



Pre-natal diagnostic testing during pregnancy

Make well-informed decisions



Dear readers,

Dear readers,

When you are pregnant, pre-natal diagnostic testing will be a topic you will certainly be faced with time and again. Additional tests and examinations beyond the standard tests provided for in the Mother-Child Health Passport are becoming more and more common.

Pregnant women have to give careful thought to whether they want to take pre-natal diagnostic tests. When deciding in favour of one or more of these tests, they will also have to think about how they are going to cope with a potentially abnormal result. As a woman, or as a couple, you need to thoroughly consider the pros and cons, and to be able to make this difficult decision, you need information and advice.

This is exactly what this brochure is for. It does not give you a detailed list of the various pre-natal diagnostic tests – lots of in-depth information about these tests is readily available elsewhere. But what it aspires to do is to raise your awareness and inspire you to give this matter the attention it deserves. If you do that, you will be able to make a well-informed decision that you can stand behind.

What is your personal attitude towards pre-natal diagnostic testing? What would you want to know and what not? Being sure about this will be very helpful when you are pregnant. All the more so if you are considering taking additional pre-natal diagnostic tests beyond the standard ones. If you are well prepared, you will be able to make a good decision for your personal situation, however stressful it may be.

You are the only one who can decide what is the best way forward for you. Please make use of the support and advice being offered. We wish you all the best!

Peter Hacker

Executive City Councillor for Social Affairs, Public Health and Sports

Kristina Hametner

Head of the Vienna Women's Health Programme

Michael Binder

Vienna Hospital Association, Directorate General

Table of contents

1. You're pregnant ... The main thing is, it's healthy!	4
2. Tests during pregnancy	6
Mother-Child Health Passport tests	7
Additional pre-natal diagnostic tests	8
3. Pre-natal diagnostic testing – yes or no?	12
What questions may help with your decision-making?	14
Advice services	16
4. The results are abnormal	18
How likely is a condition or disability?	19
Mental stress	23
5. The decision	24
I'm going to continue with the pregnancy	26
I'm going to terminate the pregnancy	31
6. Make well-informed decisions	34
Where can you get help?	35

1. You're pregnant ... The main thing is, it's healthy!



Pregnant women and future parents have lots of questions about pregnancy and birth. Naturally, the health of the child is the most important thing for the future parents.

The main thing is, it's healthy – that's what everyone wants. But how can we know whether the baby inside the mother's tummy is healthy? This brochure is about the tests that are available.

During pregnancy, medical check-ups are provided for both mother and child. Once born, the child will have further standard check-ups until it is 5 years old. All the standard tests are listed in the Mother-Child Health Passport that pregnant mothers are given by their gynaecologist.

There are also other, **extra** tests that women can have during their pregnancy. These tests are referred to as **pre-natal diagnosis**.

- > Pre-natal means: **before birth**
- > Diagnosis means: **examinations and tests**

In pre-natal diagnosis, the doctor looks if there are any problems with how your child is developing. In this way, it is possible, for instance, to find out whether the unborn child is suffering from any illness, deformity or other disorder.

Depending on the results of such diagnosis, you may have to make a **difficult decision**.

There is no right or wrong decision if the findings are abnormal. That's why it makes sense for you to consider the possible consequences of a test for you and your child before you have the test.

The information in this brochure is intended to give you an overview of the tests available and help you in your decision-making.

2. Tests during pregnancy



During pregnancy, both mother and child undergo many tests. The tests in the Mother-Child Health Passport are compulsory. There are also other tests that you can have carried out before the birth.

Mother-Child Health Passport tests

5 tests are carried out during pregnancy under this scheme.

Three of those are **ultrasound examinations**. A gynaecologist will carry out these tests at his or her surgery or doctor's office. If the gynaecologist has a contract with your health insurance fund, these examinations are free of charge for you.

What is examined?

- › The position of the child
- › The child's heartbeat
- › The position of the placenta, that's the organ in a pregnant woman's uterus (womb) that supplies nutrients to the baby
- › The amount of amniotic fluid
- › How many weeks pregnant are you?
- › The child's development

If you have more than 3 ultrasound examinations, then you will have to pay for them yourself, i.e. a 4th ultrasound examination or more will no longer be free of charge.

Additional pre-natal diagnostic tests

These tests are not compulsory. You can decide for yourself whether or not you will have which tests.

Their purpose is to monitor the development of the unborn child more closely and, for example, also examine cells from the amniotic fluid or the placenta, your blood or the amniotic fluid itself. Certain conditions, deformities and other disorders in the unborn child can be identified in this way.

The tests are carried out in specialist, specially approved pre-natal diagnostic centres.

In most cases, you have to pay for these tests yourself. That's to say, the cost is not covered by your health insurance. With the description of each test, you will also see the approximate cost. In certain cases, these tests can be carried out in a hospital.

Your health insurance will cover the costs in the following cases:

- › Where there is an increased risk of disorders in the chromosomes (components of the body's cells). For example, trisomy 21 is a well-known disorder also known as Down syndrome.
- › If you had problems in previous pregnancies.
- › If one of the tests in the Mother-Child Health Passport revealed something unusual.

If there are indications of any increased risk, extra monitoring tests can be carried out. You can decide for yourself whether or not you want to have these tests. You also have the right not to know and can refuse being tested at any time.

Before any such test, the doctor must **explain it to you** and note that they have done so in your Mother-Child Health Passport. **Don't be afraid to ask questions** if anything is unclear to you! You can also go to special advice centres. You'll find the contact details at the end of this brochure.

What additional pre-natal diagnostic tests are there?

→ First-trimester screening or nuchal (neck) fold measurement

11th – 14th week of pregnancy

A trimester is a period of 3 months. This screening, or test, takes place during the first trimester of pregnancy. That's where the name comes from. The doctor carries out an ultrasound examination to measure your baby's nuchal fold (at the back of the neck) and also examines its other organs and blood vessels. The test can indicate if the baby is disabled. If the nuchal fold is very thick, the baby **could** have a genetic abnormality.

Cost: from about EUR 100

→ Combined test

11th – 14th week of pregnancy

Here, 2 tests are carried out: The baby's nuchal fold is measured, and the mother's blood is tested for 2 hormones. The result is a figure that indicates how likely a **possible** abnormality is.

Cost: from about EUR 180

→ **Organ screening or detailed diagnosis**

20th – 22nd week of pregnancy

The doctor performs a very detailed ultrasound examination to look at the baby's organs, for example the brain, heart and kidneys. They will also check for the first time whether there is anything abnormal about the arms, legs or body shape.

Cost: from about EUR 180

→ **NIPT**

from the 10th week of pregnancy

NIPT is short for non-invasive pre-natal testing. Non-invasive means that no instruments are inserted into your body.

Blood is taken from the expectant mother and tested. This blood test is very complex and takes about 2 weeks. If the result is normal, no further tests are needed.

The test is very accurate. It is mainly carried out if the first-trimester screening showed an increased risk of chromosomal abnormality.

If the result is abnormal, an invasive test, i.e. a medical procedure where the skin is cut or instruments are inserted into a body opening, can provide further information.

Cost: from about EUR 620

The two invasive tests explained below can indicate more accurately whether there is a chromosomal abnormality and if so, which.

However, because a minor intervention is required, there is a very small risk of miscarriage, because the membranes may rupture prematurely.

Cost: each from about EUR 600

→ **Placental puncture**

10th – 13th week of pregnancy

This test is also called chorionic villus sampling.

A very fine needle is used to take a tissue sample from the placenta which is then tested in the laboratory.

→ **Amniotic fluid sampling**

16th – 20th week of pregnancy

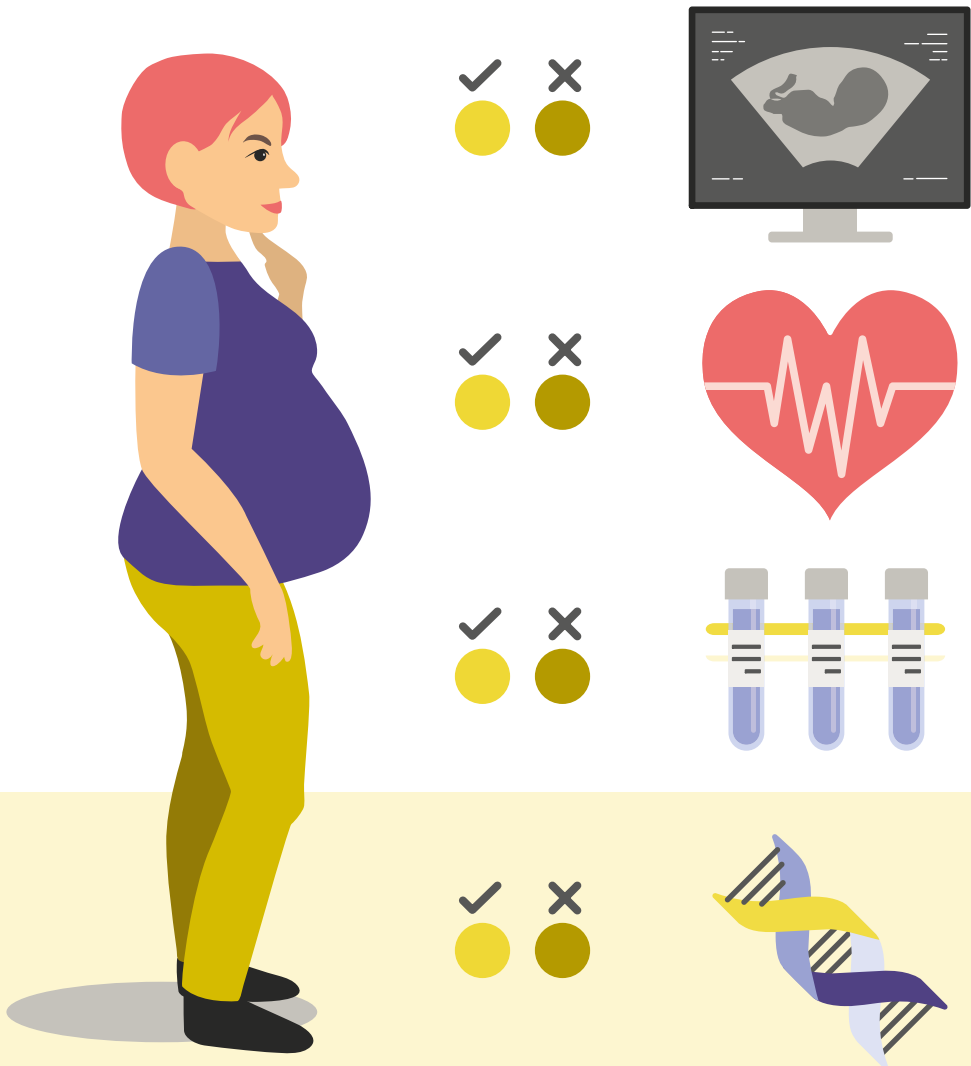
This test is also called amniocentesis.

A very fine needle is used to extract some amniotic fluid from the amniotic sac. The amniotic fluid contains cells from the baby that can be examined in the laboratory.

Your doctor will give you further details about the two tests.

The tests described here are the ones that are carried out most frequently. There are other tests such as a magnetic resonance test or an umbilical cord puncture. Your doctor will tell you whether these tests would be useful in your case.

3. Pre-natal diagnostic testing yes or no?



Before you decide to have any additional tests before the birth, please consider carefully:

- > What are my reasons for doing so?
- > Will I be able and willing to deal with the possible consequences of the tests?

Almost all children are born healthy, with no abnormalities. But there can be no guarantee that a child will be healthy.

Some conditions cannot be identified by pre-natal diagnostic testing. It can happen that certain conditions or abnormalities are missed during testing. Or they will occur only later in life.

It may also happen that the test initially shows a suspicion of a possible condition or abnormality and then later this suspicion proves to be incorrect. Then the parents have worried unnecessarily.

Testing may also mean that parents will not enjoy the pregnancy as much as they would have without the tests, because they are constantly waiting for results and are being anxious.

The results may be reassuring, but they may also cause concern.

A normal result is a relief, of course.

An abnormal result is worrying.

But once you have a result, you can then plan the birth and consider treatment options during pregnancy accordingly.

What questions may help with your decision-making?

The following questions are intended to give you food for thought. They may help you to work out how you feel about pre-natal diagnostic testing.

- › In my personal opinion, what are the arguments in favour of additional testing? What are the arguments against it?
- › Do I have enough information about what the test might show? What am I not yet clear about?
- › Do I feel I am being pressurised to have the test? Someone is putting me under pressure and that's the only reason I am considering having the test?
- › What would it mean for me to have a child with a disability or illness?
- › Which conditions can be diagnosed with pre-natal testing? And which cannot?
- › What do I actually know about disability? Do I know any persons with disabilities?
- › Can I imagine terminating the pregnancy?
- › Who is there to help me?
- › Do I need more advice?

The decision for or against pre-natal diagnostic testing depends on your personal attitude, your needs and your own judgement. Your values and your ideas about what is right and wrong are also important, as are, of course, your religious beliefs. Talking to your partner may be very helpful.



Advice services

There is lots of advice about pre-natal diagnostic testing available for you. There are various options.

You will be able to talk about both the medical issues and your personal questions, thoughts and feelings. You will also find out what help is available if your child is physically or mentally disabled.

Advice will be given in a way that is easy to understand and no-one will force you to decide one way or the other.

Please **always ask more questions** if you are uncertain or something is unclear to you.

Advice from your doctor

Your gynaecologist will advise you and answer your questions about the progress of your pregnancy and methods of pre-natal diagnostic testing. If necessary, he or she will give you the name of a suitable specialist centre.

Psycho-social advice

This type of advice gives you the time and space to discuss your personal concerns. The aim is to support you if you feel uncertain about pre-natal testing or if you are stressed or anxious. This will help you to make your decision.

Advice at Family Advice Centres is free of charge.

You'll find the contact details at the end of this brochure.

Human genetics advice

Genetics is the scientific name for the study of heredity. Human genetics advice is therefore about conditions or disabilities which can be hereditary in families. Specialists in medical genetics can work out how high the risk is that your unborn child will be affected.

If you are referred by your doctor, human genetics advice is free of charge.

Advice from a midwife

Midwives not only help you during the birth but also offer personal advice and support during pregnancy.

All women can obtain support from a midwife.

In some cases you will have to pay for it yourself.

The Mother-Child Health Passport also includes free-of-charge advice from a midwife.

4. The results are abnormal



Perhaps the results are abnormal, or someone tells you that there may be something wrong with your child.

In medical terminology, abnormal results are also called positive results.

This gives rise to lots of questions, which can be very stressful.

You will then have to make more decisions, and you may need help with that. Please **take plenty of time** getting **advice** and accept any **offers of help**.

How likely is a condition or disability?

In pre-natal diagnostic testing, certain measurements are taken and the results are recorded. From the measurements, it is possible to work out how likely the child is to have a certain condition or disability.

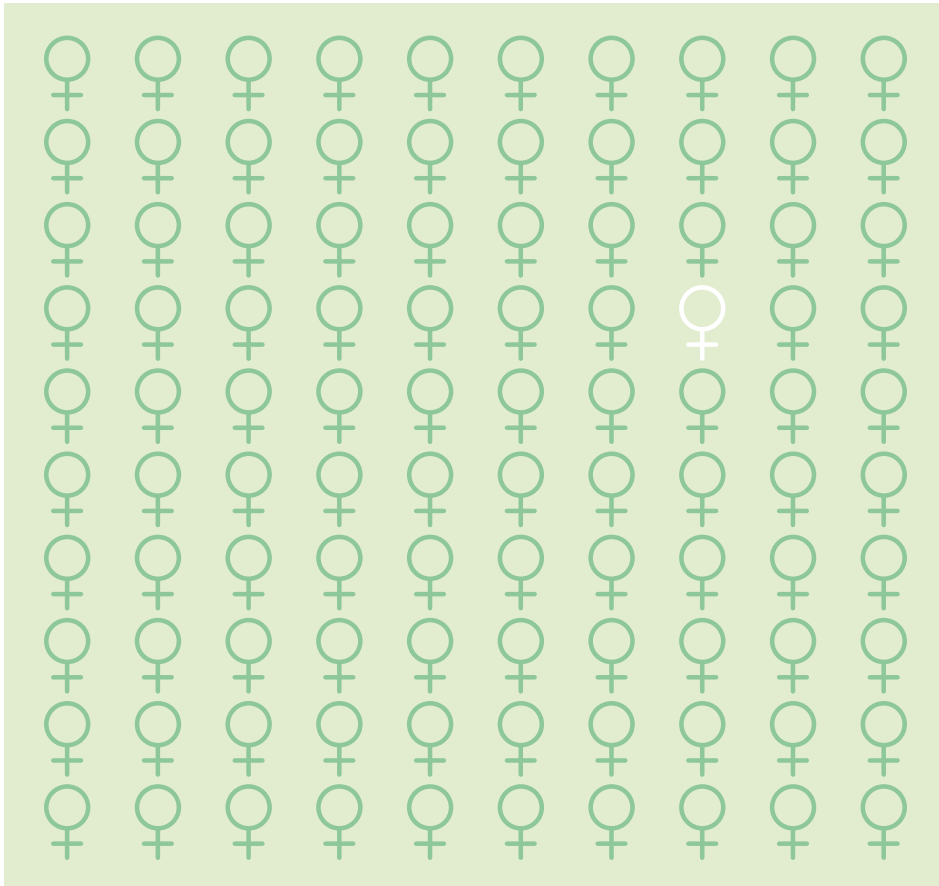
This means: an abnormal result is not a definite diagnosis!

The result only tells you how likely it is that your child has a disability or illness. Nor does the probability figure tell you how severe the possible disability or illness may be.

You need to understand something about probabilities, and we will try to explain it here in an example: The test results will show the risk of a certain condition as a probability, expressed as a ratio.

For example: the risk is 1:100.

This means that 1 in 100 women will have a child with this condition. But it also means that 99 in 100 women will have a child without that condition.



The diagram clearly illustrates how many women are affected. One in 100.

The risk for certain conditions increases with the age of the pregnant woman. For example, older mothers are somewhat more likely to have a child with trisomy 21 (Down syndrome) than very young mothers.

That's why the age of the woman is taken into account in working out the probability, and why older pregnant women more often get an abnormal result.

The most frequent conditions

Some conditions and possible problems during pregnancy can be spotted early by pre-natal diagnostic testing. That can be very helpful because knowing about these problems is important for planning the birth.

The most frequent conditions and disorders are:

- **Deformation of organs**
such as the heart, lungs or kidneys or other parts of the body such as the abdominal wall, bones, arms or legs.
- **Chromosomal disorders**
such as trisomy 21, also known as Down syndrome.
- **Complications to the pregnancy**
such as a problem with the placenta. The placenta is the organ in the uterus that supplies nutrients to the unborn child.
- **Nutritional disorders**
in the child, such as growth disorders if the child is not getting enough nutrients.

Treatment options before birth

Treatment usually consists of medication given to the mother. The medication reaches the unborn child through the umbilical cord.

Surgical interventions inside the uterus are possible only in very rare circumstances.

In recent years, the ways of treating unborn babies have improved. However, not all conditions, deformities or developmental disorders can be treated in the uterus.

Nevertheless, knowing about an illness or disorder can be very important. For example, you can plan for the birth to take place in a special hospital. The subsequent care and treatment of the new-born can also be better organised.

Mental stress

It is a huge shock to hear that your child may be ill or have a disability. At first, you will hardly be able to understand the sudden change in the situation.

It is even worse if you have never thought about the subject before. You experience all kinds of emotions and thoughts and feel really overwhelmed by them.

A completely normal pregnancy has suddenly turned into a crisis. Many of your hopes for your child have suddenly been destroyed. Perhaps you may even have to come to terms with the idea that your child will die.

For most couples, the test results also alter their relationship with their unborn child. It is suddenly difficult to see the child as a joyfully awaited new member of the family. It may also be difficult to detect the baby moving in the mother's belly.

Your feelings are in an exceptional state of turmoil. And yet you have to consider the question of what to do next. You have to understand the diagnosis and make decisions.

It's important to get accurate medical information. That will help you to make the necessary decisions.

Many of the women and couples affected in this way immediately know in their hearts which way they want to decide. Nevertheless, it's still important to take your time in reaching your decision. That's the only way to consider the situation in detail from all angles and think about what to do. It's the only way to reach a decision that you will still be happy with in years to come.

5. The decision



It is a shock to learn after pre-natal diagnostic testing that your child will probably have a disability or some other condition.

Take your time and consider calmly what you want to do now.

Essentially, you have 2 options:

I'm going to continue with the pregnancy. **or** I'm going to terminate the pregnancy.

In making this very personal decision, there is no right or wrong answer. All you can do is decide what is right for you.

You may find the following questions helpful:

- › Who do I have around me who can help?
For example, your partner, family, friends and neighbours ...
- › What am I capable of?
What personal resources do I have?
That means all the characteristics, skills and resources that could help me cope, for example, inner strength, courage, strong relationships – but also money.
- › What does my partner feel about the situation?
How will my decision affect our relationship?

There are **support services** to help with your decision-making. Take advantage of **psycho-social advice services**. You'll find the contact details at the end of this brochure.

I'm going to continue with the pregnancy



You may decide to continue with the pregnancy. You will be examined more often and monitored more closely.

In addition to the care provided by your doctor, many additional services are available for you. Perhaps you would like to be supported by a midwife or get advice from an advice centre for pregnant women. That may help you and reduce your stress.

I'm going to have a child with a disability or other condition

During this kind of pregnancy, your happiness at having a child may be mixed with fear and uncertainty. You wonder how the child will develop. Perhaps you are worried about how you will cope with the possible difficulties.

Preparing well for the arrival of your child will make you feel more confident. There are lots of ways you can get advice and assistance to support you. You could contact self-help groups or organisations for persons with disabilities. They will be happy to help you in any way they can.

Financial support may be available, and there are practical services to make living with a child with a disability or illness easier.

What will your life together really be like?

It depends on the nature of the condition or the degree of the child's disability. But also on how much help you have.

Help at home, in an institution or from foster parents:

Most parents want to care for their child at home. The Vienna Child and Youth Welfare Service (MA 11) offers special services that can be specifically tailored to the child's disability and the needs of the whole family. The City of Vienna's Child and Youth Welfare Service is there to provide support to families and protection to children.

- **Family help** for children with disabilities offers help, for 9–25 hours a week, with caring for a child with disabilities in the family home. If more care is needed, help can be provided for **up to 24 hours a day**.
- **Short-term stays** of the child at an institution for persons with disabilities are possible, from individual weekends to 4 full weeks per year

These are services provided by the Vienna Child and Youth Welfare Service.

You are not automatically entitled to these services. To be able to benefit from them, you have to meet certain requirements. And you also have to make a contribution towards the cost.

Service hotline: 01 4000-8011

- Perhaps you would like your child who has a disability or other condition to live in a **socio-educational institution**. That is possible at institutions operated by the Vienna Child and Youth Welfare Service focussing on working with the disabled. This type of support is called out-of-home care (*volle Erziehung*).

- You want to give birth to your child, but are unable or unwilling to bring it up yourself? Then perhaps you will opt for foster parents.

Foster parents take over the role of the birth parents for an unspecified period of time. The birth parents have certain rights. For example, you can visit your child regularly.

If you later decide that you want to take your child back, then that may be possible, subject to certain requirements.

I'm going to have a child that will not survive

It may be that the test results show that your child is so seriously ill or disabled that it will not survive. Either later in the pregnancy or soon after birth, it will die.

That is very painful and extremely hard to bear. You definitely need help and support.

In most cases, a natural birth is possible. You have time to prepare yourself for the birth. You can think about how you want to say good-bye to your child.

- › What will remind you of your child later?
- › Do you want a photograph of your child?
- › How would you like to grieve for your child?
- › Is there a ritual or a special procedure that will help you in your grief?

A child dying or being unable to survive is probably the most difficult emotional crisis that parents ever have to face. The pain and grief are often hard to bear. These feelings come in waves. Over time, they will become less frequent and easier to bear.

It is important to allow time to say goodbye and grieve. It can also happen that you experience other emotions, such as feelings of guilt or anger. It may be helpful to express your feelings. Perhaps you would like to write about your feelings or express them in a picture or talk about them with others who have been similarly affected. Everyone grieves in their own way. Your partner may grieve in a different way from you. Please try to understand that.

And please, you must get psychological support! You'll find the contact details at the end of this brochure.

You can find more information about this subject in a brochure published by the Federal Ministry for Families and Youth. The brochure on stillbirth and the death of a child after birth is available for download (in German) from the website **bmfj.gv.at** (*Stille Geburt und Tod des Kindes nach der Geburt*).

I'm going to terminate the pregnancy

You have the right to decide to terminate the pregnancy. If you do, you need to have a discussion with your doctor beforehand.

The final decision is up to the woman, no-one else has any right to have a say. This is laid down in law.

It may be less stressful for you to involve your partner in your decision-making and share your thoughts and fears.

Of course, it is particularly difficult if your partner has a different opinion.

In these special circumstances, pregnancies are frequently not terminated until after the 3rd month of pregnancy. This is because the pre-natal diagnostic tests cannot be carried out until the 11th week of pregnancy.

Then you still have to wait for the results. Furthermore, many deformities only become apparent later in the course of the pregnancy.

Such a late termination can only be carried out by a doctor. Under the law, it is allowed only in the following cases:

- › If the life of the pregnant woman is in grave danger or if her physical or mental health is seriously at risk.
- › If there is a serious risk that the child will suffer from a serious mental or physical disability.

There must be clear medical evidence of these risks. If such medical evidence exists, your health insurance fund will accept the cost of terminating the pregnancy.



What happens during a late termination?

The birth of the child has to be artificially induced. The pregnant woman is given medication that opens up the cervix of the uterus and starts contractions. The process of giving birth may last 2–3 days. Often, the child will die during the birth process.

However, if the pregnancy is quite advanced, the child may still show signs of life after the birth, for example a heartbeat, movements, or pulsating of the umbilical cord.

If the pregnancy is very advanced, the child may be capable of surviving outside the uterus. This may happen after the 22nd week of pregnancy. In that case, the child will be given an injection through the pregnant woman's abdominal wall that stops its heart. Then it will be certain that the child is dead when it is born.

If you are trying to reach a decision about terminating your pregnancy, **please get advice**. There are various specialist advice centres that you can turn to.

6. Make well-informed decisions



Make your own decision about pre-natal diagnostic testing. Take your time and get advice.

Whichever way you choose to go:

Make the decision with your head and your heart.

We wish you all the very best!

Where can you get help?

The following institutions in Vienna can help you in your decision-making:

- **Child and Youth Welfare Service counselling facilities (MA 11)**
Parent counselling and family centres
Service hotline: 01 4000-80 11
wien.gv.at/menschen/kind-familie/servicestellen/elternberatungsstellen.html

- **FEM women's health centre at Klinik Floridsdorf**
Brünnerstraße 68, Bauteil A3/Top 14, 1210 Vienna
Phone: 01 27700-5600
fem.at

- **FEM Süd women's health centre at Klinik Favoriten**
Kundratstraße 3, 1100 Vienna
Phone: 01 60191-5201
femsued.at

→ **City of Vienna family midwives**

Schnirchgasse 12/2, 1030 Vienna
Phone: 01 4000-87637

Geyschlägergasse 2 – 12, 1150 Vienna
Phone: 01 982 25 00

Dresdner Straße 73, 1200 Vienna
Phone: 01 331 34-20279

Langobardenstraße 128/12, 1220 Vienna
Phone: 01 285 45 37

geburtsinfo.wien/en/nach-der-geburt/angebote-nach-der-geburt/angebote-der-familienhebammen

→ **Midwives Centre – Association of Midwives
(Hebammenzentrum – Verein freier Hebammen)**

Lazarettgasse 6/2/1, 1090 Vienna
Phone: 01 408 80 22

hebammenzentrum.at

→ **Directory of psychologists and psychotherapists**

Search terms: pregnancy, termination of pregnancy
(*Thema: Schwangerschaft, Schwangerschaftsabbruch*)
psychologen.at and psyonline.at

Acknowledgements

We would like to thank the council of experts consulted for this brochure for contributing their expertise and providing welcome inputs in the year 2018:

› **Dieter Bettelheim**

Vienna General Hospital, University Hospital for Women's Medicine,
Clinical Department for Obstetrics and Fetomaternal Medicine

› **Claudia Hopfinger-Uhl**

Semmelweis Women's Clinic,
Outpatients Department for Clinical Psychology and Psychotherapy

› **Karin Müller**

Midwives Centre

› **Ingrid Pöschmann**

MA 11 – Specialist department for integration

› **Martina Reichl-Roßbacher**

MA 11 – Adopted and Fostered Children Unit

› **Konstanze Sinko-Sanz**

Centre for Child Development (ZEF), 11th District

› **Anita Weichberger**

Vienna General Hospital, University Hospital for Women's Medicine,
Clinical Psychology Outpatients Department

› **BIZEPS – Zentrum für Selbstbestimmtes Leben**

(Centre for Self-determined Life)

› **Regina Zsivkovits**

Midwives Centre

Legal notice

Publisher, media owner and responsible for content

Büro für Frauengesundheit und Gesundheitsziele
Strategische Gesundheitsversorgung Stadt Wien
Brigittenauer Lände 50-54/2/5, 1200 Wien

Project management & editing

Christina Bässler
Denise Schulz-Zak

Design Jessica Gaspar

Version March 2021

For more details on the Vienna Women's Health Programme,
numerous women's health topics and initiatives, please visit our website
frauengesundheit.wien.at

You can get in touch with us via phone or email

Phone: 01 4000-84200

E-mail: frauengesundheit@ma24.wien.gv.at

You can also download or order a free copy of all the
Vienna Women's Health Programme's publications on our website.

This brochure supports the Vienna Health Targets 1 and 5

Target 1: Right from the start: Increasing health equity for children and young people

Target 5: Strengthening health literacy of the Viennese population

