

How to relieve the pains?

- Make the baby burp after every meals.
- Put it on its abdomen in your lap or on your chest. Gently massage its abdomen clockwise with warm hand.
- Warm napkin or diaper on the abdomen will also calm the baby.
- Warm bath + warm blanket.
- Physical exercise type „cycling“ with the legs will help passing the gas.
- Taking the baby out (in suitable weather).
- Chamomile, dill, anise tea.

Seek your doctor for examination that will rule out other reasons for crying and restlessness of the baby. He will also prescribe and recommend you medicines (most frequently in the form of drops) for colic relief in infants.

Pains while passing stool
Usually they are due to constipation. It can be false or genuine.
“False constipation”
It occurs when the infant does not receive adequate quantity of milk/infant formula. In these cases, the baby passes scanty quantity of stools, once in several (2-3) days. Weight gain is inadequate or stops. You should consult your doctor and make sure how often the baby should be fed, what quantity and type of food should be given. There are cases in which the child gains weight well and still it has „false constipation“. Usually, this is due to more sluggish bowel movement. If the baby is fed with infant formula, your doctor will decide whether a switch to another type of milk would be necessary.

“Genuine constipation”
When the child does not pass spontaneously stool for more than 72 hours. Often the baby becomes restless, wails, strains, the face reddens, it may even refuse food. The stools are hard.

Seek medical attention after you have tried:

- to increase fluid intake – glucose or boiled water.
- to massage the abdomen with baby oil several times a day and make exercises type „cycling“ with the legs.

If there is no result, consult your doctor and he will suggest medicinal, dietetic or any other solution to the problem.

Pain in the groins
In premature children unilateral or bilateral inguinal hernias occur more often. They may reach large dimensions, especially while the baby is crying and straining. In case of incarceration the child becomes highly restless; the crying is constant because it is in pain. What should you do? Do not try any „adjustment-reposition“. Seek urgent medical consultation. It is appropriate to consult a paediatric surgeon who will assess the need of emergency or elective surgical correction. If no surgical intervention is required, he will advise you what to watch, what to avoid and what to do.

Vomiting
Vomiting as a symptom is common in premature babies and newborns and infants born on term. In most of the cases it is due to anatomic and functional transient immaturity of the gastrointestinal tract and is not a morbid syndrome. Therefore, after each meal the baby should be made to burp and usually, along with the air, a small quantity of milk also comes out.
When the quantity of the regurgitated (burped) breast- or infant formula is bigger and the vomitings are more frequent, this may be due to a wider stomach opening.

**Recommendations:**
- In these cases, hold your child upright and slightly bent forward, in order to make it burp repeatedly after each meal.
- Put it in bed laying aside, its head and the upper part of the body raised. You may raise a bit the bed mattress. This will prevent the risk of aspiration (milk getting in the airways) and acute breathing disorder.

Your neonatologist and/or your GP will advise you when vomiting is normal, acceptable and will tell you the criteria to lead you (calm baby, gaining adequately weight, number of diapers with urine and stools per day etc.)

**When vomiting is unusual?**
When the number of vomitings is higher than usually. When the regurgitated breast milk/infant formula is abundant, more than half of the ingested milk, comes out like a fountain, has unchanged or curdled appearance. The child is restless, crying, cannot be calmed down or on the contrary – it sleeps unusually long, it is difficult to awake, shows no signs of hunger etc. In these cases do not defer your call to your GP or a doctor on duty for examination. No matter which part of the day it is.

**Acute diarrheas**
The normal stools of *breast-fed* babies are: soft, golden yellow, with slightly sour odour, frequency up to 6-8 times a day. After the 2nd month the frequency decreases. The stools of a *bottle-fed baby* are: thicker, with sharper odour, less frequent, coloured from yellow to gray-green (depending on the type of the milk).

**When there is diarrhea?**
Passing stools more frequent than usual, stools are soft, watery, with changed odour, may have admixtures (blood, mucus). Acute diarrheas are more common in infants and in early childhood. The breast-fed babies fall ill more rarely. Diarrhea is due to viruses, bacteria or faults in diet. The premature children are considerably more vulnerable, especially to rotavirus infection. Usually, diarrhea is accompanied also with vomiting, restlessness, crying or limpness, prolonged sleep, temperature increase, food denial etc. In smaller babies there is a risk of dehydration and
worsening of the condition, which occurs more rapidly and earlier in comparison with older children.

**What shall I do?**
Count the number of stool passings so far. Pay attention to the quantity, consistency, colour, odour, presence of unusual admixtures such as blood and mucus. Keep at least one diaper with stools to show to the doctor. Measure the temperature of the baby. After each change of diaper smear baby cream on the buttocks because there is a risk of reddening and sores. If you breast-feed the baby proceed to do it at shorter intervals. The breast milk is not contraindicated in case of diarrhea. It has a pain-relieving action as well. Give also more fluids to the baby – boiled water or glucose 5%. Call your GP or a doctor on duty. After examination, he will decide whether to hospitalize the child or leave it at home for treatment.

**The baby has temperature**
The increased body temperature is often the first and even the only symptom of a number of diseases; it troubles the child, worries the parents and make them seek paediatric help.

**Which temperature is normal and when it is elevated?**
The normal body temperature is between 36.5°C in the morning and 37.2°C in the evening. Elevated body temperature is over 37°C upon axillary measurement (in the armpit) and over 37.8°C upon rectal (in the anus) or buccal (in the mouth) measurement.

**How to measure the temperature?**
Nowadays, for temperature measurement electronic, digital thermometers are mostly used that show the temperature within a short time. Rectal measurement (in the anus) is the most precise one. Smear vaseline or baby oil on the thermometer tip. The baby should be in supine position, you grip the ankles and hold the legs upwards with one hand, and with the other hand you gently insert the thermometer tip in the anus about 1 cm deep. Make sure the tip would not to go out. Shortly thereafter, a sound is heard signaling that the temperature is measured. Important! The temperature measured rectally is by 0.5°C higher than that measured in the armpit or in the groin fold. When measuring in the armpit, the thermometer tip should be put in the middle of the pit and the arm should be well pressed to the body. The temperature may be measured also in the ear by a special thermometer as well as in other ways.
How many times a day should I measure the temperature and when?
Temperature measurement is not necessary if there is no reason or doubt for fever (elevated temperature). In the course of a disease it should be measured at least twice daily – between 7-8 h in the morning and 16-17 h in the afternoon. Additional measurements are made if you believe that the child’s temperature is raised or after medicine intake etc., in order to assess the intensity of temperature drop.

How shall I know that the child has temperature?
The febrile baby is usually restless, crying and difficult to calm, the skin of the head and the body feels warm, and is red, and the skin of the limbs (hands and feet) feels cool. The baby may drink fluids thirstily or refuse to drink. In other cases, the skin becomes pale, the breathing is speeded and heavier, the baby is drowsy and difficult to awake. If you have any doubt, measure the temperature.

What to do?
First, measure the temperature – rectally or in the armpit. In order to be sure, do it again or use another thermometer. The thermometer should be in good working order – check for low batteries etc. If you have experience from a previous child, you may give syrup to the baby in case of elevated temperature. It should correspond to the baby’s age, should be within shelf life, unopened or recently opened and should be correctly stored. Read the dose for your baby in the leaflet. Suppositories are also suitable for use in infants for decrease of temperature. If the temperature is high and remains 39.5-40°C, call your doctor. Before he comes, start with wet wraps. Partial wet wraps – dip diapers in lukewarm water (18-20°C) and wrap the limbs. Put a napkin dipped in cold water on the forehead. If the temperature persists or keeps increasing, start with overall wet wrapping. Wrap the body and the limbs with a dipped in lukewarm water and wrung out diaper and cover with a blanket. When the diaper is warm, wet it again and repeat the procedure until the temperature drops to 38°C.

Should I take the child to the doctor in case of a single temperature elevation?
Call your GP and inform him about the temperature elevation – how many times you measured it, how high it was, are there any other accompanying symptoms, how the child feels, what is its condition.

Temperature in case of teething
Teething is a physiological process. Sometimes it is associated with gum
itching, softer stools, restlessness and possible temperature elevation up to and rarely above 38°C. It is appropriate to seek medical attention, in order to rule out other reasons for the abovementioned symptoms. How shall I help the baby? Give it a suitable rubber toy to rub its gums. Increase fluid intake because of the temperature. Ask your GP for suitable medicines to facilitate your baby’s teething.

**Runny nose**

The infant is breathing mainly through the nose. In case of a “snorting” nose, in the presence of nasal secretion, the baby’s breast-feeding and breathing is impeded. Prior to breast-feeding, drop 1-2 drops of saline in each nostril. Put the baby in supine position and fix the head. Raise a bit the tip of the nose, place the dropper near to the nostril without inserting it in the nose opening, so that you do not injure the nose mucosa in case of an abrupt head movement. After dropping, the baby will start sneezing. Thus the secretions will be removed. Swab gently both nostrils with a swab with a restrictor. Proceed with breast-feeding. Consult your GP, if the secretions are more abundant, watery and transparent in the beginning, and then thicken and colour. After examination, he will prescribe you drops, nasal ointments or anything else suitable for the child’s age and condition.

**Secretion from the eyes**

In case of eye secretion, it is important to pay attention to the thickness, the quantity and colour of the secretion. If the secretion is clear and watery, drop 1-2 drops of saline in both eyes. In order to do that, put the child in supine position, the head slightly drawn backwards. Draw gently the lower lid, drop from a distance, not touching the eye. The secretion is always swabbed from the outside inwards. In case of purulent (yellow, yellow-green coloured) eye secretion examination and treatment by a doctor is warranted.

**Thrush**

It is caused by fungi. It is more common in premature children. It develops in case of failure to observe the hygiene requirements, prolonged antibiotic treatment. Small white coatings (resembling milk left-overs) are formed on the oral mucosa. If the disease progresses, dense white coatings on the tongue and the cheeks are seen. It causes pain and difficulties in feeding. In order to prevent its development, boiling (sterilization) of all objects that are put into the child’s mouth – comforters, feeding-bottles, toys etc –
is necessary. Seek advice from your GP regarding the medicinal treatment.

In the course of the baby’s raising, you and your doctor are „partners”. Ask questions about things that are not clear to you, about anything you did not understand or about something that bothers you. If you are not satisfied, you have the right to seek second opinion. Find telephone numbers, business time, time for call, nights and holydays – localization and telephone of the consulting room on duty.

**When to call the doctor?**

In the beginning it is better to call more often than necessary rather than not call when you had to. Before you call put your thoughts in order.

**Specific and important symptoms, reason for calling**

High temperature, fast and loud breathing, writhing, pain, unusual vomiting, diarrhea, rashes.
The information that you will provide to the doctor is of vital significance:

1. What exactly the worrying symptoms are?
2. When did they occur?
3. How often do they occur?
4. Other symptoms, what kind?
5. What are the vital indices of the baby- temperature, paleness, difficult breathing?
6. What did you do and to what effect?
7. Do you give any medicines and what kind?
4. WEANING OF THE PREMATURE CHILD

After the sixth month of age the milk alone cannot ensure the nutrients needed for the optimal growth and development of the child’s system. This requires adding to the infant diet various semi-liquid, non-milk foods that will prepare it for having transient food and later on for the diverse typical adult food.

Weaning means gradual discontinuation of the infant breast-feeding and substituting the milk to non-milk foods in the period from 4th-6th month to the end of the first year of life.

In the different countries there are variations in regard to: the time of weaning, the use of the most common foods, the sequence of their introduction. Since the scientifically based nutrition requirements for infants are the same worldwide, universal recommendations for weaning made by various international organisations – the World Health Organisation (WHO) and the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) - are available, including the weaning of premature children as well.
Four principles of weaning according to the WHO

1. In due time – to be performed at the most appropriate age;
2. Adequate – to ensure the needed energy and nutrients;
3. Safe – this depends on the product choice, their preservation and way of food processing;
4. Proper – to attend to the food quantity and quality. The number of meals should meet the needs of the child’s system. The most appropriate age for weaning is the period between 16-24 weeks (4-6 full months).

Early weaning (before 4 full months) results in increased incidence of food allergy, risk of overweight and overload of the immature system with electrolytes, especially cooking salt. Late weaning (after 6 full months) results in nutrient deficiency and growth and development retardation of the child.

Premature children have special nutrient needs in the first months upon their discharge from the neonatology wards. They have greater needs of energy, protein, polyunsaturated fatty acids, iron and calcium in comparison with the children born on term. On the other hand, food digestion is impeded by the immaturity of the digestive system and the frequent chronic diseases, associated with prematurity.

It is important to note that premature children should be weaned according to the so-called „adjusted age“ – the age of the child calculated from the mother’s term day, and not from the actual date of birth. (If the child is born 1 month prior to term, in the 36th gestational week, the calendar age of 3 months corresponds to 2 months adjusted age.)

Sequence of introducing foods during weaning

Fruit juices – according to the current WHO and ESPGHAN guidances giving fruit juices and sauces is considered as weaning and is not recommended up to 4 months of age. During this period, milk or its substituents are adequate source of vitamins and minerals. After the 4th month, fruit juice and subsequently fruit sauce should be given between two of the meals, its quantity gradually increasing to about 30-50 ml. Apple juice is the most beneficial one. Carrot, peach, apricot juices and sauces are appropriate for
the following months. The sweet fruits: grapes, pears, plums have laxative effect, and the sour ones – morello cherries and apples – have constipating effect. Imported fruits that are not growing in our country – citruses, kiwi, mango etc. – are offered after 1 year of age.

Juices are given between, not instead of meals. Recommended quantity should not be exceeded, and habituation of the child to drink juice instead of water is harmful.

**Milk-vegetable purée** is traditionally the first food for weaning in our country. Potato-carrot purées are best tolerated, since they facilitate digestion and have anti-diarrhea effect. Ready-for-use commercial products are being increasingly used. Vegetable purées, containing milk, are ready for consumption. Milk should be added to those, containing only vegetables, to make the food completely nourishing. After the 6th month the content of the vegetable purées is varied. Addition of hard-boiled egg yolk is useful; it is a valuable source of iron, fats and fat-soluble vitamins. Vegetable purées is given at midday meals.

Milk gruel. The first gruel should be gluten-free – usually rice-based, with no additional components or only with one kind of fruit. Commercial gruels, containing milk, are ready for consumption after dissolving in water. Non-milk gruels are dissolved in the milk that is fed to the child. The gruel should be given once daily and should substitute the afternoon breast-feeding. It may also be the first weaning food in the premature children. Gluten-containing gruels, containing wheat, rye, maize should be introduced after the 6th month. Both early giving of gluten – before 6 months of age - and avoiding it after 8 months of age is harmful, since the child cannot get used to taking this protein widely present in the main cereals.

### Further foods are also introduced up to 1 year of age as follows:

<table>
<thead>
<tr>
<th>Food Description</th>
<th>Introduce In:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meat-vegetable purée</td>
<td>7th month</td>
</tr>
<tr>
<td>Sop with cheese</td>
<td>7th-8th month (substitutes the second meal in the morning)</td>
</tr>
<tr>
<td>Bouillon and soup within the midday meal</td>
<td>9th month</td>
</tr>
<tr>
<td>Gradual introduction of transient food</td>
<td>10th-12th month</td>
</tr>
</tbody>
</table>
Some basic rules during weaning

1. The child is weaned only when it is healthy.
2. Any change in nutrition is made alone, with no further changes in the following 3-5 days.
3. The time for weaning and introduction of the respective foods is observed.
4. Introduction of new foods is gradual, aiming at adaptation of digestion. Full portion is reached within a week.
5. If the child refuses a food or if indigestion occurs, the respective food is temporarily stopped.
6. The child’s food should always be tasted. At that, the temperature, the consistency and the taste are assessed.

Nutrition in the infant period is especially important for the premature children and has a long-term effect on health. Adequate breast-feeding, along with timely weaning with appropriate foods, ensures maximum development of the physical and mental potential of the child in the following years. Concomitantly, the basis for proper nutritional habits and for prevention of some chronic disease development such as asthma, diabetes and obesity is formed.
5. Locomotor Development of the Newborn Baby and Peculiarities of Premature Infants

Before reaching independent walking and free playing with hands, the newborn (the term one or the premature one) passes through certain stages of its neuro-motor development, both in the common (gross) motor skills, and in the fine manipulation (fine motor skills) with upper limbs.

Many factors influence the development and shaping of the locomotor system in the newborn and the infant, as well as on the pattern of the cross-legged walking in humans. Such factors include:

1. Primitive reflexes and mechanisms residing and disappearing, which affect the state of the muscular tone. Slowing their extinction is associated with negative changes in muscle tone and delayed motor development.
2. Reactions of straightening against gravity and related support planes.
3. Taking a different position and related reference points and planes.
4. Stimulation of age-adequate balancing effects, ensuring the retention of age-designated positions.
5. Activation of certain age-determined moves, forward movement, and movements to the side.
6. Turn on different planes of movement, specific to certain age and the relevant to them balance reactions.
7. Adoption of the center of gravity movement along different planes.
8. The status of the muscle tone, activation of the muscle activity and directions of the movements.
9. Presence or absence of inner need to move.
10. Formation and development of a body scheme and the related orientation in space.
11. Acquisition and development of sensorimotor experience.

K. Bobath says “balancing the position of the body is achieved by working the muscles of the infant against the action of gravity”.

The acquisition of its own sensorimotor experience (SME) is extremely important for the proper nerve-motor development of the infant. It is acquired gradually and independently, the child should be left only to communicate with the outside world according to its age capabilities and
achieved motor skills. SME is based on the independent muscle activity of the infant against gravity.

It is wrong the parent to put the child in different positions, which it can not keep by itself, because that submits false pillars which do not bring proper information to the developing brain on the control of the center of gravity, of the body scheme and the position in space, and therefore the commands of the brain to the muscles are not correct, leading to incomplete muscle-contractility chain and inadequate balance reactions.

The infant, depending on its calendar age, uses planes of various sizes and various reference points, both on belly position and lying on his back. The used planes and reference points change in a certain way with the growth of the infant until independent walking is achieved.

- For example, the support of the newborn, lying on its belly, is entirely on the whole abdomen and the forearms;
- In the first quarter, the support gradually and smoothly reduces in size and is located in the forearms and pelvis (symmetrical elbow support);
- In the second quarter, in the same way, the support plane gradually decreases and locates in the palms and thighs (palms support), and, in addition to the sagittal plane, the center of gravity begins to move also in the frontal plane (single elbow support – a snatch from a symmetrical elbow support);
- In the third quarter, the support continues gradually to decrease and is located only in the hands and knees (a four-pillar standing), with the appearance of moving forward (creeping provided by three-pillar standing, as the center of gravity moves already in sagittal, frontal and transverse planes);
- In the fourth quarter, from creeping through knee standing and half-kneeling, the child takes a two-foot support, while mastering single-foot support through sagittal walking on furniture and placing hands, is related to the emergence of independent walking.
In the process of self-straightening and toddling, the infant uses different contact surfaces and points (abdomen, pelvis, hips, feet and forearms, elbows and palms), by which independently, but gradually and smoothly, controls the center of gravity, together with this building a scheme of its body that serves as orientation in space. The SME undergoes a smooth and gradual development, related to the maturation of the brain, which by itself is an accumulation of information through trial and error.

Development of motor skills

*From a prone position (baby lying on its belly)*

Mapping gross motor skills of calendar age:

- **1.5 months** - forearm support
- **3 months** - symmetrical elbow support
- **4.5 months** - a single elbow support
- **6 months** - palm support
- **7.5 months** - four-pillar standing
- **9 months** - crawling, standing on his knees, straightening on the vertical axis
- **10.5 months** - creeping on the vertical axis, sideways walking
- **12 months** - walking (broad-based - „Winnie walking“)
- **15 months** - self-straightening up from the floor („a dog walk“)
- **18 months** - self-straightening up from the floor through half-kneeling, going up stairs with one hand support

Sometimes, young and inexperienced parents, who have often read wrong information, wishing their child to walk „faster“ !!!, violate this pattern of motor development, by passive holding or placing the infant in positions, appropriate for a greater calendar age (e.g. seating between cushions at the age of 4-5 months, straight posture being supported under the arms at the age of 6-8 months, walking on one or two hands at the age of 9-10 months), or use different devices (e.g. a spider type of walkers or trucks, and „Jumper“ belts), which often distort the normal neuro-motor development of the child.
From a supine position (the baby lying on its back)
Mapping gross and fine motor skills at calendar age:

- **1.5 months** – asymmetric position „fencer”, non-targeted movements of the hands
- **3 months** – fixates and follows with eyes, a centered position of the hands
- **4.5 months** – turning to a side position; visual-motor coordination: hand-mouth-hand, targeted snatch behind the midline of the body, the hand takes the gripping function, start of stereognosis;
- **6 months** – turning from back to belly; „key grip” – thumb to the side of the flexed index finger;
- **7.5 months** – oblique seating, side seating; visual-motor coordination, hand-foot-mouth; „tweezers grip” – a contact between the index finger and the thumb;
- **9 months** – seating in the long plane (with straight knees); „pincer grip” – touching the tips of the index finger and the thumb;
- **10.5 months** – an isolated stretch of the index finger
Some specific features of premature infants

The maturation of all organs and systems, including central nervous system (CNS) and muscle apparatus in preterm infants is not completed. The immaturity of the nervous system can be characterized by incomplete differentiation of the brain substance, the insufficient development of the responses of the vestibular system, the lower degree of myelinization of the main conduction fibres, the lower overall muscle tone, the predominance of the tone of the extensor (expandable) muscles, and a lack of primitive reflexes. The immature muscle apparatus most often represents less muscular force, and in particular of the flexor (shrinking) muscles, which develop in full force and endurance in the last 8-12 weeks and are essential to overcoming the gravity by turning from abdominal or back position of the newborn.

The aforementioned CNS abnormalities in premature infants are sometimes combined with asphyxia (Apgar 6 and less) and/or various types and degree of cerebral hemorrhage, which causes „oxygen starvation” of the brain, and are responsible for the following possible problems in neuro-motor development of the premature child.

Does the child need rehabilitation and if YES, what kind?

1. Not every preterm infants needs a specialized rehabilitation, but it is necessary the baby to be followed up by a doctor, specialist in pediatric neurology and/or by a doctor, specializing in physical and rehabilitation medicine (FRM) with experience in children neurorehabilitation, who could make the necessary assessment of inclusion specialized stimulation of the motor development.

The most accurate in evaluating the motor development of the child is the combined neuro-kinesiology examination, which includes testing the following:

- **Spontaneous motility** (what the child can perform alone);
- **Testing of tendon and periosteal reflexes**, as well as dynamics (presence and disappearance) of primitive reflexes and mechanisms
- **Provoked motility** (stimulation of the vestibular system of the baby by certain movements in space, which trigger activation of certain muscle groups and chains, such as by the type of muscle activation and the complex of movements, „the correctness of the brain commandment” can be assessed).
2. Do not trust the medical or healthcare professionals who soothe you that “because the child is premature, it could be lagging behind in the neuro-motor development.” We must recalculate the calendar age of the child including the prematurity period by estimating the so-called “corrected age” of the newborn. Once the corrected age is calculated, the baby should follow the respective stages in its motor development. (e.g. if the baby is 6 calendar months, and was born three months earlier, then his “corrected age” is three months, and the motor requirements must meet those of a three-month old baby), and if it does not cover them, a specialized medical care should be sought.

3. Like any term newborn, the premature baby also needs a massage and passive movements during the first few months until the moment the child begins to turn to the side by itself (4.5 months corrected age).

4. However, stimulating hands and feet that must be excluded from the massage as those are areas that unlock very primitive reflexes and mechanisms, which being continuously activated in one immature and / or traumatized CNS could lead to some undesirable deviations in the neuro-motor development of the premature baby.

5. Newborn premature babies especially, apart from the massage and the passive movements, also need specific „embryonic“ positioning when carried by the parent and / or when awake. The embryonic positioning at carrying is as follows: the baby is put with its back to the parent between the carrying arm and his body, the inner leg of the child is fixed by the carrying arm of the parent and the outer leg astride it, the head is located between the biceps of the carrying arm of the parent and his rib muscle. In this position, the child feels support the from the back and from the sides along the whole body, much like to the position during the mother’s...
pregnancy. This position gives peace and antigravity facilitation for the child, reduces the strength of the cervical and posterior thigh extensors of the child, which in premature babies have expressed precedence that may lead to delays in the function of the cervical and ventral flexors and from there to a delay in the motor development of the premature baby.

Embryonic „nest type” positioning when awaken and lying on the back: After the first week, the premature baby should be allowed to stay awake lying both on the back and on the belly. Due to the prevalence of the strength of the extensor muscles (extensors) lying on hits, that being a reflex (labyrinth tonic reflex), and due to immaturity of both the central nervous system and the muscles, it is recommended the child to be positioned in a fetal „type nest“ position. Such nests are recommended to be used both in the NICU and at home until the age of 3.5–4 months, when the attempts of the baby to turn to the side start to appear.

6. While wishing to enjoy our child and to play with it (swinging like the airplane; giving the finger to be gripped by the palm; tossing the child like an elevator: supporting it at the armpits to stand upright or step), we provoke an immature vestibular system and immature muscle groups and chains,
which are not ready to bear the corresponding burden, therefore we unlock inadequate motor responses, which often deform more or less the motor development of the baby or block it partially.

7. If you notice any asymmetry in the motion of the lower or upper limbs, you should seek specialized medical consultation as fast as possible: a pediatric neurologist and/or specialist in physical and rehabilitation medicine with expertise in child neuro-rehabilitation.

8. The specialized rehabilitation in neonates and infants includes stimulation of movements by various methods, some of which are applied in our country. The specialist pediatric neuro-rehabilitation (neuro-stimulation) is carried out in specialized hospitals by trained physicians - specialists in physical and rehabilitation medicine and therapists (physical therapists, physiotherapists, occupational therapists). The massage and the passive movements in present retardation or “deformation” of the motor development have no significant therapeutic value and their application represents a loss of rehabilitation time. Some pediatricians, pediatric neurologists and therapists suggest to the parents to use stimulation of some movements of the newborn and the baby by activating primitive reflexes and mechanisms (foothold and creeping - Bauer reflex; contraction of the fingers - gripping reflex of Robinson; contraction of the toes - plantar gripping reflex; spreading of toes - Babinski reflex; sharp hands unfolding and embracing - reflex of Moreau; horizontally holding the chest in the air for stretching the head - Landau reflex; and others), leading to the activation and retention of the activity of the wrong muscle groups and chains, which in immature central nervous system of the premature newborns, easily leads to distortion or delay of the neuro-motor development of the baby and increased risk of fixing these incorrect motor patterns in time and shaping the clinical picture of cerebral palsy.
6. PROPHYLACTIC EXAMINATIONS

Prophylactic examinations by a general practitioner (GP)

Examinations after the discharge examinations are done by your GP. They are more frequent than in term healthy children. They represent a weekly or twice a month assessment of: the weight, the height and the head circumference, as well as the fontanelles according to premature infants’ growth curves. Healthy premature babies go through a period of accelerated growth in the first months. They quickly reach their peers. Children born weighing less than 1500 g and those especially less than 1000 g cannot catch up with their peers in growth by the third year. The follow-up is done by your pediatrician. You have to right make an examination and a consultation with a neonatologist as per your wish or following a referral by the GP.

Immunizations – they are mandatory and it is recommended to be implemented in time according to the degree of prematurity, the corrected age, any comorbidities, and complications. They are carried out by the GP after consultation with the neonatologist, the treating neurologist, pulmonologist or other professionals, involved in the treatment and monitoring of the child.

Prevention and treatment of premature baby late anemia

Late anemia of the premature baby occurs more often in children born before gestation week 32. It develops at the end of the first month after birth. It is strongest in the 2nd and 3rd month. It is characterized with pale skin and visible mucous membranes (lips, ocular mucosa of the lower eyelid), the child might not be gaining enough weight, might be getting tired faster when, etc. It is found by a blood sample - blood withdrawn from the baby’s finger or venous blood. It is appointed by a pediatrician or a neonatologist at the end of the first or second month after discharge of the child. Prophylaxis or treatment with iron preparations, vitamins, and eventually transfusion (blood transfusion), which is performed in a hospital, are initiated in accordance with the results (values of hemoglobin, hematocrit and iron). Periodic monitoring of blood parameters to correct the doses of medicines is necessary.

Premature baby rickets prevention

It is performed with intake of vitamin D in the form of drops. The intake
starts during as soon as the stay in the department. It continues after discharge in certain doses and duration as prescribed by the GP.

**Prophylactic eye (ophthalmic) examination**

**Ophthalmologist** – eye doctor.

**Pediatric ophthalmologist** – with additional qualification in eye diseases in children. Ophthalmology is the branch of medicine that deals with diseases of the visual analyzer and their treatment. The visual analyzer is an element of fundamental cognitive function for the adaptation of the living organism. 80% of the human sensory information is provided only by sight. Objective: early detection and early treatment of established eye abnormalities. Retinopathy of the premature baby (PH) - sight-threatening condition in premature children. Mandatory eye screening is done in Bulgaria.

**In which premature children having an eye examination is mandatory?**
1. Premature infants weighing less than 1500 grams with a gestational age or under gestation week 32
2. Children on mechanical ventilation for more than 72 hours or on oxygen therapy of over 30 days.

**When and by whom is the examination performed?**
1. The first examination is done at week 4-6 by a pediatric ophthalmologist.
2. The frequency of subsequent examinations is determined by the ophthalmologist.

**How is the examination carried out?**
1. By indirect ophthalmoscopy after dilation of the pupils. The examination is short and painless.
2. Examination with a digital retinal camera (RetCam) is gaining ground as the primary method for the study of premature infants. A local drip anesthesia is administered before the examination together with eye drops to dilate the pupils.

Basic methods of treatment in severe forms of PR are cryotherapy, laser therapy, and surgical treatment.
What you should be careful about?

If after the third adjusted month, your baby is still not reaching for toys, not looking for the view of the mother / the father, does not follow the figure of a man emerging from the room, or it turns one or both eyes to the side - you should contact a pediatric ophthalmologist. Bear in mind that all the above alarming symptoms could also be neurological in nature, so it is best to consult with a pediatric neurologist.

Prophylactic pediatric neurologist examination

Neurologist – a doctor who deals with the treatment of the nervous system and its disorders.

Pediatric neurologist – with additional qualification in diseases of the nervous system in children.

Which children are subject to such an examination and when?
A neurological consultation is required for all premature babies below 2000 grams after 2 months of adjusted age in view of early and timely rehabilitation or other treatment. The purpose is to prevent and / or reduce the possible delay in the motor development of the child. The neurologist may appoint additional tests such as an EEG (electroencephalography), TFU (transfontanelle ultrasound) and others.

Transfontanelle ultrasonography (TFU) is an ultrasound examination, which is non-invasive and provides with important information about the status of the child's brain immediately after birth and later on. The method can be used in the months of suckling until of closure of the large fontanel of the head. The method is harmless, which gives an opportunity for a regular checkup of the brain’s development. Early diagnosis is a prerequisite of timely treatment.

Electroencephalography (EEG) – an examination which helps to measure the electrical activity of the brain. Special sensors are attached to the head - electrode, which are connected to a computer. The computer device records the electrical activity of the brain, and using a monitor or a hard copy, the information can be obtained. It is intended to register the brain
wave activity that is altered in a variety of physiological or pathological conditions. It is widely used in the evaluation of epilepsy.

**The pediatric neurologist may appoint a consultation exam by a physiotherapist or doctor of physical medicine, if necessary. The kinesiotherapist is a health professional who examines and assesses the functional state of humans and determines the rehabilitation potential; develops and implements kinesitherapeutical programs for the clinically diagnosed by a doctor diseases; conducts specialized treatment, prevention and rehabilitation.**

**Prophylactic examination by an ENT specialist (oto-rhinolaryngologist – ears, nose, throat)**

**Which children are subject to such an examination and when?**

More often hearing deviations occur in premature infants born weighing less than 1500 grams. Deviations of the hearing can be identified by the treating neonatologist or an ENT specialist before the discharge of the child. The examination is painless and short (5-10 minutes.), with a special equipment for testing of the hearing of the newborn. After the discharge of the baby, a consultation with an ENT specialist should be done as soon as possible upon detecting abnormalities of hearing from the GP or the parents.

**Prophylactic examination by an orthopedist**

**Orthopedist** – a doctor who deals with problems of bones.

**Pediatric orthopedist** – with additional qualification in diseases of the bone structures in children.

Orthopedics deals with the occurrence, prevention, diagnosis and treatment of congenital and acquired defects in the form or the function of the musculoskeletal system, in other words, bones, joints, muscles and tendons, as well as the rehabilitation of patients.

**Which children are subject to such an examination and when?**

In premature infants weighing less than 2000 grams at birth. As early as
possible after discharge of the child. Normally, a second examination is due after six months of age or at the discretion of consulting orthopedician.

**Prophylactic examination by a pulmonologist**

**Pulmonologist** – a physician experienced in the treatment and prevention of respiratory diseases, in particular - the lungs.

**Which children are subject to such an examination and when?**
In premature infants with a diagnosis of BPD at discharge.

Bronchopulmonary dysplasia (BPD) is a chronic lung disease. The frequency is higher at a gestational age of 30 weeks and weighing less than 1500 g. Those weighing less than 1000 g are most at risk. A consultative examination by a pulmonologist of these children as early as possible after discharge of the child is necessary. The follow-up and the treatment of children with BPD is carried out by a team - a GP (general practitioner), a pediatric pulmonologist, a neonatologist, pediatric cardiologist. The family is also part of the team. It carries out specific and continuous home treatment. In recent years, a specific prevention of RSV infection is being carried out in these children. You will be informed about it by your neonatologist, who will carry out the prophylaxis in the autumn-winter season together with the GP. In the majority of cases, a gradual improvement of clinical symptoms occur, and lung function is normalized till the age of 2. Asthma may develop later in some cases.

**Prophylactic pediatric surgeon examination**

**Surgeon** – a specialist doctor in performing surgery.

**Pediatric surgeon** – with additional qualification in surgical diseases in children.

**Which children are subject to a pediatric surgeon examination and when?**
The preterm children often develop hernias: umbilical and inguinal.

**Umbilical herniation**: rarely requires surgery. It is usually corrected with a dressing and subsequent development of the muscles of the anterior abdominal wall.
Inguinal herniations: they are often bilateral and quite large (as walnut or larger), but rarely lead to incarceration (entrapment). Early consultation is mandatory: during the stay in the hospital or following your pediatrician decision on when to refer you to an examination by a pediatric surgeon.
CONCLUSION

With everything said above, we might have stirred up contradictory emotions in you. Perhaps you are still asking yourself what to expect, what will happen. The truth is that nobody can guarantee how things will develop with your baby, but we would like to assure you that you should never give up hope, no matter how hard and hopeless everything seems to you now. These miniature babies are much stronger than you think.

Have you heard the story about the smallest premature baby who survived in the world? Her name is Amillia Taylor and she is an absolute proof of how resilient these small heroes can be. Amillia was born in the 21st gestation week and 6 days – more than two weeks earlier than the limit for viability determined by the American law. Amillia’s birth weight was the unthinkable for a newborn baby – 284 grams and her height was only 24 centimetres – not bigger than an ordinary pen. According to all specialists, Amillia’s story is a real wonder. She spent more than 4 months in the neonatal intensive care unit.

Although being an exception, this child is one of the bright illustrations of how advanced medicine is today. Until recently, the survival of a child with weight below 1000 g was nearly impossible. Nowadays it is not an exception to save a baby weighing only 500 grams.

Our aim is not to create a deceptive idea that everything is rosy and your baby is not exposed to any risk at all. We believe that the objective information and sober assessment of the situation are extremely important to you as parents. The adequate care for your child begins with the adequate acceptance of things the way they are. It would be equally harmful to vacillate from one extreme to another, between the blind confidence that everything will be serene and the despair, thinking that the worst is to happen.

Statistics shows that the percentage of premature survivors keeps going up. There exists the risk of different kinds of disability, but there is also a high probability that your baby will cope and grow up healthy.

Get armed with a lot of patience and remember that in their first year premature babies develop according to their corrected age. Do not compare them with the full term babies of your relatives and friends. You had better accept what your child will develop at his/her own rates. Sometimes this
happens even more slowly than the corrected age, especially if the child has spent a long adaptation period in the hospital. However, this is normal to expect. There are so many reasons which excuse them. Yet if you still think that your child does not grow at all, does not react to external stimuli etc., you have to go to specialists. A few opinions are never too many. Do not forget that you are with the child every day and you are the best reference point for the doctor! The podiatrist sees the child once a month, while you are with him/her 24 hour a day. Do not underestimate your mother’s intuition. It is better to have vain alarm than late interference. Most probably, everything will be fine, but you, too, will calm down after the consultation with a specialist. Even if a problem is established, in most of the cases the timely diagnosis and early prevention are a guarantee for successful treatment and/or provision of an optimal quality of life for your child.

We hope we have been useful to you and wish you from the heart to have your baby discharged soon! Let they grow up health, happy and strong!
~ ORGANISATIONS THAT CAN BE OF USE ~

**National Association for Breastfeeding**
Consultants provide help and support to breastfeeding mothers throughout the country. On their website, you can find articles and stories about breastfeeding, as well as a list of consultants by towns.

**National telephone:** 0896 418 488  
**Website:** [http://www.podkrepazakarmene.com](http://www.podkrepazakarmene.com)

**La Leche League Bulgaria**
Information and support for breastfeeding from mothers to mothers. La Leche League is a voluntary organisation with branches all over the world, whose mission is to help, encourage and support all mothers who want to breastfeed their babies.

**National telephone:** 0888 555 385  
**Website:** [http://www.lllb.org](http://www.lllb.org)

**Association Pogledni me (Look at Me)**
Parents’ organisation helping parents with any kind of information about children with disabilities.

**For contact:** 0878 999 013  
**Website:** [http://poglednime-bg.simplesite.com](http://poglednime-bg.simplesite.com)

**Poppies for Mary Foundation**
Poppies for Mary is a foundation for support for parents who have experienced intrauterine or perinatal death of a child. This means that their baby died in the womb (and was born dead) or died in the first hours, days or weeks after birth.

**For contact:** Dr. Boyana Petkova, 0887 846 667  
**Website:** [http://www.poppies-for-mary.org](http://www.poppies-for-mary.org)
There are experiences where personal pain becomes a mission and sorrow and tears turn into a driving force of significant changes. Premature birth appears to be such kind of experience.

Foundation Our Premature Children has become a reality because our personal pain united us in the common idea to help other parents like their babies and us. Foundation Our Premature Children is the first non-governmental organisation founded in support of the Bulgarian premature children and their families.

If this book has been useful and you have the wish to support our activity, you can do this by donating to the following bank account:

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Thank you for your confidence!
ALL ABOUT PREMATURE BABIES
Nadya Drenska, Foundation ‘Our Premature Children’
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