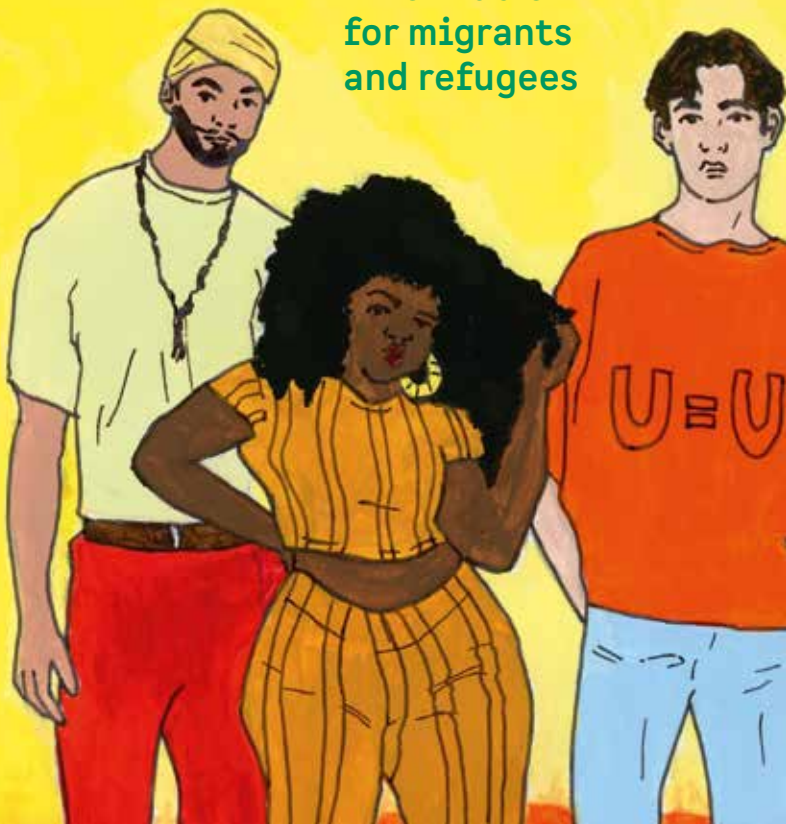


# Living positive with HIV

Information  
for migrants  
and refugees





# Living positive with HIV

Information  
for migrants  
and refugees



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## Introduction

Nowadays, HIV can be successfully treated: HIV medication suppresses the replication of HIV in the body and thus prevents AIDS. If people who are HIV-positive start their treatment in good time and take their medication regularly, they have very good chances of living a long and healthy life with the virus.

Even those who are diagnosed and start their treatment at a later stage have a good chance that their immune system will recover.

**Important: You can start HIV treatment at any time, but the earlier the better.**

After an HIV diagnosis, many questions and uncertainties may arise, in particular if you have recently arrived in a new country, for example:

- What is HIV and how does it affect my body?
- How can I stay healthy?
- What are the options for treatment?
- What should I do if I don't have any health insurance or papers?

- Will I be deported because of my HIV infection?
- What things do I need to be aware of with regard to the treatment?
- How can I avoid passing on the HIV infection to others?
- What can I do to ensure that my baby is born healthy?
- Are there any self-help groups for migrants where I could get support?
- Who can I turn to if I experience discrimination or racism?

This booklet will provide you with information about living with HIV in Germany. It will also help you to find doctors, organisations or groups who can give you advice and support. And we hope to reassure you that it is possible to live a positive and good life with HIV.





## What is HIV? How does it affect my body?

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HIV is a virus that primarily affects the cells of the immune system. Without treatment with HIV medication, the virus will weaken the body's capacity to fight against pathogens and defective body cells and cause damage to organs such as the kidneys, the bones and the brain. If you have become infected with HIV but do not take any medication, you can develop AIDS, a potentially fatal disease.

**The good news: Even if a person has AIDS, their immune system can recover again if they take HIV medication, and the AIDS symptoms will disappear again.**



# Access to HIV treatment and care in Germany

## People who have health insurance

The best thing to do is make an appointment at the practice of a doctor who specialises in HIV. There you will be able to discuss what you can do to improve your health, which medication you will need to take to treat the HIV infection and how you can avoid passing on HIV to others.

You can obtain the addresses of such HIV specialist doctors from AIDS service organisations. Your health insurance fund will cover the costs for the medication and for any examinations required.

**If you are too nervous to go to a doctor because you cannot speak German, you can again get help from the AIDS service organisations. They will often be able to put you in touch with interpreters who will show sensitivity for your particular situation. Furthermore, they also have contact details for doctors who speak other languages**

apart from German. AIDS service organisations also know how to access funding for the services of the interpreters.

## **Persons who have a temporary residence permit (“Aufenthaltsgestattung”), persons facing deportation and persons with a tolerance permit (“Duldung”)**

HIV-positive persons who are currently undergoing asylum proceedings for whom the right to asylum, refugee protection and obstacles to deportation have been refused, or who are tolerated persons or are now facing deportation, fall under the jurisdiction of the Asylum Seekers Benefits Act (Asylbewerberleistungsgesetz (AsylbLG)).

If you fall into one of these categories, the social security office (“Sozialamt”) will cover the costs of medical treatment of acute pain and diseases as well as all examinations and treatment related to pregnancy for the first 18 months of your stay in Germany. This includes all the

treatments that are required to prevent the HIV infection from becoming worse. In particular this means HIV medication. In this case, you will first need to go to the social security office to obtain a medical treatment document that is valid for a limited period of time, with which you then can go to a doctor. In some cities, you are not given a medical treatment document but instead a health insurance card (“Gesundheitskarte”) with which you can go directly to a doctor.

After 18 months, the social security office will register you with a health insurance fund. You will receive a health card and will be able to go directly to a doctor with this card.

**Incidentally: An HIV infection does not have any negative effect on your residency status. It will not lead to you being forced to leave Germany. Under certain circumstances, an HIV infection can represent an obstacle to deportation (“Abschiebehindernis”) in the asylum procedure. Be sure to get legal advice in good time – if at all possible before your hearing.**

## **Students enrolled at a university or other higher education institution**

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If you are under 30 years of age, you can and should take out statutory health insurance. If you present your enrolment certificate to the health insurance company, you will be offered a reduced rate for students. Your health insurance fund will cover the costs for all the treatment for the HIV infection, in particular for the required medication.

If you are 30 years of age or older, you will need to take out private health insurance. Many of the cheaper health insurance policies do not cover the costs of HIV treatment. If the HIV infection is diagnosed in the course of the contractual period, it may be that the contract will not be renewed, or it may be terminated. If you find yourself in this situation, you should contact an AIDS service organisation urgently and take legal advice.

## People without papers

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If you do not have papers, speak to a **Clearing-stelle**, an **AIDS service organisation** or a **Medibüro** so that you can nevertheless get help (more information on page 41). These institutions will offer you anonymous advice – you will not need to give them your name. You will be able to clarify the possible options for getting treatment for your HIV infection. The most important point is to verify whether it will be possible to legalise your stay in Germany. If you have a residence permit, it is usually possible to get health insurance cover.

## EU citizens with no health insurance

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If you come from another EU country and you do not have any health insurance, you will need to get advice at an independent consulting service (clearing centre (in German called “Clearingstellen”), AIDS service organisation, Medibüro, etc. – more information on page 41).





## **HIV treatment (antiretroviral therapy = ART)**

### **How does the HIV treatment work?**

HIV medication suppresses the replication of HIV in the body and thus prevents AIDS. It is often sufficient to take one tablet a day.

**As HIV is a so-called retrovirus, HIV medication is known as antiretroviral medication and the treatment for HIV is called antiretroviral therapy, often abbreviated to ART.**

If you are HIV-positive, it is advisable to start the treatment (therapy) as early as possible and you should take your HIV medication regularly – without any interruptions.

Treatment for HIV also includes regular check-ups – even if you are feeling fine. By means of blood tests, for example, it can be determined whether the therapy is working.

HIV drugs cannot remove the virus from the body, however, as some viruses are able to “sleep” in certain cells. This means that you cannot be cured by taking HIV drugs. The drugs must be taken regularly and life-long because otherwise HIV will start to replicate itself again. Without antiretroviral therapy (ART), the HIV infection almost always leads to the life-threatening illness AIDS.

## **What if I have problems with the antiretroviral therapy (ART)?**

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If an ART does not work effectively or causes problems – for example, if you experience undesirable side effects which you are not able to deal with, such as constant diarrhoea – you should go to your doctor and ask to change to a different therapy.

## **U=U (Undetectable = Untransmissible)**

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HIV medication suppresses the replication of the viruses in the body, meaning that, at some point, evidence of the viruses can no longer be detected in the blood. (We then refer to an “undetectable viral load”.) This means that HIV can no longer be transmitted to others – even during sex without a condom. Expressed in a short form, we speak of U=U (Undetectable = Untransmissible).

This is good news for everyone, whether they are HIV-positive or not, as it reduces the level of fear associated with the subject. It means that: If you take your HIV drugs regularly, you cannot pass on HIV during sexual intercourse – Protection through treatment (also called Treatment as prevention). It also means you will be able to have children without having to worry that you will pass on the HIV infection to your partner.

Preconditions: It is essential that the HIV medication is taken regularly, without any interruption, and that a doctor checks on a regular basis whether the treatment is working.



# How can a transmission of HIV during sexual intercourse be prevented?

All of the following methods will prevent HIV transmission during sex:

- **Condoms** – there are also “female condoms/femidoms” – prevent HIV transmission during sex.  
*Condoms not only provide protection from HIV, but also prevent unplanned pregnancies. They also reduce the risk of transmission of sexually transmitted diseases. You can purchase them in pharmacies, chemist’s shops, supermarkets, from many vending machines and online.*
- **Protection through treatment** (also called “Treatment as prevention”) – with successful treatment, HIV can no longer be detected in the blood and can no longer be transmitted to others during sex – even during sex without a condom. To get to this stage, it is important for the HIV medication to be taken regularly, without any interruption, and for a doctor to check on a regular basis whether treatment is working.

*“Protection through treatment” / “Treatment as prevention” only provides protection against HIV, not against sexually transmitted diseases or pregnancy.*

- **PrEP** – HIV-negative persons can take an HIV medication to protect themselves against infection with HIV. This is known as “Pre-Exposure Prophylaxis”, usually abbreviated to PrEP. It means you take medicine to prevent an HIV infection. You can get information and consultation on PrEP from AIDS service organisations, specialist HIV medical practices and from the public health offices.  
*PrEP only provides protection against HIV, not against sexually transmitted diseases or pregnancy.*

You can also combine these methods, for example by using condoms even though the HIV-positive partner is taking HIV medication.

**Important: In any partnership, it is important to talk about these issues openly and to decide together which method(s) of protection will be best for each person in the relationship. You can also take your partner with you when you go to get advice.**







## **Pregnancy, birth, breastfeeding**

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Many women and men with HIV want to have children. This is still an option: It is also possible for a person who is infected with HIV to conceive a child, get pregnant, give birth and breastfeed their child, without HIV being transmitted to their partner or to the child.

### **Conceiving a child**

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If HIV-positive persons take their HIV medication regularly (without any interruptions) and if HIV is no longer detectable in their blood, HIV cannot be transmitted during sex. This means: HIV-negative partners cannot become infected and HIV will not be transmitted to the baby during conception. We recommend arranging an appointment with a specialist HIV doctor, together with your partner, to get comprehensive advice on the subject.

There are also two other options:

- If the woman is HIV-positive, the child can be conceived by means of in-vitro fertilisation (IVF) using the sperm of her male partner.
- If the man is HIV-positive, his sperm will be “washed”. This means that HIV is removed from his sperm in the laboratory. The IVF process is then carried out.

## **Will the baby be healthy?**

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Nowadays, mother-to-child transmission can be prevented in almost all cases if the mother undergoes an antiretroviral therapy and through a range of further measures.

The most important factor is that the HIV drugs are taken regularly, that the woman has regular medical check-ups (at a gynaecology practice, a specialist HIV practice or an HIV outpatient clinic) and that she receives support and guidance from a medical team who have experience in HIV.

If the mother's viral load is undetectable, then it is usually possible for her to have a vaginal birth. In some cases, it will be necessary for a Caesarean section to be performed.

If the mother was being effectively treated with an HIV therapy before the pregnancy, throughout the pregnancy and at the time of birth, then it will not be necessary for the newborn to be given preventative HIV treatment. Otherwise, the baby will be given HIV medication, as a rule for a period of two to four weeks.

## **Can HIV-positive mothers breastfeed their babies?**

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If the conditions are ideal – the mother's viral load is undetectable and stable at this level and she is having regular medical check-ups – then it will usually be possible for her to breastfeed her child. If an HIV-positive mother wants to breastfeed, she should seek comprehensive advice in advance from her HIV doctor.



## HIV and religion

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Religion plays an important role in the lives of many migrants and refugees – perhaps for you too. A person's religious community can be like a second large family to them, offering protection from loneliness, exclusion or racism.

Faith and prayer can heal your soul. But they cannot heal a chronic disease such as HIV. For this reason: Take your HIV medication and pray too. The prayers will save your soul and the medication will save your body. Nowadays, HIV medication makes it possible for those affected to have a high quality of life.

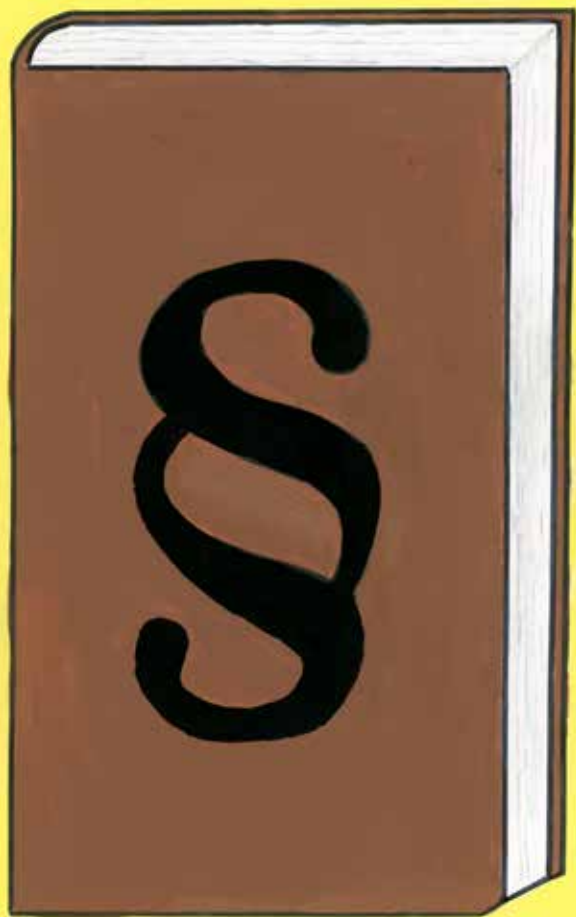


**Jobs**  
**Job offers**  
**Work**

## HIV at work

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There are people with HIV working in all professions, for example, as doctors, in nursing, as pre-school teachers and in the food processing sector. Employers do not have the right to ask about your HIV status. There are exceptions to this in a very small number of professions where HIV could play a role – for example, because people living with HIV are not permitted to travel to some countries. Likewise, you do not need to tell your colleagues that you are HIV-positive.





## **HIV and criminal law in Germany**

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Intentionally and carelessly passing on HIV is categorised under German law as causing bodily harm and in some circumstances is considered a punishable offence. This is under the presumption that you know about your HIV infection.

In order that a penalty can actually be imposed, criminal charges must first be filed. The important thing in such a case is to refuse to make any statement until you have spoken to a lawyer – you can get help from AIDS service organisations.

Whether criminal proceedings go ahead and whether the person will be sentenced depends (among other things) on whether the HIV-positive person did everything they could to prevent HIV transmission – for example, used condoms or regularly took their HIV medication so that HIV could not be transmitted during sexual intercourse.

However, it isn't possible to predict in advance how the court will ultimately decide.

**Important** In Germany you are not legally obliged to tell your sexual partners that you are HIV-positive.

**Tip** If you and your partner mutually agree not to use condoms, it makes sense to reach this agreement in front of witnesses or to document the agreement.



refugees  
welcome

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## What can you do if you are experiencing discrimination?

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Many people are structurally discriminated against in Germany, for example through laws or regulations, or on account of widespread ways of thinking or prejudices. Structural discrimination against refugees or migrants without papers can be seen, for example, in the fact that they have only limited or no access to medical care in Germany.

Refugees and migrants also face stigmatisation and discrimination within the community of people with HIV, when dealing with the German authorities or at work – on account of their skin colour or their religion. This comes from underlying racist attitudes.

An HIV infection can also be a source of discrimination. Migrants with HIV often experience discrimination, for example, in hospital (being refused medical treatment) or when dealing with the German authorities.

If you are being discriminated against, you should seek help from a migration consulting service and tell them about the discrimination you have experienced.

- They will tell you what options there are to take action and where you can get support.
- Furthermore, you can make contact with people who have had similar experiences and talk with them.
- Some consulting services offer workshops that will help you to deal with discrimination. For example, the German AIDS service organisation (Deutsche Aidshilfe) offers empowerment training for HIV-positive migrants and refugees. The courses are free of charge – all you need to do is register.

If you have made the decision to fight back against HIV-related discrimination (for example, by lodging a complaint), you can get support from AIDS service organisations and from the point of contact for HIV-related discrimination at the German AIDS service organisation (Deutsche Aidshilfe). Information and addresses can be found at [www.hiv-diskriminierung.de](http://www.hiv-diskriminierung.de).



# HIV treatment and counselling: addresses

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## HIV practitioners

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If you are HIV-positive and you have health insurance, we would advise you to go to an HIV practitioner. You can find these in all larger cities in Germany. Addresses of HIV practitioners can be found online at [www.dagnae.de/aerzte](http://www.dagnae.de/aerzte).

## AIDS service organisations

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If you would like to get information on HIV or if you are living with HIV, you can go to an AIDS service organisation in your local area or give them a call. There are AIDS service organisations in all larger cities, and also in many smaller ones (Addresses: [www.aidshilfe.de/adressen](http://www.aidshilfe.de/adressen)). AIDS service organisations are non-governmental organisations. These organisations also help with finding a doctor's practice, interpreters, a self-help group or organisations that assist people who have no papers. Some AIDS service organisations can also offer support with questions related to residence permits or social welfare

law and/or can put you in touch with lawyers who specialise in these fields. You do not have to reveal your name to AIDS service organisations either; the advisors are subject to a duty of confidentiality (they are not allowed to tell anyone else what you say to them).

## **Public health offices**

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In many cities there are public health offices; sometimes they have a different name such as "health centre" ("Gesundheitszentrum"). They are part of the public health system in Germany. You do not have to reveal your name there and the staff are subject to a duty of confidentiality (they are not allowed to tell anyone else what you say to them). Even if you do not have any health insurance, you can still talk to the public health office to get assistance.



## Organisations that offer support to people without papers or health insurance

If you are living in Germany but do not have a valid residence permit or any health insurance, you can get in touch with the following organisations:

**Clearingstelle:** There are clearing centres (in German called “Clearingstellen”) in a number of different German cities. The staff there can help to clarify questions relating to residence permits and social welfare law and, in many cases, can help you to gain access to the regular health care system. If this is not possible, most Clearingstellen are able to issue treatment documents (“anonymer Krankenschein”) which will allow you to get anonymous medical treatment. Currently only the Clearingstelle in Berlin and CASAblanca in Hamburg are able to arrange HIV treatment for persons without health insurance.

There are also doctors working for **Ärzte der Welt (Doctors of the World)**, **Malteser Medical Care for People with no Health Insurance** and **Medibüros** who offer treatment to people with no papers or health insurance if they suddenly fall ill or sustain an injury or if they are pregnant.

**A list of addresses of the Clearingstellen and Medibüros/Medinetze can be found at [www.aidshilfe.de/clearingstellen-medibueros](http://www.aidshilfe.de/clearingstellen-medibueros).**

## **Self-help groups: You are not alone!**

It is difficult to deal with a positive test result on your own. Migrants are often afraid of talking about their HIV status because they are worried that they will be rejected by their own community and/or stigmatised by German society. Refugees are also afraid that it might mean that they will be deported. This makes them feel very alone.

The nationwide meetings for HIV-positive migrants and their children organised by Deutsche Aidshilfe offer a way for people to find others to share their experiences within a protected environment, as do the meetings organised by AfroLebenPlus, a nationwide network for HIV-positive migrants. At these meetings, you can spend a number of days in a pleasant atmosphere with other migrants living with HIV.

In many German cities, there are also self-help groups where you can chat and share experiences with others, find new friends and get involved. You can find information on these groups from the AIDS service organisations or from the migration consulting services.

## **Nationwide meetings for HIV-positive migrants and their children**

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The nationwide meetings that are conceived and organised by the German AIDS service organisation (Deutsche Aidshilfe) together with the AfroLebenPlus network give people the opportunity to share their experiences and to network and aim to make them more resilient for everyday life with HIV. They also provide lots of useful information, for example on topics such as antiretroviral therapy and its possible side effects, “protection through therapy”, pregnancy and birth, migration and trauma, depression and HIV, Asylum seeker law, EU law, the health care system in Germany, religion and health, and empowerment for People of Colour (PoC).

The meetings are held in German, English and French. If required, translations into Arabic or Russian can also be organised.

All HIV-positive migrants – including refugees – and their children who are living in Germany are sincerely welcome to attend. The meetings are free of charge, all you need to do is register.

### **Contact**

Alphonsine Bakambamba:

[alphonsine.bakambamba@dah.aidshilfe.de](mailto:alphonsine.bakambamba@dah.aidshilfe.de)

## **AfroLebenPlus network**

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The AfroLebenPlus network is a nationwide network of HIV-positive migrants who are involved in HIV prevention and activism. The currently 20 members of the network come predominantly from the countries in Sub-Saharan Africa; they speak various different languages and are engaged in prevention work at various locations throughout Germany. They are well-connected within their respective communities, they are engaged in preventive as well as political work, and they are committed to improving the situation of HIV-positive migrants.

The nationwide meetings of the members of the network take place twice a year and give them an opportunity to share experiences and ideas, as well as fostering mutual empowerment and nationwide networking. There is also the chance to develop appropriate prevention measures for migrants or to get involved in some great projects with other migrants, in a joint initiative with Deutsche Aidshilfe e. V. The network is always happy to welcome new members. The meetings are free of charge, all you need to do is register.

### **Contact**

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## Websites

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- Information on HIV/AIDS in 12 languages:  
[www.zanzu.de/de/infektionen/hiv-und-aids](http://www.zanzu.de/de/infektionen/hiv-und-aids)
- Information for queer refugees in five languages:  
[www.queerrefugeeswelcome.de](http://www.queerrefugeeswelcome.de)
- HIV practitioners:  
[www.dagnae.de/aerzte](http://www.dagnae.de/aerzte)

## Telephone counselling on all topics related to HIV

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- German AIDS service organisation (Deutsche Aidshilfe) (German and English):  
[www.aidshilfe.de/telefonische-beratung](http://www.aidshilfe.de/telefonische-beratung)
- Federal Centre for Health Education (BZgA) (German and English):  
[www.bzga.de/service/infotelefone/hiv-und-aids](http://www.bzga.de/service/infotelefone/hiv-und-aids)

# Impressum

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