



Extreme premature birth

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INTRODUCTION

You recently found out that your child might be born extremely prematurely. Every baby and every birth are different, but the more premature a baby is born, the greater the risks of complications. This brochure aims to give you a general idea about premature births to prepare you for a talk with the neonatologist and gynaecologist.

YOUR BABY IS YOUNGER THAN 24 WEEKS

At UZ Leuven babies younger than 24 weeks are systematically not actively treated because the baby's chances of survival and quality of life are very low. Only if parents explicitly request active treatment will therapy be started.

YOUR BABY IS BETWEEN 24 AND 26 WEEKS

For babies born between 24 and 26 weeks the chances of survival and the quality of life are very different and difficult to predict. These babies have a 60% survival rate. The medical team will discuss the best possible approach in detail with you.

GOOD OUTLOOK TO MILD DISABILITY

Of the babies who survive, approximately 60% has a good outlook to a mild disability.

With a good outlook we mean your child will be able to follow normal education and will develop normally without requiring extra support.

What does mild disability mean?

For example:

- X Underdeveloped fine motor skills and co-ordination which will require physiotherapy.
- X Normal education with extra support.
- X Special education (i.e. school for normally gifted children, but with a serious learning deficit).
- X ADHD or characteristics of autism.
- X Wearing glasses from a very young age.

MODERATE TO VERY SEVERE DISABILITY

40% of the babies who survive will develop a moderate to a very severe disability.

What do we understand under a moderate to a very severe disability?

For example:

- ✓ Delayed motor skills development. Often there is more stiffness or less flexibility (rigidity) in the arms and/or legs and less strength in the torso. In severe cases the child may suffer cerebral palsy. This means the child builds up tension in the muscles (spasticity). In case of a severe form these children may not be able to walk.
- ✓ A mental disability, ranging from light to severe (IQ less than 80). This means the child will not be able to follow normal education, not even with extra support. In the most severe forms, education is very limited and the child will not be able to live an independent life.

- ✓ A severe form of autism, behavioural problems or ADHD.
- ✓ Visual disability which requires extra support.

These are of course average figures which are strongly affected by various factors.

Positive factors:

- X Girls are slightly better off.
- X Singleton pregnancies.
- X Medication to develop the lungs (corticosteroids) was administered to prepare the baby.

Negative factors:

- ✓ Boys are slightly worse off.
- ✓ Multiple pregnancies.
- ✓ Congenital disorders.
- ✓ Infections in the uterus.
- ✓ Loss of amniotic fluid before birth.
- ✓ Bad growth of the baby before birth.



TREATMENT

There are two possibilities in the treatment of extreme premature birth (before 26 weeks):

I. Intensive treatment

An intensive treatment means both pregnancy and birth are subject to intensive monitoring.

During pregnancy

Treatment during pregnancy implies that medication to develop the lungs (corticosteroids) will be administered starting from two days before the 24th week. This is to improve the development of the fetal lungs which increases the chances of survival and reduces the risk of complications. From the 24th week the baby is intensively monitored. This usually means the mother stays in the hospital and the baby's heartbeat is regularly monitored, combined with regular ultrasound follow-ups. When the baby shows an irregular heartbeat and is in distress, a choice has to be made to induce delivery of the baby or to perform a caesarean section. This choice is made in joint consultation with the gynaecologist.

After the birth of the child

After your baby is born, he will be immediately treated by the neonatologist, a paediatrician specialised in premature babies, and receive all the necessary support. Intensive care includes all possible treatments a child needs to stay alive, e.g. artificial respiration, blood tests, medication, catheters, etc. Regular tests are also carried out in the first week, such as an ultrasound of the brains. In case of serious

complications a decision will have to be made whether to continue intensive care. Good test results in the first week do not necessarily exclude further complications or difficulties.

2. Conservative attitude

During pregnancy

If you adopt a conservative attitude, there is no intensive monitoring during the pregnancy between 24 and 26 weeks and only two days before the 26th week will medication to develop the lungs be administered. The mother can, if medically possible and justified, go home.

After the birth of the child

If your baby is born between 24 and 26 weeks, help and support is provided in case of a conservative attitude, but no intensive care. This is referred to as palliative care or comfort care. This means that everything possible is done to allow the baby to spend its little time on the world peacefully and pain-free, without intensive life-saving measures.

How can parents have a say in this?

As a future parent it is very difficult to have to make these serious decisions. The medical team is very aware of this. This is why the gynaecologist and neonatologist will have a talk to you to answer all your questions and support you as much as possible in this difficult decision. Every situation is different which is why it is very difficult to give a general recommendation.

YOUR BABY IS 26 WEEKS OR OLDER

For babies born from 26 weeks on, intensive care is started, unless there are indications that the baby's outlook is very bad. In Belgium the survival rate of babies born at 26 weeks is more than 80%.

CONTACT DETAILS

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dr. Maissa Rayyan
dr. Liesbeth Thewissen
dr. An Eerdekens
Ingrid Deroover – head nurse

SUPPORT ORGANISATIONS

Kind en Gezin

Kind en Gezin line: Tel. 078 15 01 00
(every working day from 8 a.m. to 8 p.m.)
www.kindengezin.be

Cozapo

Contactgroep zwangerschapsafbreking na prenataal onderzoek
(Contact group pregnancy termination after prenatal examination)
www.cozapo.org

Fara

Luister- en informatiepunt rond zwangerschapskeuzes
(Listening and information point about pregnancy choices)
Tel. 016 38 69 50
www.faranet.be

SELF-HELP GROUPS

Zelfhulpgroep voor ouders van een overleden baby

(Self-help group for parents of a baby who died)
'Met lege handen' vzw
www.metlegehanden.be
Tel. 0495 65 18 08 (Marleen Vertommen)

Vlaamse Vereniging voor Ouders van Couveusekinderen

(Flemish Association for Parents of Incubator children)
(VVOC)
www.vvoc.be

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Design and implementation

This text has been drawn up by the neonatology department in co-operation with the communication department.

This brochure is also available at www.uzleuven.be/en/brochure/700822.

Comments or suggestions pertaining to this brochure can be submitted via communicatie@uzleuven.be.

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Published by
UZ Leuven
Herestraat 49
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