




HIV, desire to have children, and pregnancy

Information for women with HIV
and others who are interested

Womens' Health Center Munich

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Having a family and children is very important to many people. It is often a very personal matter that depends on many factors.

What is the aim of this brochure?

Whether the man, the woman or both are living with HIV is often not the issue. However, some questions may come up, and we would like to provide answers on the following pages.

If you are living with HIV and would like to have a child, or if you are HIV positive and pregnant, we would like to use this brochure to support you along

the way. People close to you – like your partner, family members or friends – can also access information here.

Of course, this brochure cannot replace talking to your doctor or a professional counseling service. You will therefore find referral information for organisations you can contact for additional advice and support at the end of the brochure.

The most important things first

Are you living with HIV and would like to have a child? Have you been diagnosed with HIV infection as part of an antenatal health check?

The most important thing for you to know is that, despite your HIV infection, you can give birth to a healthy child!

HIV infection is no reason not to have children. Treating HIV with medication – called combination therapy – is very effective and successful. It means that,



today, people living with HIV have an almost normal life expectancy and a good quality of life.

The treatment lowers the amount of virus particles in the blood to below the limit of detection. Once this so-called 'viral load' remains, through successful treatment, permanently 'undetectable', couples no longer need to use condoms and can conceive naturally. However, both partners should agree to this.

Effective HIV treatment also protects the child. For expecting mothers who receive optimal medical care and whose viral load is undetectable at the time of giving birth, it means that today, 99 out of 100 women with an HIV infection give birth to a baby free from HIV.

Have your questions answered here

Whether you have been living with your HIV infection for a while or only learned about it only recently – you are likely to be asking yourself many questions. We would like to try and answer these questions on the following pages, and to provide additional information:

You can also access support from AIDS organisations and other counselling services. Many counselling services can put you in touch with other mothers, also with those from different countries. Talking to other mothers living with HIV can help you make a decision.

General Informationen on HIV and pregnancy

Whether you are living with HIV and would like to have a child, or have learned during your pregnancy that you are HIV positive – the same is true for both these situations:

- Medicine has made great progress in recent years. Most larger German cities have gynaecology clinics that specialise in pregnancy for women living with HIV. However, smaller towns also have clinics that can support pregnant women living with HIV until the birth, and their children thereafter. Ask your counselling service for information about your options, and about which ones may suit you best.

Doctors in Germany now have a lot of experience with pregnancy in women living with HIV. Treating HIV infection with combination therapy can reduce the risk of infection for the baby to such an extent that HIV transmission now only occurs in very rare cases.

It mostly only happens if the mother did not know about her infection or if there were problems with her HIV treatment.

Today, more than 99% of HIV-positive pregnant women in Germany give birth to healthy children who are free from HIV!

You can do yourself and your child a favour by attending all scheduled antenatal health checks at your gynaecologist's practice, all additional tests with your HIV specialist, and later also those provided by the paediatrician. All these doctors will take good care of you.

Please note: your HIV infection must not be documented in your maternal health passport ('Mutterpass'). It only documents whether an HIV test was conducted or not.

Becoming pregnant



When is the best time for a pregnancy?

It is particularly important that you and your partner feel that it's the right time to start a family. Of course, it helps if you are feeling healthy and your viral load is low.

If you are on treatment already, you can get pregnant even while taking your anti-HIV medication. Many anti-HIV drugs have been proven not to have any negative effects on your child,

but for some this is not certain. Talk to your doctor about whether your treatment is safe for your child: never discontinue treatment without talking to your doctor while trying to become pregnant.

One thing is always important: that your HIV doctors and your gynaecologist know your medical history and your test results. They can support you in your decision and together with you find the best form of treatment.

Do I need to have any special tests?

If you would like to get pregnant, talk to your doctor about any additional medical examinations that may be important, e.g. testing for sexually transmitted infections. Treatment for some infections should be completed before you become pregnant, so that your baby can develop healthily in the womb.



Many women experience irregular, shortened or extended menstruation cycles (monthly periods). If you are worried about this and want to know whether you can get pregnant, talk with your gynaecologist about it. It may be necessary for you to take hormone supplements.

If you are starting to take anti-HIV drugs for the first time during your pregnancy, a resistance test will be performed first. It examines whether the virus in your blood is resistant to specific medications. If so, drugs that are effective without harming your baby will be selected.

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

You can get pregnant by your partner without him being at risk of infection. If you are both fertile, there are several options:

- If you are taking anti-HIV drugs regularly and your viral load is undetectable, there is no risk for your partner. If you are using a hormone-based contraceptive (e.g. the pill, a hormone coil IUD, three-monthly injections, etc.), talk to your gynaecologist about how to discontinue or have it removed. Sometimes it may take a while before you become pregnant. Do not put yourself

under pressure. Ask your gynaecologist how to calculate your ovulation date. Even just knowing the right time of the month helps many couples become pregnant.

- If you are not yet on treatment for HIV or your viral load has not become undetectable despite the medication, you can become pregnant without risk using 'self-insemination'. This means inserting the semen into the vagina yourself. This is how you do it:

First, you need your partner's semen. You can take it from the condom – which must be a spermicide-free one – after ordinary protected intercourse. Alternatively, your partner can ejaculate into a sterile container, e.g. a glass jar that has been boiled in water.

You can then draw the semen up into a syringe – without the needle! – and insert it into your own vagina. You can also pour the semen into a diaphragm or a cervical cap, which you then insert.



It is best to perform the first self-insemination about three days before you ovulate, and a second one on the actual day of ovulation at the latest. Additional attempts typically do not improve your chances.

Not all couples manage to conceive a child this way. You and your partner may need to be patient. Usually, several attempts are needed before you become pregnant.

Even if it takes a while: it is important that both of you avoid getting stressed about it as much as possible – and don't hesitate to get advice.

If your menstruation is two or three days overdue, you can take a pregnancy test, either at home or at your gynaecologist's practice.

My partner is also HIV positive – what do we have to consider?

If you are both taking your anti-HIV medication regularly and your viral loads are both undetectable, you can conceive a child by having sex without a condom on your fertile days, just like any other couple. If you don't become pregnant, fertility problems may be the cause. More on this in the next chapter.

In addition to HIV, there are also other sexually transmitted infections (e.g. chlamydia or hepatitis B). You or your partner will not be protected

against these while you are not using condoms. Some of these infections may put your health and that of your child at risk if left untreated. It is important that these are detected in time to allow for effective treatment.

No matter whether your partner is HIV positive or negative: if you want to get pregnant, you and your partner should make sure that you have no other sexually transmitted infections, or have them treated. Talk to your HIV specialist if you have any questions about this. It is a good idea to also involve your partner.

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

Fertility problems are common in women as well as in men, including in people without HIV.

If you have tried to become pregnant without success for several months, discuss with your partner whether to go for fertility testing.

Stress, a bad diet, infections, smoking, alcohol and various medications may weaken fertility in either sex.

Therefore, always both partners should get tested.

Sometimes, a little relaxation and a healthier lifestyle are all it takes. Sometimes, you need to take hormone supplements for a while. If the causes of your infertility are more complex, you may need some form of fertility treatment, e.g. 'in vitro fertilisation (IVF)', to become pregnant. These treatments can be very complicated, stressful and expensive. A fertility clinic can advise you about the options open to you. Initial counselling and fertility testing for you and your partner are available free of charge.

In the simplest case, insemination, the doctor will inject the semen into your uterus through a thin tube at the time of ovulation. In other methods, fertilisation takes place outside the

womb. For this, egg cells are removed from the woman and combined with the man's sperm cells in the laboratory. The fertilised eggs are then transferred to the uterus.

It will almost always take several attempts before a pregnancy occurs, and sometimes they remain unsuccessful despite every effort being made. Fertility treatment may be more or less expensive, depending on the method and number of attempts. Statutory health funds will cover at most half of the costs for no more than three treatments.



You and your partner can access an initial counselling appointment and examination at many fertility clinics in Germany. Many of these also offer hormone treatment, insemination or IVF to people living with HIV. However, some facilities are not up to date on their HIV knowledge. It is therefore possible that you may be refused treatment. Do not be discouraged by this. Your HIV specialist or counselling service will advise you.

If you feel discriminated against at a doctor's practice or in hospital because of your HIV infection, you can contact the HIV Anti-Discrimination Office at the Deutsche AIDS-Hilfe (German AIDS organisation) in Berlin, where you will receive support. This often leads to good outcomes for those affected. Contact details are included at the end of this brochure.



Pregnancy

How do I stay healthy throughout the pregnancy?

You can protect your own health and that of your child while pregnant. When you are well, your child will also be well. If you are in good health despite your HIV infection, your pregnancy will not have a negative effect on your health.

Your body will change during the pregnancy. You will find that many things are different to what you are used to. Some women feel miserable, weak and tired, while others blossom.

Every pregnancy is different and comes with its own challenges. This is perfectly normal. Perhaps reading a book with pregnancy advice or talking to experienced mothers may help you.

No matter whether a woman is living with HIV or not, her immune system will weaken somewhat during pregnancy. Your body may then be a little more susceptible to infections. They can almost always be successfully treated, as long as they are detected early enough.

The CD4 count (CD4 cells are an important part of the immune system) may drop slightly during pregnancy. This is normal. After the birth of the child, immune system markers will return to what they were before the pregnancy.

There is a lot that you can do during the pregnancy to take care of yourself and your baby: lots of exercise, particularly outdoors, is good for you. Fresh fruit and vegetables ensure that you are getting enough vitamins and nutrients. Cigarettes, alcohol and other drugs harm you and your child – it is



best to refrain from them completely during the pregnancy. Talk to your doctor if this is difficult for you.

It is also important that you attend all scheduled health checks during your pregnancy – with your HIV specialist and your gynaecologist. Your doctors should collaborate with each other. However, they need your permission to exchange important information and test results.

If you have unprotected sex during pregnancy, you may contract other sexually transmitted infections. This may endanger both your health and that of your child. A condom can protect you well, but does not provide absolute safety. If in doubt, see your doctor so that any infection can be treated in time.

There are ways of detecting vaginal infections early through regular pH testing (measuring the level of acidity inside the vagina) in order to prevent premature births. Talk to your gynaecologist about whether this preventive measure makes sense for you and your child.

Will the medication I have to take harm my child?

Most drugs used to treat people with HIV today are effective and have few or no side effects. Not all medications are harmless for your baby, however. Therefore, using the correct treatment – and changing anti-HIV drugs if necessary – is important during pregnancy.

Luckily, there are a number of anti-HIV medications that have been used for many years without harming babies. Your doctors will know which medications are best for you and your baby.

Please never discontinue HIV treatment without talking to your doctor. This may cause the development of resistance. Some medicines may then cease to be effective.

How do I protect my child against HIV?

In principle, HIV can be transmitted from mother to child during pregnancy, childbirth or breastfeeding. If the

mother's HIV infection is untreated and no other protective measures are taken, the risk of infection is 20 percent in Germany.

Three steps can safely prevent the baby from becoming infected with HIV:

- 1: HIV treatment for the mother to reduce her viral load**
- 2: Prophylactic (preventive) HIV treatment for the newborn**
- 3: Not breastfeeding the baby**



1. Reducing viral load

Not all HIV-positive women take medication against HIV. Even if you feel healthy and have a low viral load, you can pass on HIV to your baby. Talk to your doctor about when best to start taking anti-HIV medication.

If you started HIV treatment before becoming pregnant, you can talk to your HIV specialist about how to continue treatment, and whether you may need to change medication.

If you are already on anti-HIV medication, you need to continue to take it regularly. Otherwise, your viral

load may suddenly increase or resistant strains of HIV may develop. These will no longer be susceptible to certain medications. Some people experience side effects, but not everybody does. Also, some women experience a lot of vomiting during pregnancy, making it difficult to take tablets. Others cannot get used to taking tablets, or are afraid that the drugs will harm the child.

Taking your medication regularly is the best thing you can do to care of yourself and your child.

Talk to your doctors if this is difficult for you. They have experience in dealing with problems like this. It is

often possible to work out good solutions together. Counselling services and an exchange of experiences with other people living with HIV may also help you manage your treatment well.

2. Prophylactic (preventive) HIV treatment for the newborn

After birth, your baby will be treated with anti-HIV medication for two to four weeks. This is a safety measure to ensure that, in the unlikely case of transmission, preventive action has been taken in time. The staff on the maternity ward of your hospital will

show you how to give the medication to your baby. You will be able to do this yourself when you have returned home. Most newborns tolerate the medication very well. While receiving the medication, your baby will be examined regularly to ensure everything is safe.

3. Not breastfeeding

Breast milk also contains HIV, and it can therefore be transmitted while breastfeeding. Breastfeeding may also cause injuries and bleeding to the nipples. In this case, the virus may enter the milk with your blood. Also important: while you will no longer

have any virus in your breast milk if you are on treatment, it will contain some residue from the anti-HIV medication. Unfortunately, it is not known how this may affect the health of the child. For this reason, it is safer to

bottle-feed your child instead of breastfeeding. Talk to your HIV specialist if you have any questions. Very good baby formula is available in Germany. You don't need to be concerned about bottle-feeding your child.



Because women are often expected to breastfeed their babies, it may be very difficult for you to decide against breastfeeding. You may experience questions that imply criticism about why you don't breastfeed. There may be many reasons for this – work out how to respond together with a counsellor or other HIV-positive mothers.

Even if you don't breastfeed your baby, you can provide it with everything it needs: love, care and security. Give your child plenty of closeness and time when feeding, singing, playing, bathing it, and with a special massage. This also creates a strong bond between you and your child.

How will I give birth to my baby?

Today, many women living with HIV have 'natural' vaginal births. Your viral load must be undetectable before the birth to make this possible. Your baby will then be safely protected against HIV infection. There must also be no other 'obstetric risk' – any medical problem that may pose a risk for the health of mother or child during a vaginal birth.

If viral load is not undetectable, or if doctors believe that there is an obstetric risk, they will recommend a caesarean section. In women living with HIV, caesarean sections are carried out before contractions begin, i.e. around the 38th week of the pregnancy.

Don't worry if you are going to have a caesarean section. Many mothers give birth by caesarean section in Germany. Apart from HIV, there can be many other reasons for this, e.g. if the child is not positioned correctly in the womb.

A caesarean section rarely takes more than 40 minutes. You will be awake during the procedure, but you will not feel any pain, and you will be able to take your baby into your arms immediately. Complications for mother or child are very rare during a caesarean section.

Talk to your gynaecologist about the different options for giving birth, but also about your own wishes and fears.

It is a good idea to contact the hospital where you want to give birth right at the beginning of your pregnancy. They will have an outpatient maternity clinic where you will have your examinations and can discuss your questions. The doctors there should collaborate with the gynaecologist who is taking care of you during your pregnancy.

To be well-prepared for childbirth, you – or you and your partner together – can attend antenatal classes. Health funds usually cover the costs. Ask your maternity hospital or pregnancy counselling service for more information.

I have been circumcised. Will this affect pregnancy or childbirth?

Some women were circumcised as children or adolescents. This means that their clitoris and/or the inner and outer labia of the vulva were partially or completely removed. Depending on its extent, circumcision of the genitals may cause great problems during sex, pregnancy and childbirth.

Your doctor will tell you if a caesarean section will be safer and better for your and your child's health.



You can obtain advice and support at a counselling centre for female circumcision. Contact details are listed at the end of this brochure.

A newborn baby is shown sleeping peacefully, wrapped in a white blanket. The baby's face is the central focus, with eyes closed and a calm expression. The entire image is overlaid with a semi-transparent green filter. The text "After giving birth" is positioned in the lower right quadrant of the image.

After giving birth

What is important to know after childbirth?

The time after the birth of your child may be exciting, tiring, and sometimes stressful. A midwife providing aftercare can help you during the initial period with your newborn child. The costs are covered by your health fund.

Of course, it is also important that you have a paediatrician you can trust. Your baby will likely have to take anti-HIV medication for a few weeks, even if has not been infected. It can therefore be very helpful to have a paediatrician who is familiar with HIV.

The baby will be examined very carefully right after birth, and then several

times until it is six months old. This means you can be very certain soon after birth about whether HIV was transmitted to your child or not.

Even during the pregnancy, every mother is already passing antibodies from her own immune system on to the baby so that the child will have a good start in life. Their number will diminish with age as the baby's body builds up its own immune system.

Usually, the HIV antibodies from the mother can be detected in the child's blood for up to 18 months after the birth. During this time, an HIV antibody test of your child will come back positive, but this does not mean that your child is infected.



What happens if my child is HIV positive?

This has, luckily, become very rare. But if it happens, it is important to know that people living with HIV have a near-normal life expectancy today thanks to anti-HIV medication. This applies to children as well! Adults as well as children can be successfully treated, and can live a good life with their HIV infection.

Children may also experience the side effects of anti-HIV medication. Your pediatrician should therefore closely monitor the development of your child.

Having a child with HIV is not an easy situation. However, there are services available to support you and your family. Ask your paediatrician or your local AIDS service organisation. It is also important that your child never feels alone with his or her questions, receives support from your family and friends, and has the opportunity to exchange experiences with others when he or she is old enough.

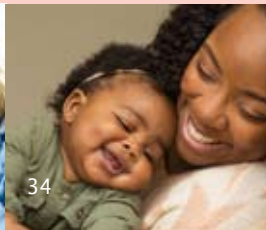
Use all counseling services available. It can often be very helpful to talk to other mothers who are in a similar situation.



Where can I get advice and help?

Often, HIV is also a family matter, and it may affect all the people who are close to you in different ways. There may be times when you need support from family members and friends to manage everything you have to do, but also to be able to deal with depressive feelings and fears.

Make use of the assistance offered by professional counselling services for yourself, for your partner and for your children. Accept help in financial and legal matters, e.g. regarding health insurance or financial assistance – before, during and after pregnancy.



There are organisations that offer assistance and counselling in many cities. Most professional counselling services offer a confidential environment. Some HIV counselling services can also put you in touch with groups for women and men from different countries.

If you feel uncertain or are afraid of discrimination, you can make a phonecall first. This is easily possible with many organisations and counselling services.



Use the range of options available! A large number of contact points is listed on the following pages.

Information on HIV and AIDS, contact details of AIDS organisations and other counseling services

Deutsche AIDS-Hilfe e.V. (Federation of German AIDS Service Organisations Inc.)

Wilhelmstr. 138, D-10963 Berlin

Phone: 030 - 69 00 87-0

Email: dah@aidshilfe.de

www.aidshilfe.de

includes:

Kontaktstelle HIV-bezogene Diskriminierung (HIV Anti-Discrimination Office)

Contact: Kerstin Mörsch

Phone: 030 - 69 00 87-67

Email: gendiskriminierung@dah.aidshilfe.de

Frauen und HIV (Women and HIV)

A web portal of the Deutschen Aids-Hilfe e.V. (DAH)

www.frauenundhiv.info

Netzwerk Frauen und Aids (Women and AIDS Network)

www.netzwerkfrauenundaids.de

Bundeszentrale für gesundheitliche Aufklärung (Federal Center for Health Education, (BZgA)

Phone: 01805 - 55 54 44

www.aidsberatung.de

www.gib-aids-keine-chance/beratung/fremdsprachig

Zanzu

A BZgA web portal on sexual health and
knowing your body

Information in 13 languages

www.zanzu.de

Information for pregnant women

Pro familia

**Deutsche Gesellschaft für Familienplanung,
Sexualpädagogik und Sexualberatung e.V.**

**(German Society for Family Planning, Sexuality
Education and Counselling)**

Bundesverband (Federal Office)
Stresemannallee 3, D-60596 Frankfurt/Main
Phone: 069 - 63 90 02
www.profamilia.de

Information for women from other countries

Afrikaherz – gesundheitliche Aufklärung für afrikanische Frauen
(Heart of Africa – health information for African women)

Petersburger Str. 92, D-10247 Berlin
Phone: 030 - 422 47 06
Email: afrikaherz@via-in-berlin.de

Xochicuicatl e.V.
Latin American women's association

Winsstr. 58, D-10405 Berlin
Phone 030 - 278 63 29
Email: mail@xochicuicatl.de
www.xochicuicatl.de

Netzwerk „Afro-Leben plus“ (African Life Plus)

© Deutsche AIDS-Hilfe e.V.
Wilhelmstr. 138, D-10963 Berlin
Phone: 0160 - 95013326
Email: dah@afrolebenplus.de
www.hiv-migration.de

Information on medical practices and hospitals that specialise in pregnancy for women living with HIV

Arbeitsgemeinschaft für HIV in Gynäkologie und Geburtshilfe
(HIV Gynaecology and Obstetrics Working Group)

c/o PD Dr. med. Andrea Gingelmaier
August-Exter-Str. 4, D-81245 München
Phone: 089 - 88 20 36
Email: info@gynpraxis-pasing.de

Information on fertility treatment

Fertility Center Berlin

Spandauer Damm 130, D-14050 Berlin

Phone: 030 - 30 35-49 37

Email: info@fertilitycenter-berlin.de

www.fertilitycenter-berlin.de

Counselling and support for circumcised women

Terre des Femmes e.V.

Brunnenstr. 128, D-13355 Berlin

Phone: 030 - 40 50 46 99-0

Email: genitalverstuemmelung@frauenrechte.de

www.frauenrechte.de

(I)NTACT e.V.

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

(International Action against the Circumcision of Girls and Women Inc.)

Saargemünder Str. 95, D-66119 Saarbrücken

Phone: 0681 - 324 00, Email: info@intact-ev.de

www.intact-ev.de

Recommended reading

DHIVA – Zeitschrift für Frauen, Sexualität und Gesundheit

Available at www.stiftung-gssg.org

Films

Positiv schwanger (Pregnant and Positive)

Film about wanting to have children, pregnancy and being parents. Interviews/personal stories of mothers living with HIV

German version: www.positivschwanger.de

English version: <http://positive-pregnant.de/the-film>

Projekt Lifeboat (The Lifeboat Project)

Films about pregnancy, motherhood and HIV

With subtitles in multiple languages www.stiftung-gssg.org/youtube

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Projekt „Positive Frauen“

Grimmstraße 1

80336 Munich

Phone. 089 - 129 11 95

Fax 089 - 129 84 18

Email fgz@fgz-muc.de

www.fgz-muc.de

Text:

Ulrike Sonnenberg-Schwan, Munich

Editorial services:

Harriet Langanke, Cologne

Technical consultants:

PD Dr. med. Andrea Gingelmaier, Munich

Franziska Borkel, Karlsruhe

Kelly Cavalcanti, Cologne

Translations:

Ethnomedizinisches Zentrum e.V., Hannover

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FrauenGesundheitsZentrum München (Women's Health Centre Munich)



Grimmstraße 1 · 80336 Munich · Phone 089 - 129 11 95 · Fax 089 - 129 84 18 · Email fgz@fgz-muc.de · www.fgz-muc.de