Your gynaecologist informed you about the possibility your baby might be born far too early. Normal pregnancy lasts about 40 weeks. Any baby born into a pregnancy shorter than 37 weeks is called premature.

The longer the baby stays in the uterus, the better it's outlook in regard to long-term health. Usually babies born after week 34 experience no serious problems. Risk of complications increase the more premature the baby is born. The problem is underdevelopment of important organs like lungs, brain and the digestive tract (stomach, bowels). Preterm babies are also more susceptible to infections since their immune system is not yet completely formed.

The shorter the duration of the pregnancy, the higher the chances of problems after birth for your baby. Another important criterium is birthweight. The lower the birth weight of your baby, the higher it’s chances of problems. Other factors that increase the baby’s risks are perinatal infections, lack of oxygen at birth, and possible congenital or inherited disorders.

Your extremely preterm baby, medical treatment and your role as a parent

It is important you get the opportunity and privacy to take the time to discuss this with each other. Friends or family may help and support you. Or you can call on the spiritual care department of the hospital. A medical social worker or a priest, a reverent, an imam or a humanistic spiritual advisor could help you to get a clear picture of what’s best for you and your baby, now and in the future.

6. Your physicians

You have had this conversation with:

Gynaecologist Dr. ____________________________

Neonatologist Dr. ____________________________

Authors Mrs. P.M. de Jong, NICU nurse, LUMC Leiden

Mrs. A.T.A.M Claassen, NICU nurse, EKZ / AMC Amsterdam

Dr T.R. de Haan, neonatologist EKZ / AMC Amsterdam

Mw. Drs. B.A. Houtzager, gezondheidspyscholoog

Photo Nienke Elenbaas

If you feel like talking to someone who has no relation to the hospital, you can contact the VOC, the Dutch Association for Parents of babies in Incubators, www.couveuseouders.nl or phone 070-3862535.
2. Perinatal Center *(Mother and Child Center)*

Babies born before week 32 are always transferred to a Neonatal Intensive Care Unit (NICU). The NICU is part of a Perinatal Center (an alliance of Obstetrics/Gynaecology and Pediatrics/NICU).

**Before arrival in the perinatal center**

When it becomes likely you will be giving birth at less than 32 weeks your doctor will try to have you moved to one of the Perinatal Centers. This is done to optimize the birth and treatment of your preterm baby to give it the best possible chance and care. You will be transferred to a Gynaecological High Care Department if there are problems with your own health, so doctors and nurses specialized in very complicated pregnancies can take care of you. Medical policy at the NICU is made by neonatologists, pediatricians and nurses specialized in extremely preterm babies.

Obstetrics and NICU coordinate medical policy concerning your pregnancy and the birth and treatment of your baby. When you're admitted and a premature birth seems likely you will be scheduled for an appointment with a neonatologist as soon as possible. He or she will inform you about everything concerning delivery and transfer to the NICU.

3. Chances of survival and quality of life

Dutch neonatologists have put the lowest gestational age for babies to be treated at 24 weeks, based on recent improvements of medical knowledge and newborn intensive care. Parent consent is mandatory for treatment of babies born between 24 and 25 weeks. Intensive care treatment of babies born before 24 weeks is not started due to very low chances for survival and very large chances for severe handicaps later in life.

Mortality as well as physical and mental handicaps increase with shorter duration of pregnancy and/or lower birth weight of the baby. The kinds of handicap or their severity cannot be realistically predicted at birth. Much depends on the time spent at the IC Neonatology/NICU. Generally, the fewer the complications the better the baby's chances for the future.

4. Discussion about treatment

Whenever possible, parents will be scheduled for an interview with a neonatologist when an extremely preterm delivery threatens. During this interview, negative aspects concerning your baby’s chances will be discussed. These include:

- Very short duration of pregnancy
- Infection of the child before or during birth
- Very low birth weight
- Membranes have ruptured weeks ago
- Congenital diseases of the baby
- Problems unfolding during the time spent at the IC Neonatology/NICU due to underdevelopment, like infections, problems of the brain, the lungs or the intestines
- Chances of survival and handicaps

Your neonatologist may decide invasive and risky treatment is not in the best interests of your child if your baby is born in a very poor condition. This will of course be discussed with you and your child will be allowed to die. If this happens, you will be guided and accompanied by the intensive care team. All care will be taken your baby won’t have to suffer needlessly.

5. A stressful period

After the birth and a reasonably good start, your baby will be transferred to the NICU. During it’s stay at this department, you will get regular progress reports from your physician and nurse in charge. You will then be informed about all important changes in the condition of your baby.

During this difficult period, which could be weeks, your baby may still die. If the baby’s condition deteriorates severely it may become necessary to decide whether invasive and risky treatment should be restricted or even stopped. The final responsibility for treatment falls to the medical team.

When the condition of your baby deteriorates during or shortly after birth, hard questions will be asked and hard decisions will have to be made. Whether or not to choose intensive care for your baby is among the hardest decisions of your life. It is important to keep in mind that there is much more to this difficult situation than survival.