



POSITIVELY PREGNANT

ENGLISCH

aidshilfe.de

 Deutsche
AIDS-Hilfe

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DEAR READER,

→ YOU ARE PREGNANT AND HIV POSITIVE.

It is important that you are well cared for from the very beginning of the pregnancy so that you remain healthy and your child is not infected with HIV. This booklet will give you the necessary information. Much of this may be new and unfamiliar for you, because you may come from a culture in which pregnancy or illness are viewed differently than in Germany and in which traditional medicine plays a larger role. And much of what you find in this booklet may even scare you, such as the numerous examinations that are recommended for pregnant women. However, being well informed can often take away one's fears. This is another reason why it is important to seek extensive advice from doctors and other experts.



→ YOU ARE NOT ALONE.

If you have questions or are looking for someone with whom you can speak openly about your worries and problems: the local branches of the **AIDSHILFE** (AIDS support service) will be pleased to help you (see Information and Advice, p. 30). There, you can get advice, either in person,

over the telephone or by e-mail, regarding welfare services, medical care, residence rights, child care, rehabilitation and all subjects relating to HIV infection. The people who work in the Aidshilfe will also tell you where you can meet other HIV positive women such as in self-help groups or at meetings for HIV positives (see Information and Advice, p. 30). They will also provide information about foundations such as the Deutsche AIDS-Stiftung (German AIDS foundation) or the Stiftung "Mutter und Kind" ("mother and child" foundation) which give support in case of financial hardships, and they can also help you to fill out and submit the appropriate application forms for such support.



In the Aidshilfe, you don't have to give your name or pay anything: all services are free of charge.

→ **YOU NEED A GOOD DOCTOR.**

Perhaps you would rather have a midwife, but as an HIV positive woman you and your child need doctors with experience in HIV treatment and in caring for HIV positive pregnant women and whom you can trust. These specialists will not tell you what you have to do, but rather help you to make the correct decisions for you and your child.



You can get addresses at the Aidshilfe near you or at the Arbeitsgemeinschaft für HIV in Gynäkologie und Geburtshilfe¹ (working group for HIV in gynecology and midwifery). At the Aidshilfe, they also tell you where you can get good medical care if you don't have health insurance, are living without papers, or have applied for asylum.

In case of problems with the German language: Ask your Aidshilfe or the above-mentioned Arbeitsgemeinschaft for doctors who speak English, French or another language in which you can communicate well. There are interpreters in many clinics.

→ ARE YOU CONSIDERING TERMINATING THE PREGNANCY?

Perhaps you feel that a child would worsen your situation. Or you definitely do not want to have an HIV infected child. Then you may wish to terminate the pregnancy – which is possible in Germany under certain circumstances. But perhaps your partner or your family are pressing you to have the child. Or you are afraid that you will be discriminated in your community if it becomes known that you terminated the pregnancy. If you don't know

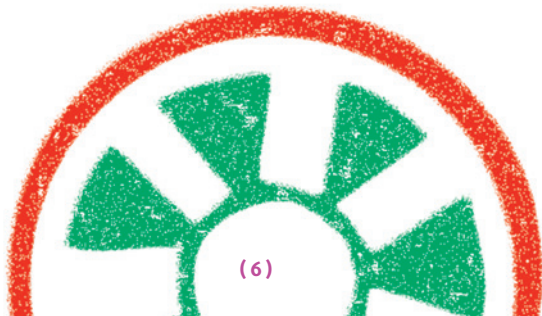
¹ Arbeitsgemeinschaft für HIV in Gynäkologie und Geburtshilfe,
c/o Dr. Annette Haberl, HIVCENTER, Theodor-Stern-Kai 7 / Haus 68, 60590
Frankfurt am Main, Tel. 069 / 6301-7680, E-Mail annette.haberl@hivcenter.de

what you should do, you should turn to a pregnancy advisory office. Here, they will help you to make a decision. You can get the addresses of such offices at the local Aidshilfen.

It is important that you decide as quickly as possible: The later a pregnancy is terminated, the greater the potential physical and emotional damage can be. If termination is the option chosen, then the pregnancy must be terminated within the first 14 weeks after the beginning of the last period.

→ **NO ONE WILL KNOW THAT YOU ARE HIV POSITIVE.**

Advisors, doctors, and the medical personnel are legally obliged to maintain confidentiality in Germany. Whatever you discuss with them therefore remains a secret – no one will find out anything about it. You also don't need to worry that the doctors will give you "special" treatment that could indicate to other patients that you are HIV positive. They will treat you just like all of the other patients.



PROTECTIVE MEASURES FOR YOUR CHILD

“Will my child be healthy?” This question will be particularly on your mind. What you should know is this: HIV can be transmitted from mother to child during pregnancy, during birth, and during breastfeeding, because HIV is also carried in breast milk. Without measures to protect the child, the risk of passing HIV from mother to child is 20 % in Germany. If all protective measures are taken, the risk of HIV transmission is less than 1 %.

YOUR CHILD CAN BE PROTECTED FROM HIV INFECTION:

- **IF** you are regularly examined by your gynecologist and your HIV doctor
- **IF** you take anti-HIV medication during pregnancy
- **IF** your child's birth is attended by a team of doctors who are well informed on HIV
- **IF** you do not breastfeed
- **IF** your child receives an HIV prophylaxis for 4 weeks

Your doctor will inform you of all details. If you don't understand something: Do not hesitate to ask questions!



THE PREGNANCY

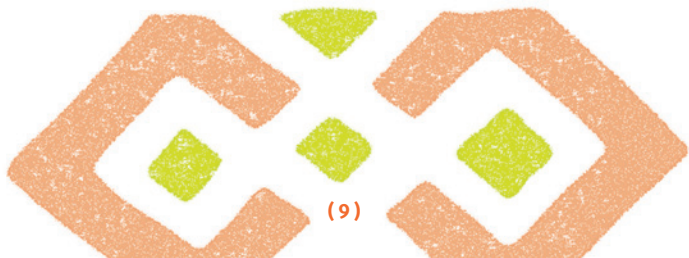
FOR THE HEALTH OF MOTHER AND CHILD

During pregnancy, it is particularly important to live as healthily as possible. The more you do for yourself, the greater the chance that you will have a healthy child.

Perhaps you would like to follow the rules that exist in your homeland, concerning, for example, which foods pregnant women should eat and which are taboo for them. Such rules may be very helpful in your homeland for hygienic or other reasons, but they may be harmful to HIV positive women. We therefore advise you to ask your doctor what is good for you and your child and what is not. Here are a few important recommendations:

→ **KEEP ACTIVE**

Movement stimulates circulation and prevents typical pregnancy problems such as back pain and vein problems. Walking in the fresh air, swimming, and gymnastics are good for your health!



→ EAT HEALTHILY

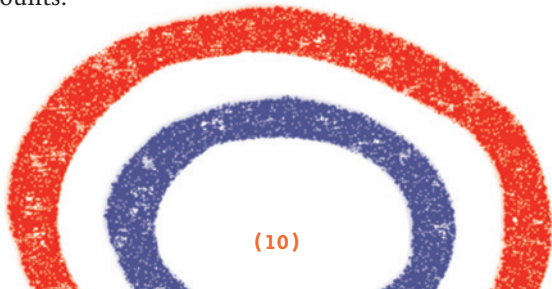
A varied diet with lots of vegetables and fruit supplies you with all of the important nutrients and vitamins.

If you have nutritional questions, consult your doctor or a pregnancy advisory office.

If you live in an accommodation centre with poor food: consult a social advisory office (such as the Arbeiterwohlfahrt, Caritas or Diakonie) or the Aidshilfe near you to find out what can be done to ensure that you can eat more healthily.

→ DRINK LESS COFFEE

Normal coffee contains caffeine. This active ingredient passes through the placenta into the blood circulation of the child, increases its heart rate and stresses its nervous system. Therefore, you should not drink more than two cups of coffee per day. Caffeine-free coffee, on the other hand, is not harmful and can be drunk in greater amounts.



→ **DON'T TAKE ANY DRUGS, IF POSSIBLE**

Tobacco and *alcohol* not only damage your own health, but also the health of your child. For this reason, you should avoid cigarettes and alcohol during pregnancy as far as possible.

The same is true for drugs, such as *crack*, *cocaine*, *ecstasy* or *sleeping pills* and *sedatives*. For women who regularly use *heroin*, we recommend treatment with substitutes (substitution therapy) during pregnancy. Those already taking substitute medication should not decide on their own to reduce the dose, as this could cause premature labor. The risk of transmitting HIV to the child would then be very high.

If you take drugs: speak to a doctor about this and consult a drug advisory office.

→ **SEXUALLY TRANSMITTED INFECTIONS: PREVENTION, DIAGNOSIS AND TREATMENT**

Sexually transmitted infections (such as syphilis, gonorrhea, hepatitis, herpes or chlamydia) would put additional strain on your immune system and endanger your child. Some of these infections can be transmitted to the child during pregnancy or during birth and can cause serious illness in the child. These infections can also raise the risk

of premature birth, which in turn increases the risk of transmitting HIV to the child. That is why it is important that they are recognized and treated as soon as possible and that you protect yourself against them. Condoms reduce the risk of contracting these infections during sex – and they protect your sex partner from an HIV infection.



↑
CONDOM

→ IF YOU ARE CIRCUMCISED ...

... this can easily lead to complications. During pregnancy, infections in the genital area can lead to inflammations and be very dangerous for the mother as well as the child. And during natural childbirth, the scar may tear – the risk of transmitting HIV from the mother to the child is then very high.

In order to avoid such complications, you should talk to your doctor. In Germany, there are also advisory offices for circumcised women, which you can contact confidentially (see p. 31 for addresses).

HIV TREATMENT

In general, women are advised not to take any medication during pregnancy if possible, because this could harm the child. You, too, should only take what you really need; in your case this may be HIV-medication. Therapy with this medication prevents you from becoming sick and also helps prevent HIV from being transmitted to your child.

By now, thousands of HIV-positive women have taken HIV-medication during pregnancy, and have given birth to healthy children. According to current knowledge, deformities and other health defects are no more frequent than in other children. If you are still afraid that the medication could harm your child, you should speak to your HIV doctor about this.

IF YOU ARE NOT YET TAKING HIV MEDICATION ...

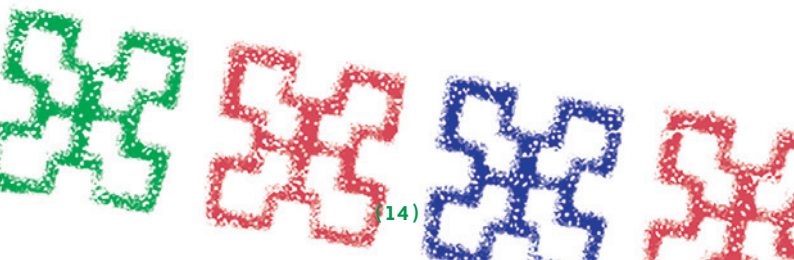
... your doctor will advise you to commence medication in order to protect your child against HIV.

IF YOU ARE ALREADY UNDERGOING HIV THERAPY ...

... your doctor will check whether you are taking HIV medication that could harm you or your child. If so, your doctor will prescribe different HIV medication.

TAKE YOUR HIV MEDICATION REGULARLY

During HIV therapy, it is particularly important that you take the pills regularly and in the prescribed number and do not skip a dose. If there is not enough medication present in your body, HIV can become resistant to it – and then the medication is no longer effective.



If you frequently suffer from nausea and vomiting in the first weeks of pregnancy, your body may not have enough time to absorb the medication.



And if you feel sick all the time, it may be difficult for you to take the medication as prescribed. Do not stop taking your medication by yourself, but consult your doctor as soon as possible.

IF YOU ARE TAKING OTHER MEDICATION ...

... such as healing herbs or traditional medicine from your homeland, you should inform your doctor about it. Together with HIV medication, these agents can have serious side effects or cause the HIV medication to not work properly.

EXAMINATIONS

In Germany, all pregnant women are advised to have regular medical examinations. Not because pregnancy is an “illness”, but to avoid complications. For you as an HIV positive woman, this is particularly important – even if you feel well and have no symptoms.

LABORATORY VALUES

You should have your blood examined regularly: The “laboratory values” determined here give important information about your health.

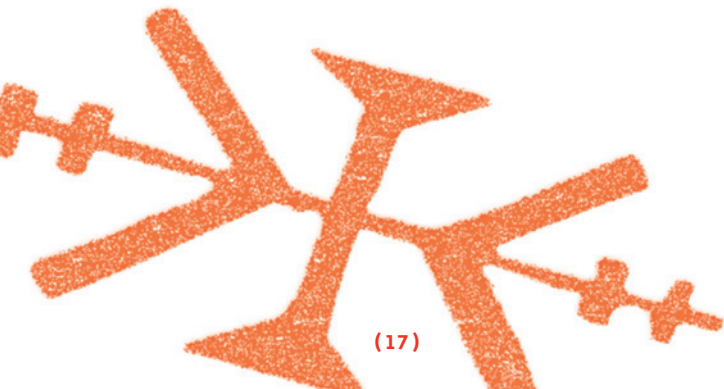
THE FOLLOWING SHOULD BE CHECKED:

- **BLOOD COUNT** at least once a month, in order to check for anemia.
- **VIRAL LOAD** (number of viruses in the blood) at least every two months. The viral load provides information about how active the virus is and how well the HIV medication is working.
- **IMMUNE CELLS** (number of CD4 cells in the blood) at least every two months. This laboratory value provides information about the condition of your immune system.
- **LIVER VALUES** at least once a month, to see whether you are tolerating your medication well.

RESISTANCE TEST

This test is carried out before HIV medication is used for the first time in order to find out whether the virus is already resistant to certain types of medication. This could be the case if you became infected by someone who was already undergoing HIV treatment and in whom the medication was no longer working properly. A resistance test is also performed if the laboratory values indicate that the HIV therapy is ineffective. The medication that is no longer effective is then replaced by different HIV medication.

For the resistance test, the doctor takes a blood sample to have it examined in a laboratory.



GLUCOSE TEST

Both pregnancy and HIV therapy can cause diabetes, which can cause harm to the unborn child. Your doctor will therefore offer you a glucose test between the 24th and 28th week of pregnancy. For this, you will be given glucose syrup and a blood sample will be taken from you. If the test indicates diabetes, you may need to be treated to protect the child.

GYNECOLOGICAL EXAMINATION

HIV positive pregnant women are advised to have a gynecological examination every two to three weeks. In this examination, the doctor will listen to the heartbeat of the child and check the child's position and size by feeling the mother's belly. He will check the size of the uterus to find out how the child is developing. He will check whether the cervix is closed or already open, whether there is a weakness in the cervix (this makes a miscarriage more likely) and whether there are any infections in the vagina. The doctor will also check the mother's general state of health, for example, by taking her pulse and blood pressure and by examining her urine.

ULTRASOUND (SONOGRAM)

Your doctor will advise you to have a sonogram at least three times during pregnancy. The examination is carried out either through the surface of the belly or through the vagina. This examination is not dangerous for either the mother or the child, and does not hurt. With ultrasound, the doctor can see how the child is developing and whether it has any deformities. Physical problems of the mother can also be detected. It is important to recognize complications as early as possible so that the woman can be optimally treated during pregnancy and the child while still in the mother's body or after birth.



↑
ULTRASOUND

COLPOSCOPY

Infections with certain types of human papilloma virus (HPV) can lead to cervical cancer, which occurs more frequently in HIV-infected women than in women who are not infected. If detected early, its preliminary stages can be treated without problems. At the start of the pregnancy, the doctor carries out a colposcopy examination, in which he takes a sample of cells from the cervix.

INFECTIOUS DISEASES

Infectious diseases can endanger the health of the child if they are not treated. These include e.g. hepatitis B and C, cytomegaly, fungal infections of the vagina, chlamydia, tuberculosis and toxoplasmosis. Most of these diseases can be readily treated even during pregnancy.

ACT QUICKLY WHEN PROBLEMS ARISE!

Complications during pregnancy increase the risk of HIV being passed on to the child. In order to prevent this, you should go to hospital as quickly as possible if you suffer

- **BLEEDING**
- **A FEELING OF PRESSURE IN THE LOWER ABDOMEN**
- **PRETERM LABOR PAINS**
- **LOSS OF AMNIOTIC FLUID (WATERS BREAKING)**



THE BIRTH

Like most mothers, you may want to have your child naturally. This is possible if the medication has been effective, that is, if no traces of HIV may be detected in your blood. If however the virus is still detectable in your blood, your child can easily become infected with HIV during a vaginal birth. During a planned cesarean section the child is not subjected to any contractions, and it is quickly (within a few minutes) removed from the abdomen and immediately cleaned: this prevents the child from exposure to HIV. Ask your HIV-specialist which type of delivery is best suited for you and your child, and which hospital offers the best-informed team of medical practitioners.

Most people are understandably afraid of operations. But a cesarean section only lasts a total of 25 to 40 minutes. It is performed very gently and is a routine operation. In Germany, about 30 % of all babies are born this way. The doctors at the hospital will answer any question you may have on cesarean birth.



In the hospital, you will probably have to forego traditional birth ceremonies that you may be accustomed to from your homeland. Only your partner is allowed to be present during the birth. Other family members or friends may only visit you in the patient room after birth.

PLANNED CESAREAN SECTION

Birth by cesarean section makes it possible to prepare all measures necessary without being rushed, and to avoid most complications. A cesarean section is not carried out in the week of the estimated delivery date, but is planned for the 38th week of pregnancy. If your doctor sets a fixed date, the hospital can bring in doctors and pediatricians for the birth who are experienced with HIV infection and can provide you with optimum care.

It is best if only the lower half of the body is anesthetized during a cesarean section. Here, you can experience the birth wide awake and without any pain and the child is not exposed to any anesthetics. After the birth, you can hold and stroke your child while still on the operating table. In some cases, a cesarean section may also be carried out with a general anesthetic. The doctors at the hospital will answer your questions regarding a cesarean section.

IF ANYONE ASKS YOU ...

... why you had your child with a cesarean section and you do not want to tell them the real reason, you can say the following: “The child wasn’t positioned correctly in the womb, so to be on the safe side the doctors delivered it by cesarean section.”

NATURAL CHILDBIRTH

If the medication you have received has led to a sufficient decrease of HIV, so that it may no longer be detected in your blood, it is possible to give birth naturally. The risk of infection is evaluated as equal to that of a cesarean birth. Vaginal birth is also considered better if you are planning to have more children: after a cesarean section, the abdominal walls and the uterus retain scars, which may impede future cesareans.

However, only few hospitals are able to accommodate HIV-positive deliveries: natural childbirth may not be planned, and may take very long – up to ten hours, or even longer – and a specialized team of doctors needs to be on call during the entire duration of the birth.





THE NEWBORN BABY

After the birth, the clinic will take good care of you and your child. It is important that your child continues to be cared for by a doctor after being released from the clinic. A pediatrician who is familiar with children of HIV positive mothers is best suited for this. You can get addresses at your local Aidshilfe.

HIV PROPHYLAXIS

After the birth, your child will receive HIV medication for four weeks. This makes it possible to further reduce the risk of the child being infected by HIV.

Most women can take their babies home and give them the medication themselves. Here too: The medication must be given as prescribed so that it is effective. The medication is usually accepted and tolerated well by the babies.



BOTTLE-FEEDING INSTEAD OF BREAST MILK

Many women want to breastfeed because they rightfully believe that breast milk is the best for the child. We still recommend HIV positive mothers to avoid this. Up to now not all risks for the child which might be caused by breastfeeding are cleared out. For this reason, give your child bottled (formula) milk and do not breastfeed. After the birth, you will receive medication to block the production of breast milk.

Bottle-feeding is only a problem where there is no clean water. In Germany, drinking water is purified and disinfected. Baby formula mixed with boiled tap water is therefore safe. And disease-causing bacteria can be safely killed by placing bottles and teats in boiling water for three minutes.

IF ANYONE ASKS YOU ...

... why you are not breastfeeding and you do not want to tell them the real reason, you can say the following: “After the birth, my breast glands became inflamed, so I had to stop breastfeeding.” Such inflammations are common.



HIV TESTS

Like most HIV positive mothers, you will want to know quite soon whether your child is healthy. The



first test is carried out right after the birth, additional tests after the second and sixth week and between the fourth and sixth month after birth. If these tests do not find HIV in the blood of your child, it is relatively certain that it is not infected. Final certainty is provided by an HIV antibody test, which is carried out between the 18th and 24th month of life.

This period of waiting can cause strong emotional stress. Your partner, family members and good friends can give important support. The people who work in the Aidshilfe are also there for you and can tell you where you can find additional support, for example, from the counselors of ProFamilia or a psychologist.

So that you and your child can continue to receive optimum care, you should stay in contact with your doctor as long as possible after the birth. This also makes sense even if your child is not infected with HIV. If the doctors know how you and your child are doing, they can learn from this and further improve medical care for pregnant women with HIV.

INFORMATION AND ADVICE

The addresses of the local Aidshilfen can be found in the telephone book or under www.aidshilfe.de. **The Deutsche AIDS-Hilfe e.V.** will be happy to inform you of an Aidshilfe near you (telephone 030 / 69 00 87-0). Counselling is offered by telephone at 0180-33-19411 (9 cents/min. from a landline, maximum of 42 cents/min. from German mobile phone networks) or online at www.aidshilfe-beratung.de. The **Bundeszentrale für gesundheitliche Aufklärung** (German Federal Center for Health Education) offers counselling by telephone at 0221 / 89 20 31 or at www.aidsberatung.de in the Internet.

Our nationwide meetings for people living with HIV (Positiventreffen) are available for women and men together or just for women, and also for migrants. The Deutsche AIDS-Hilfe e.V. can inform you about the dates of these meetings.

Information and support is offered by the “**Afro-Leben+**” network (www.afrolebenplus.de), which you can contact via Deutsche AIDS-Hilfe by telephone (030 / 69 00 87-19).

You can get free information material from the Deutsche AIDS-Hilfe (tel. 030 / 69 00 87-0; Internet: www.aidshilfe.de > Infothek > Material bestellen), from local Aidshilfen or from the Bundeszentrale für gesundheitliche Aufklärung (Internet: www.bzga.de).

ADVICE AND SUPPORT FOR CIRCUMCISED WOMEN

Terre des Femmes e.V.

Brunnenstr. 128, 13355 Berlin

Tel. 030 / 40 50 46 99-0

KUTAIRI – Telefonberatung gegen weibliche Genitalbeschneidung

Tel. 0211 / 98 59 57 89 – d@kutairi.de – www.kutairi.de

Afrikaherz – gesundheitliche Aufklärung für afrikanische Frauen

Petersburger Str. 92, 10247 Berlin

Tel. 030 / 29 00 69 49

afrikaherz@via-in-berlin.de – www.via-in-berlin.de

AGISRA Köln e.V. – Beratungsstelle für Migrantinnen

Martinstr. 20a, 50667 Köln

Tel. 0221 / 12 40 19 – info@agisra.org – www.agisra.org

DEUTSCHE AIDS-HILFE E.V., Wilhelmstr. 138, 10963 Berlin

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SPECIAL NOTE: This booklet was written to the best of our knowledge and according to the latest standard of knowledge (December 2012). Even so, there is no possibility to fully exclude errors. Moreover, medical research proceeds very rapidly which is particularly the case in the field of HIV/AIDS. This means: what is up-to-date today, may be out of date tomorrow. We therefore ask our readers to keep themselves informed by reading the latest publications on this topic.

