



Basic information on treating HIV infection

überreicht durch / courtesy of

therapy?

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What can you expect from anti-HIV therapy?

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There are now more than 20 so-called antiretroviral drugs available for treating HIV infection. They suppress the multiplication of HIV. In antiretroviral therapy (ART), several of these drugs are combined with one another, which is why it is also known as combination therapy.

If the therapy is started early and the pills are taken regularly, patients have the best chances of living many years and decades with HIV – including a good quality of life and an almost normal life expectancy.

Although these drugs work well against HIV, they cannot remove the virus from the body, so the HIV infection cannot be cured. To prevent life-threatening diseases, these medications will most likely need to be taken for the rest of one's life.



What does HIV do to the immune system?

HIV stands for human immunodeficiency virus: It weakens the ability of the human body to defend itself against pathogens (viruses, bacteria, fungi). HIV also attacks the T helper cells (also called CD4 cells), which control other immune cells in the defence against pathogens, and multiplies inside them. In addition, the virus causes changes and damage to various organs, such as the intestines, the kidneys, the bones or the brain.

If an HIV infection is left untreated (for example, if a person has not had an HIV test and is unaware of being infected), it often takes years before signs such as a persistent feeling of illness or constant diarrhoea become noticeable or before life-threatening illnesses occur (which is then referred to as AIDS). How the infection is progressing and how severely the immune system is being damaged by HIV can be determined by measuring the CD4 cell count and the viral load:

CD4 cell (helper cell) count

As a rule, healthy people have 500–1,500 helper cells per microlitre (= one millionth of a litre) of blood. In people with HIV who are not receiving treatment, the number of helper cells and their ability to function decreases more and more in the course of the infection until the immune system can no longer do its job properly. At levels below 200 helper cells, in particular, there is a high risk that pathogens that would cause no problems for healthy people may “seize the opportunity” to trigger life-threatening diseases (opportunistic infections).

Viral load

The greater the quantity of the virus in the blood (viral load), the more stress is placed on the immune system. By contrast, a low viral load means that the virus is reproducing only slowly and the immune system is being damaged less severely. In successful antiretroviral therapy, the quantity of HIV in the blood is so

low that it can no longer be detected using common methods (“viral load below the detection limit”). But HIV “lies dormant” in certain body cells and the immune system is still slightly overactive.

The helper cell count and the viral load can be influenced by various factors that have nothing to do with HIV, for example influenza (flu) or stress. So in order to know how the infection is developing or how well the antiretroviral therapy is working, it is necessary to check these values repeatedly over a longer period of time.



**Why is a good relationship between
doctor and patient so important?**

The success of HIV therapy depends not only on the patient's willingness to undergo treatment and to follow the programme exactly as he or she should, but also on the doctor's experience. The AIDS service organisations (Aidshilfen) will provide information (also anonymously) about where to find experienced doctors in the region, and can also help with additional health information. The doctor's skill lies in selecting a treatment together with the patient that quickly reduces the viral load below the detection limit and can also keep it at that level. The treatment should be compatible with the patient's daily life (e.g. work, sexuality and drug use), be adapted to any other diseases and cause as few unpleasant side effects as possible.

The patient needs to be able to talk openly and in confidence with the doctor about matters such as the difficulty of taking medications in the workplace, side effects, problems with sexuality or alcohol and drug use. It is important to know that the doctor and the practice staff are required by law to maintain confidentiality.



**When should combination
therapy be started?**

Current guidelines recommend that HIV therapy should be started soon after the diagnosis, regardless of the viral load and the helper cell count. But as long as the helper cell count is higher than 500 per microlitre, there may be good reasons to delay starting the therapy in individual cases. In any event, you will have enough time to get detailed advice; your local AIDS service organisation (Aidshilfe) will be happy to put you in contact with experienced doctors.

However, very often people only find out that they are infected with HIV when their immune system is already severely damaged and they are diagnosed with a serious illness such as tuberculosis, a fungal infection of the oesophagus or pneumonia. In such cases, the most important thing is treating that disease until the patient is getting better, since usually the body cannot cope with getting therapy for the HIV infection at the same time. Even in these cases, there is still time to adjust to the new situation, to gather information and get advice.



**Which combination is
the right one?**



For the treatment to work right from the start, various factors are considered, including:

Are there HIV strains present that are resistant to one or several anti-HIV drugs? In Germany, this is currently the case in about 10 percent of newly diagnosed HIV infections.

What medication regimen best fits the patient's daily routine? Some drugs need to be taken with food, others on an empty stomach, some once a day, some twice a day.

How can side effects such as diarrhoea or dizziness affect work, private life and sexuality?

What illnesses does the patient have apart from the HIV infection? Patients with chronic hepatitis B, for example, should receive HIV drugs that simultaneously combat viral hepatitis. Some HIV drugs cannot be used with other medications that are taken in order to treat another illness.

How far advanced is the HIV infection? Certain combinations work less well than others if the immune system has been heavily damaged (AIDS) or the viral load is high.





**What is important when taking
the medication?**

The aim of HIV therapy is to prevent the virus from multiplying, and thus to put a lasting stop to the destruction of helper cells and other damage. In order to achieve this, the HIV drugs must always be present in the blood in sufficient quantities, i.e. they must reach the necessary blood level. If the blood level of a drug is too low, then multiplication of the virus is not stopped effectively enough, and the virus becomes resistant, i.e. it becomes insensitive to this drug, and sometimes also to other HIV drugs that the patient has not even taken yet (“cross-resistance”). If the blood level is too high, it can make the side effects more severe.

In order to reach the correct blood level, the drugs need to be taken in the prescribed dose and at the prescribed times. In the case of some medications, you also have to follow some dietary rules. To make sure you do not forget a dose, watches with an alarm function and pill boxes with different compartments (available from the chemist's) can be helpful. Once the box is filled with all the drugs, you can quickly see if you have taken the morning or evening dose, for example.

Since these medications cannot remove the virus from the body, they will most likely need to be taken for the rest of one's life to effectively suppress the production of the virus. However, if the therapy is frequently interrupted or the medications are taken irregularly, HIV may multiply again and develop resistance to the medications used.

**How can you tell if therapy
is successful?**



The quantity of the virus drops.

This process takes a few weeks to months. After three months, the viral load should be so low that it is “below the detection limit” (today, this is around 20 to 40 virus copies per millilitre of blood). However, this does not mean that there is no longer any of the virus in the body: therapy does not make anyone virus-free.

The number of helper cells rises and the immune system recovers.

When the multiplication of the virus is suppressed, hardly any helper cells are being infected. Where therapy is successful, their numbers rise again, although this takes longer than it does for the viral load to drop. The immune system will recover, which you can support through a balanced diet, sufficient sleep, sports and keeping active as well as less alcohol and nicotine.



What are the side effects like?

Like all medicines, those used to fight HIV also have unwanted effects, called side effects, which are listed in the package inserts. Don't be too worried by these; for legal reasons, all unwanted side effects that have ever occurred anywhere must be listed. Most people with HIV get on well with their treatment.

It is more important to be aware of the most frequent side effects of the prescribed therapy in order to be prepared for them.

Acute side effects

Acute side effects can occur in the first few weeks after starting to take a drug. Frequent side effects include a bloated feeling, lack of appetite, nausea, diarrhoea or constipation, dizziness and sleep problems. Some of these side effects can be treated easily, for example with medicines or proven home remedies, or even avoided by changing the times at which the drug is taken.

Side effects can be particularly strong in the first two weeks after starting or changing therapies. This should be taken into account if the patient has to do more than normal or is under a lot of stress (e.g. at work or in his or her studies).

Long-term side effects

Long-term side effects, for example metabolic disorders such as diabetes or high blood lipids, may occur months or years later. Kidney function and bone structure may also be affected.

Depression and sexual problems may also occur, with the HIV infection itself and other factors such as age, use of illicit drugs, nicotine and alcohol or mental stress usually also playing a role in such cases.

Sports, exercise, a balanced diet and less nicotine and alcohol can also reduce the negative effects of the drugs on the nerves and the metabolism.

If the side effects are too severe ...

... patients should not decide on their own to stop taking their medications. They should go to an HIV specialist to discuss the possibility of switching to other HIV drugs that have fewer or more manageable side effects.



**What if the treatment causes
too many problems?**

If a combination does not work properly or causes too many problems, it should be changed as early as possible, for example if

the viral load has still not fallen below the detection limit within three months of starting therapy

a patient has difficulty taking the drugs as prescribed

a patient is experiencing unwanted side effects that are unmanageable or risky

resistance occurs, i.e. HIV has become insensitive to one or more of the drugs.

It is important to know that “treatment failure” or the development of resistance is not necessarily due to the patient not taking the therapy properly. In some people, for example, the metabolism is so active that the medications pass through the body too quickly; this means that the necessary blood level cannot be reached or can only be reached for a very short time. Other factors such as drug interactions, damaged mucous membranes in the intestines or other illnesses can also play a part.

The image is a vertical composition. The top half shows a sky filled with heavy, grey, and white clouds. A solid green horizontal band cuts across the middle of the image, containing the text 'What about sex?'. Below this band, the image shows a dark, turbulent sea with white-capped waves. In the far distance, a range of low mountains or hills is visible under a pale sky. A thin white horizontal line is drawn across the sea, roughly at the level of the green band.

What about sex?

Effective treatment causes the quantity of the virus in blood, semen and mucous membranes to drop significantly. If the viral load in the blood has been below the detection limit for at least six months, the drugs are taken consistently and the viral load is measured by a medical professional every three months, HIV cannot be transmitted when having sex without a condom.

If an HIV-positive person with an undetectable viral load and an HIV-negative or untested person are faced with the question of whether or not they should have sex without a condom, the DAH recommends that they have a discussion about it and make a decision together that both are comfortable with.

HIV-negative or untested people need to be able to trust that their HIV-positive partners meet the requirements for “treatment as prevention”. Everyone needs to decide for themselves whether they have such a trusting bond. This is more likely to be the case in serious relationships than in casual sexual encounters.

We recommend using condoms whenever there is any doubt. The same goes if a discussion and a joint decision are not possible.

Condoms also provide protection against other sexually transmitted diseases against which HIV drugs are not effective. However, sexually transmitted diseases can be transmitted despite using condoms and often do not produce noticeable symptoms. We therefore recommend getting tested and, if necessary, treated at least once a year.

Caution is advised about using erectile dysfunction drugs such as Viagra®, Cialis® or Levitra®; their use should always be discussed with the doctor providing treatment! When taking HIV medications belonging to the class of protease inhibitors, a small fraction of the normal dose of an erectile dysfunction drug is usually enough to produce the desired effect. Taking a normal dose may cause severe side effects such as a severe drop in blood pressure.



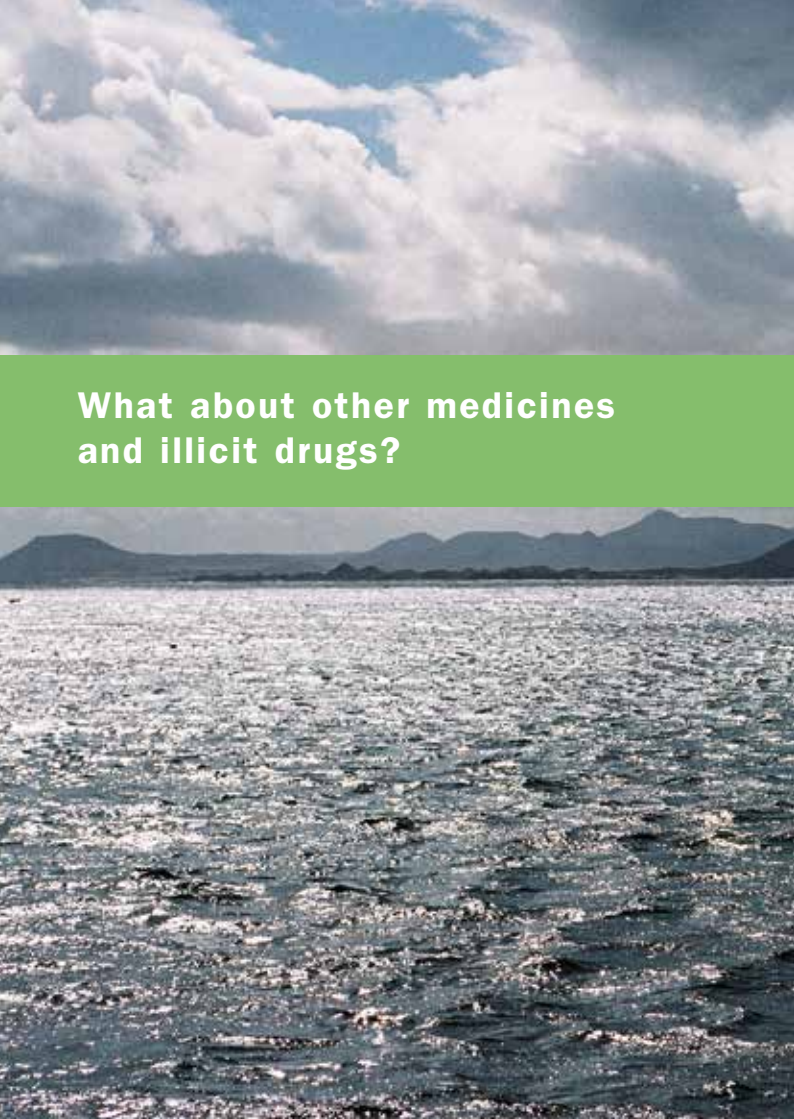
What about pregnancy?

HIV-positive men with a detectable viral load cannot pass on the virus to the child during conception, but they can infect the woman (who can then potentially infect the child); this can be prevented by “sperm washing” and subsequent artificial fertilisation.

If the man’s viral load is consistently below the detection limit as a result of HIV therapy, a natural conception is also possible. The use of medications by the father-to-be does not harm the child.

HIV-positive women with a detectable viral load can transmit HIV to their partners and their babies if no preventive measures are taken. If the woman regularly takes anti-HIV drugs and her viral load is consistently below the detection limit, her partner cannot be infected during conception.

The risk of HIV transmission from the mother to her baby can be reduced to below 1% if the mother takes anti-HIV drugs to lower the viral load in the blood to below the detection limit and the newborn receives preventive treatment with anti-HIV drugs for several weeks. If the mother's viral load is consistently below the detection limit, the child can also be delivered in a natural birth; otherwise, a planned Caesarean section is recommended. In any event, receiving medical support from HIV specialists is important.



**What about other medicines
and illicit drugs?**

Dangerous interactions can occur between HIV drugs, other medicines, alcohol and illicit drugs. Some HIV drugs delay the breakdown of illicit drugs in the body, which means that the drugs act longer and have a stronger effect. Other HIV drugs lower the level of substitution drugs in the body, which can lead to withdrawal symptoms. Alcohol worsens the side effects of HIV drugs, and the herbal substance St. John's wort, which is often used for depression, can make certain HIV drugs ineffective, allowing resistance to develop. It is essential for the doctor to know which medicines and illicit drugs you are taking. Don't worry – he or she will not pass such information on to the authorities or the police.

A blue sky with white clouds, partially obscured by a green horizontal band. The text "What about travel?" is written in white on the green band.

What about travel?

Wherever you are travelling, important medicines should be kept in your hand luggage so that you are not left without them if suitcases arrive late or are lost. In a small number of countries, especially in the Middle East, there are restrictions on people with HIV entering or staying in the country. For more information, please visit the website www.hivtravel.org.



What about vaccinations?



Vaccinations (e.g. against hepatitis A and B, influenza or pneumococcal pneumonia) are particularly important for people with HIV and a weak immune system, because they are more susceptible to infection. If the helper cell count is low, the protection given by a vaccination which you received in the past can be lost. If the immune system then improves as a result of HIV therapy, it should be checked whether vaccinations (hepatitis A, hepatitis B, tetanus, diphtheria, polio, ...) need to be boosted.





Sources of information

Booklets of Deutsche AIDS-Hilfe e.V.

We talk about it (2016)

Information about HIV and AIDS (order number 044017, www.aidshilfe.de/shop/pdf/7708)

Good to know (2016)

Information on HIV-testing (order number 044013, www.aidshilfe.de/shop/pdf/7710)

Your health, your rights (2017)

Bilingual brochure with information on sexual health and the health care system in Germany (order number 024101, www.aidshilfe.de/shop/pdf/8612)

These and other booklets can be ordered free of charge at the local AIDS service organisations (Aidshilfen; for addresses see www.aidshilfe.de) as well as at Deutsche AIDS-Hilfe e. V. in Berlin, internet: www.aidshilfe.de, e-mail: versand@dah.aidshilfe.de.

Information on the Internet

www.aidshilfe.de

The website of Deutsche AIDS-Hilfe e.V. (DAH) with information in English (just click on the British flag)

www.aidsmap.com

www.thebody.com

www.poz.com

Personal counselling ...

... is offered by the AIDS service organisations (addresses in the phone book, at the DAH and at www.aidshilfe.de). They can also tell you the names of doctors who are experienced in HIV treatment and will be happy to put you in touch with other people with HIV and AIDS.

The AIDS service organisations' nationwide telephone counselling service can be reached on 0180 / 33 / 19411 (Mondays to Fridays 9.00 am – 9.00 pm, Saturdays and Sundays 12.00 noon – 2.00 pm; 9 cents per minute from the German fixed-line network, no more than 42 cents per minute from German mobile networks). Online counselling is available at www.aidshilfe-beratung.de.

The Federal Centre for Health Education also offers counselling on 01805 555 444 (14 cents per minute from the German fixed-line network, no more than 42 cents per minute from German mobile networks) as well as online at www.aidsberatung.de.