




HIV, the desire for children, and pregnancy

Information for HIV positive women
and those concerned

FrauenGesundheitsZentrum München

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What is the purpose of this pamphlet?

For many people, having a family and children is very important. Frequently, being HIV positive doesn't change that.

The goal of this pamphlet is to accompany you as you fulfil your desire to have a child. It is also a source of information for people who are close to you, such as your partner, relatives and friends.

Of course, this pamphlet does not take the place of a visit to your doctor and a professional information centre. At the end of the pamphlet is a list with several addresses of organisations where you can find additional advice and support.

Question upon question...

How can I get pregnant without putting my partner at risk? When is the best time for pregnancy? Will I be able to or want to care for a child despite having HIV? Even if my child is ill? Who will care for my child if I become ill or die? Can I rely on my family and friends? How will a pregnancy and child change my life? How do I manage the pressure of having to decide whether or not to have a child?



And if I don't get pregnant - can I find another outlook for my life?

Most women who have HIV and a desire for children ask themselves these and many other questions. Because becoming a mother with HIV is not an easy decision. It is important to take your time and not let others put pressure on you.

Even though your desire for a child may affect your family, your partnership, and your friends:

Whether or not to have a child remains entirely your own, personal decision.

You should talk about all of your questions, hopes and concerns with people whom you trust and who will not put pressure on you. That may be your partner, or it may be friends or relatives.

AIDS support centres and other information centres for people with HIV are also good sources of support. HIV positive women who already have children can give you important tips and advice. Many information centres will provide contact to mothers, including women from other countries.



Becoming pregnant

You are HIV positive and are wondering: “Can I even have children?”
The answer is: **Yes! Even women with HIV can become pregnant and have healthy children.**

The medical field has made great advancements in recent years. There are gynaecological hospitals in most large German cities that specialise in pregnancy for HIV positive women.

Doctors in Germany now have a great deal of experience treating HIV positive, expecting women. By using advanced

methods for treating HIV in expecting women, they can considerably lower the risk of infection to the baby.

If you and your doctors – HIV specialists, your gynaecologist and later the child’s paediatrician – work together closely and trustingly, both your and your child’s health will benefit.

More than 98% of HIV positive, expecting women in Germany have healthy children!

Despite this, there is unfortunately no guarantee that your baby will be born without infection.

When is the best time for pregnancy?



The best time to become pregnant is when you feel healthy, the viral load is low and the number of CD4 cells is high. CD4 cells indicate how strong your immune system is. The risk of infecting your baby is higher if you have a genital infection, if you have already developed AIDS, if the viral load is high and the number of CD4 cells is low.

If you are not yet taking any medication for HIV, you might want to consider whether to get pregnant before you need treatment.

If you have already started a treatment regimen:

You can still become pregnant despite taking medication.

For this reason, do not stop treatment on your own if you want to become pregnant. Whether and for how long your treatment will be interrupted during pregnancy is something that should be discussed with your HIV specialists.

Important in any case: Your HIV specialist and your gynaecologist know your medical history and laboratory results. They can help you with the decision-making process and, together with you, determine the best possible treatment. That includes choosing medication that won't harm your unborn baby.

Which special tests should I have?

If you would like to become pregnant, discuss with your doctor which tests are important, in addition to your routine HIV-specific tests.

- Certain infections should be treated completely before you become pregnant. This will allow your baby a healthy development in the womb. Untreated sexually transmitted diseases weaken your immune system and increase the risk of HIV transmission to your baby.

HIV positive women sometimes experience menstrual difficulties, such as irregular or prolonged periods. If you suspect that something is not right, you should discuss this with your gynaecologist. It may be necessary for you to take hormones in order to become pregnant.

If you take HIV medication for the first time during pregnancy, a resistance test will be performed beforehand. It will determine whether the virus in your blood is non-susceptible to certain drugs. Effective medication can then be selected.

My partner is HIV negative – how can we conceive a child without risk?

You can get pregnant without a risk of infection to your partner:

If you and your partner are fertile, your best option is what is known as “**self-insemination**”.

You should do this on your most fertile days, i.e. at the time of ovulation, which is around the middle of your cycle.



Your gynaecologist can help you determine the exact time of ovulation.

Self-insemination means that you inject your partner's sperm directly into your vagina. The following methods can be used to do this:

First, you need to collect your partner's sperm. You can take it out of a condom following regular intercourse – make sure you use a spermicide-free condom. Or your partner can ejaculate into a sterile container, such as a jar that has been sterilised in boiling water.

You can then draw the sperm into a syringe – without a needle! – and inject it into the vagina.

Or you can put the sperm into a diaphragm or cervical cap and then insert it.

It is most effective to perform the first self-insemination approximately three days before ovulation and a second insemination on the day of ovulation, at the latest. Further attempts are not usually effective.

Not all couples are able to conceive a child using this method. In any event, you and your partner will need to be patient, since several attempts are usually needed to achieve pregnancy.

Even if it takes a long time: it is vital that you and your partner make it as stress-free as possible. And do not hesitate to ask for help.

If your menstrual period is late by two or three days, you can perform a pregnancy test either at home or at your gynaecologist's practice.



My partner is also HIV positive – what do we have to keep in mind?

HIV positive men can also father healthy children. Some women will become pregnant through unprotected intercourse with their partner.

However, it may be beneficial for your health to forgo the use of condoms only around the time of ovulation. If you are both HIV positive, you may infect each other with different strains of HIV. However, this does not happen often. During unprotected intercourse,

you can also become infected with other sexually transmitted diseases. These can weaken your immune system and lead to serious problems for your and your baby's health.

Whether your partner is HIV positive or negative, one thing is essential:

- If you want to become pregnant, you and your partner should rule out other sexually transmitted diseases or have them treated.
- Discuss this with your HIV specialist.

What can I do if I don't become pregnant?

Fertility issues in both women and men are widespread, irrespective of HIV.



● If you have tried to conceive for several months without success, you and your partner should consider having your fertility checked.

Stress, poor nutrition, infections, smoking, alcohol and some medication can lower fertility in both sexes. Therefore, both partners should be examined.

Sometimes a little relaxation and a healthier lifestyle can help improve fertility. And sometimes hormones taken over a period of time are helpful.



Pregnancy

During your pregnancy, you can take steps to protect your own health and that of your child.

It is therefore important that you go for your routine testing – to your HIV specialist as well as to your gynaecologist – during pregnancy.

And there are many other things you can do for yourself and your baby: exercise, especially outdoors, is good for you. Fresh fruit and vegetables ensure that you get enough vitamins and nutrients.

Cigarettes, alcohol and other drugs can harm you and your child – the best thing to do is completely abstain from them during pregnancy. Talk to your doctor if this is difficult for you.

Also: Protect yourself from sexually transmitted diseases during pregnancy by using condoms.

What effect does pregnancy have on my health?

If you are healthy – apart from the HIV infection – and if your immune system is strong, pregnancy will probably not have a negative effect on your health.

It is a normal response of the female immune system to become a little weaker during pregnancy. Your body could be somewhat more susceptible to infections. When they are detected early enough, they can almost always be successfully treated.



After the baby's birth, the values of the immune system return to their pre-pregnancy levels.

Is the medication I have to take harmful to my child?

Most medication that you should take during pregnancy to fight HIV is not harmful to your child. The healthier you are, the better it is for your baby, too.

We still do not know very much about the side effects and risks of antiretroviral treatment for unborn children. Especially little is known about possible long-term effects. In animal trials, some drugs have led to deformities. Others produced only temporary side effects in infants.

Fortunately, however, there are a number of drugs that have been used for many years with no harm to babies.

Your doctors know which medication is best for you and your baby.

Under no circumstances should you stop taking your medication on your own. Otherwise, resistance may develop and some treatments will later no longer be effective.

Infections that occur during pregnancy can almost always be treated with medication that is safe for your unborn child.



How can I protect my child from HIV?

HIV can be transmitted from mother to child. This can happen during pregnancy, during childbirth and through breastfeeding.



Without precautions, the risk of transmission in Germany is 20 percent.

The risk of infection to the baby can be reduced to less than two percent through these four steps:

1. **With medication that reduces the viral load**
2. **With a planned Cesarean section**
3. **With a preventive anti-HIV treatment for the infant**
4. **By not breastfeeding**

1. Reducing the viral load

The viral load indicates the quantity of the HI virus in your blood. Anti-HIV medication – known as ‘combination therapy’ – reduces this viral load. When the viral load is so low that the HI virus can no longer be detected, the risk of transmitting the virus to the baby is much lower.

Not all HIV positive women take anti-HIV medication. But even if you feel healthy and have a minimal viral load, you can transmit HIV to your baby. It is therefore recommended that all pregnant women with HIV take medication starting at least in week 32 of their pregnancy.

If you already started treatment before becoming pregnant, you can discuss with your HIV specialist whether you should interrupt the regimen for the first three months of pregnancy. This is sometimes possible, depending on your health and the stability of your immune system. Of course, your doctors will carefully monitor your immune system during such a break in treatment.

If you take anti-HIV medication, you must do so exactly as prescribed. Otherwise, HI viruses can develop that are resistant, i.e. they no longer respond to certain drugs. If the treatment has side effects, you should discuss them with your doctor.

2. Planned Cesarean section

In Germany, HIV positive women only rarely have a vaginal childbirth. Specialised women's hospitals are particularly cautious and most often recommend Cesarean sections for HIV positive expectant women. If in any way possible, these women have the Cesarean section before labour begins, around the 38th week of pregnancy. This reduces the risk of HIV infection for the child.

Perhaps you would prefer a vaginal birth; perhaps the idea of a Cesarean section frightens you. Speak with your gynaecologist about your wishes and concerns.

Your family or friends might ask why you're not having your baby the 'normal' way. In Germany, many women give birth via Cesarean section. Irrespective of HIV, there are many other reasons for making this decision, e.g. if the baby is not positioned correctly in the womb.

A Cesarean section rarely takes longer than 40 minutes. You are awake during the procedure, but are not in pain, and you can hold your baby in your arms immediately. Cesarean sections only very rarely lead to complications for the mother or child.

3. Preventive treatment for the infant

Following the birth, your baby will be treated with anti-HIV medication for two to four weeks. This reduces the risk of HIV infection for your child even further. In most cases, you can take your baby home after a few days and give him/her the medication yourself. You should be very conscientious when doing this. The drugs are only effective when your child receives them exactly as they are prescribed. Fortunately, they are almost always well tolerated.

4. Not breastfeeding

HI viruses are present in breast milk and can therefore be transmitted during nursing. In addition, nursing can irritate the nipples and cause them to bleed, which would allow viruses in the blood to be passed through the milk.

Therefore, it is very important to bottle-feed your infant and not breastfeed. Worldwide, many infants contract the HI virus from their mothers because they are breastfed. Unfortunately, not all countries have such good alternatives for infant feeding as Germany does.

It is possible that you might find it very difficult not to breastfeed. Many people simply expect women to nurse their infants.

At times, you may be asked critically why you are not breastfeeding. There



are so many reasons why not – speak with a counsellor or other HIV positive mothers about how you can answer such questions.

Even if you cannot breastfeed your baby, you can give him or her everything he/she needs: love, care and security. Keep your baby very close and spend a lot of time feeding, singing, playing, bathing and doing special massages. This also helps form a strong bond between you and your child.

I have been circumcised. Will this impact the pregnancy or birth?

Some women were circumcised as girls or young women. This means that the clitoris and/or the inner and outer labia have been partially or completely removed. Depending on the severity, this mutilation of the genitals can cause great difficulties during intercourse, pregnancy and childbirth.

Especially for infibulated, HIV positive women, a vaginal birth can increase the risk for transmitting HIV to the baby. A Cesarean section is safer both for your health and that of your child.



**You can find help and advice at
counselling centres for female
genital mutilation.**



After giving birth

The period following the birth of your baby can be exciting and sometimes stressful. You might be very anxious about whether the HIV infection was transmitted to your baby.

You will need a great deal of support from your partner, your family or close friends during this time. You can also turn to information centres if necessary.

In addition, it is very important to have paediatricians who specialise in HIV infection in children.

When will I know if my child is healthy?

Up to 18 months after the birth, HIV antibodies from the mother circulate in the child's blood. This will result in a positive test, but it does not mean that your child is infected. Children are now examined immediately following birth and then several times over the next six months using very sensitive detection methods.

After six months at the latest, you will be able to know with a high degree of certainty whether your child is healthy. An HIV antibody test performed after approx. 18 months will give absolute certainty.



What happens if my child is HIV positive?

Today, most HIV positive children can experience good health for many years. Treatment options for both adults and children have improved greatly.

However, side effects of HIV treatment can also appear in children. It is therefore necessary that your paediatrician very closely monitors your child's development.

The drugs, which have to be taken regularly, the many visits to the doctor and the tests can be very stressful for

children and parents. And no one can tell you when or if your child will become ill.

Having a child with HIV is not easy, and you will need a great deal of support from your family and friends.

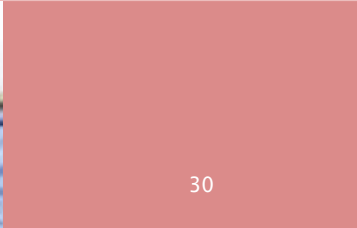
Take advantage of all of the information and counselling options available. It is often helpful to talk to other mothers who are in the same situation.



Where can I find help and advice?

HIV is often a family matter and it can affect all of the people who are close to you in different ways. There will be times when you will need support from your relatives and friends in order to cope with all of the challenges, as well as with feelings of depression and fear.

Be sure to take advantage of help from professional information centres for yourself, your partner and your children. Get help in legal or financial matters, for instance with regard to medical insurance or financial assistance before, during and after pregnancy.



Many cities have organisations that can offer help and advice. Most professional counselling facilities will provide a confidential atmosphere. Some AIDS information centres can also put you in contact with groups for men and women from different countries.

If you feel unsure or are worried about discrimination, you can make an initial contact via telephone; this is not a problem at many organisations and information centres.



Take advantage of the diverse range of options! On the following pages you can find a whole array of helpful addresses.

Information on HIV and AIDS, addresses of AIDS support and other information centres

Deutsche AIDS-Hilfe e.V. (AIDS support Germany)

Dieffenbachstr. 33
10967 Berlin
Tel.: 030 - 69 00 87-0
E-mail: dah@aidshilfe.de
www.aidshilfe.de

Bundeszentrale für gesundheitliche Aufklärung (National centre for health education)

Tel.: 01805 - 55 54 44
www.aidsberatung.de
www.gib-aids-keine-chance/beratung/fremdsprachig

Bundesarbeitsgemeinschaft „Kinder im Umfeld von HIV/AIDS“ (National consortium “Children in an HIV/AIDS environment”)

c/o Hildesheimer AIDS-Hilfe e.V.
Bernwardstr. 3, 31134 Hildesheim
Tel.: 05121 - 13 31 27
E-mail: kinder@hildesheimer-aids-hilfe.de
www.hildesheimer-aids-hilfe.de

Information for women from various countries

Afrikaherz – gesundheitliche Aufklärung für afrikanische Frauen (Health education for African women)

Petersburger Str. 92, 10247 Berlin
Tel.: 030 - 422 47 06
E-mail: afrikaherz@via-in-berlin.de

G.R.A.F. - gGmbH
Gesellschaft für die Rechte afrikanischer Frauen
(Society for the rights of African women)
c/o Praxiszentrum Kaiserdamm
Kaiserdamm 24
14057 Berlin
Tel: 030 - 301 139 40
E-mail: graf_brd@yahoo.de
www.graf-berlin.de

TAMPEP
Transnational AIDS/STD Prevention Among
Migrant Prostitutes in Europe
Project Amnesty for Women
Städtegruppe Hamburg e.V.
Große Bergstr. 231
22767 Hamburg
Tel.: +49 (0)40 - 38 47 53
E-mail: info@amnestyforwomen.de

Xochicuicatl e.V.
(Latin American Women's Association)
Winsstr. 58
10405 Berlin
Tel: 030 - 278 63 29
E-mail: mail@xochicuicatl.de
www.xochicuicatl.de

Information on HIV/AIDS for people from Africa

Light of Africa NRW e.V.
Oelschlägerstraße 59
47798 Krefeld
Tel.: 02151 - 360 04 44
E-mail: info@loa-nrw.org
www.loa-nrw.org

Netzwerk „Afro-Leben“
Tel.: 0160 - 95013326
E-mail: afroleben2000@yahoo.de

Addresses of surgeries and clinics specialising in HIV positive pregnant women

Arbeitsgemeinschaft für HIV in Gynäkologie und Geburtshilfe

(Consortium for HIV in gynaecology and obstetrics)

c/o Dr. Andrea Gingelmaier
Ludwig-Maximilian-Universität,
1. Frauenklinik Innenstadt
Maistraße 11, 80337 München
E-mail: andrea.gingelmaier@med.uni-muenchen.de

Counselling and support for circumcised women

Terre des Femmes e.V.

Konrad-Adenauer-Str. 40, 72072 Tübingen
Tel.: 07071 - 79 73-11
E-mail: genitalverstuemmelung@frauenrechte.de
www.frauenrechte.de

(I)NTACT e.V.

Internationale Aktion gegen die Beschneidung von Mädchen und Frauen e.V.

(International campaign against the circumcision of girls and women)

Johannisstr. 4
66111 Saarbrücken
Tel.: 0681 - 324 00
E-mail: info@intact-ev.de
www.intact-ev.de

To read

“Positively pregnant” – “Enceinte positive”
– “Grávida e soropositiva”

Pamphlet by Deutsche AIDS-Hilfe for HIV positive, expecting women from Africa.

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