



Basic information on treating HIV infection

Englisch

therapy?

Überreicht durch – Handed out by



**What can you expect from
anti-HIV therapy?**



There are now more than 20 so-called anti-retroviral drugs available for treating HIV infection. All these drugs suppress the multiplication of HIV in human cells. In anti-retroviral therapy (= ART, also called highly active anti-retroviral therapy = HAART), several of these drugs are combined with one another. That is why it is also called combination therapy.

When ART is successful, hardly any more of the virus is produced. So the pressure is taken off the immune system; it can recover and is better able to defend the body against germs (pathogens) that cause disease. For this reason, the health and life expectancy of people with HIV in Germany has improved considerably. We cannot yet say for certain how long a person can live with HIV these days, as the therapies have been available in this form only since 1996. But what is clear is that when the treatment takes effect, we are talking about many years, perhaps even decades.

Although the 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, it is necessary to take the medication 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). Amongst others, HIV attacks the helper cells (also called CD4 cells), which control other immune cells in the defence against pathogens, and multiplies inside them.

If the HIV infection is not treated (for example if a person has not had an HIV test and does not know that he or she is infected), it often takes many years before he or she notices the first signs (e.g. feeling ill all the time, constant diarrhoea etc.) or before the stage of AIDS, with life-threatening illnesses, is reached. However, it is possible to find out much earlier how severely the immune system has been damaged by HIV, by determining the number of helper cells and the viral load:

Helper cell count

As a rule, healthy people have 500–1,500 helper cells per microlitre (= one millionth of a litre) of blood. In the case of people with HIV, the number of helper cells and their functioning decreases more and more in the course of the infection, until the immune system can no longer do its job properly. At levels of less than 200 helper cells, there is a high risk that pathogens that would pose no problems for healthy people will trigger life-threatening diseases (opportunistic infections). Besides the number of helper cells, an important role is also played by the proportion of helper cells to the other lymphocytes (= a sub-

group of the white blood cells, and the most important defence cells in the body) – at least one third should be helper cells.

Viral load

The greater the quantity of the virus in the blood (the viral load), the more stress is placed on the immune system. A low viral load means that the virus is reproducing only slowly, and the immune system is less severely damaged.

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, it is necessary to check these values several times 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 the best possible treatment for the individual person with HIV; in other words, a treatment that can be best fitted into the patient's everyday life, that causes as few annoying side-effects as possible, and that works best against the virus.

It is important here that the "chemistry" between the patient and the doctor is right. The patient needs to be able to talk openly with the doctor and to feel able to trust him or her, for example when talking about the difficulty of taking medication at the workplace, about side effects, about problems with sexuality, about using alcohol and illicit drugs. One thing that is important to know is that the doctor and the practice staff must, by law, keep confidentiality.



**When should combination
therapy start?**



Not too late! Don't delay starting treatment until the immune system is so weakened that there are fewer than 200 helper cells per microlitre of blood – the immune system then needs a lot longer to recover, and may suffer lasting damage. Therapy is usually started when the absolute helper cell count is in the range between 350 and 250.

> One exception is the treatment of an acute infection, in other words one when the person has been infected with HIV acquired only a few days previously. Studies are currently being carried out to see whether this very early treatment is worthwhile.

The point at which the doctor will advise therapy to be started in individual cases also depends, for example, on how high the viral load is, whether the patient is already feeling ill (if for example he or she feels tired all the time, run down, weak and prone to illness), or whether he or she has other diseases (e. g. chronic hepatitis).

At present, opinion is rather to start treatment when the helper cell count drops below 350 than below 250. Although patients have to deal with side effects and resistances earlier, treatment prevents the virus from damaging the immune system and the body.

How long can I take to decide?

Most people who face the decision about whether to start therapy or not have already been infected for several years, and have regular examinations. Even if the values get worse (lower helper cell count, high viral load), there are still several weeks in which to decide about whether and when to start therapy.

However, very often people find out that they are infected with HIV only when they are diagnosed with a serious illness such as 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.



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

What is the patient's daily routine and what type of medication fits this best? Some drugs have to be taken with food, some 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 appear to work less well than others in later stages (AIDS).



**Which combination is
the right one?**



What is important when taking the medication?

The aim of HIV therapy is to stop the virus from multiplying, and thus to put a lasting stop to the destruction of helper cells. In order to achieve this, the HIV drugs must always be present in the blood in sufficient quantities; that is, 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, this 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; and in the case of some medications, you have to be careful what you eat as well. 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.

The quantity of the virus drops.

This process takes from a few weeks to months. After six months at the latest, the viral load should be so low that it is “below the detection limit” (today this is around 20 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 multiplication of the virus is suppressed, fewer 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. Once the immune system has recovered, the body is then better able to use its own resources to defend itself against pathogens. People with HIV who had been feeling tired and run down for a long time now have more strength and energy. You can also help to support your immune system, for example through a balanced diet, sufficient sleep, less alcohol and nicotine, sports and keeping active.



How can you tell if therapy is successful?



What are the side effects like?

Like all medicines, those used to fight HIV have unwanted effects along with the effects that are intended – these “side effects” are listed on the product leaflets. Don't be too worried by these; for legal reasons, all the unwanted side effects must be listed that have ever occurred anywhere. However, 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 are bloated feeling, lack of appetite, nausea, diarrhoea or constipation, dizziness and sleep problems. Some of these side effects are easy to deal with, for example with medicines or familiar household remedies, or by changing the times at which the drug is taken.



The unwanted side effects can be particularly severe in the first two weeks after starting therapy. For this reason, therapy should not be started 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). Just in case there are side effects, the patient can be signed off sick (krankgeschrieben) or can plan to take a few days off.

Long term side effects

Long term side effects can occur after some months or years. The most well known is lipodystrophy, a disorder of the distribution of body fat. This often seems to be the worst side effect for a lot of patients, since it makes them look different (e.g. their cheeks might get very thin, they may get more fat on their neck or stomach, they may have less fat on their arms, legs and buttocks). Another long-term side effect that occurs frequently is nerve damage, which causes pain and numbness as well as tingling and burning in arms and legs (peripheral neuropathy). Metabolic disorders, depression and sexual problems can also occur, with other factors usually also playing a role

here, such as e.g. age, use of illicit drugs, nicotine and alcohol, a wrong diet, not being active, and mental stress.

Sport, activity, a balanced diet and less nicotine and alcohol can reduce the effects of the drugs on the nerves and fat metabolism.

If the side-effects are too severe ...

... then the patient should discuss all the difficulties with the doctor – the earlier, the better. It may then be possible for example to switch to HIV drugs with a different range of side effects, before resistance occurs and other drugs may no longer be usable.

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 six months of starting therapy

the viral load drops as desired, but the number of helper cells does not rise

a patient has difficulty in taking the drugs as prescribed

unwanted side effects occur which the patient cannot deal with, or which are risky

resistances occur, i.e. if 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 medicines 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 interactions between medicines, damage to the mucous membrane in the intestines, or other illnesses can also play a part.

An aerial photograph of a large body of water, possibly a lake or a wide river, with a grid overlay. The water is a mix of dark blue and green, with some lighter patches. The grid is composed of thin white lines. A prominent vertical blue line runs down the right side of the image. A horizontal green bar is positioned across the middle of the image, containing white text.


What if the treatment causes too many problems?




How long must you keep taking the medication?



Since the drugs cannot remove the virus from the body, you need to take them for the rest of your life in order to effectively suppress the virus production. However, once their immune system has recovered and they need a break after years of therapy, some people with HIV interrupt treatment for a few weeks or months. At present, opinion is that the risks of “treatment interruptions” might outweigh their benefits: The viral load can go up very quickly so that the patient feels very sick and is more infectious, and resistances can occur.



Patients should never interrupt therapy on their own initiative, but should plan it only with the agreement of their doctors!



Once the immune system has recovered after therapy has started, and you have regained energy, sex often becomes more enjoyable again. Although the risk of infecting your partner during unprotected sex is much lower when therapy is successful (the viral load is below the detection limit), the risk is still there, so we recommend safer sex: using condoms for vaginal and anal intercourse, not allowing any semen into the mouth during oral sex (“pull out before coming”), not allowing any blood/semen to come into contact with mucous membranes (e.g. in the eyes) or open wounds. Using condoms not only provides protection from HIV, but also lowers the risk of becoming infected with other sexually transmitted diseases such as syphilis or gonorrhoea – these diseases not only place an additional strain on the immune system, but increase the risk of infecting others with HIV during sex.

When a person with HIV who has not started therapy yet or who has interrupted treatment has unprotected sex with another HIV positive person, a “super-infection” with a further strain of the virus is possible. This can lead to resistance against medication and could mean that the illness develops more quickly.

What about sex?

Beware: Because substances that increase potency can interact with HIV drugs, their use should be discussed with the doctor providing treatment.



What about pregnancy?

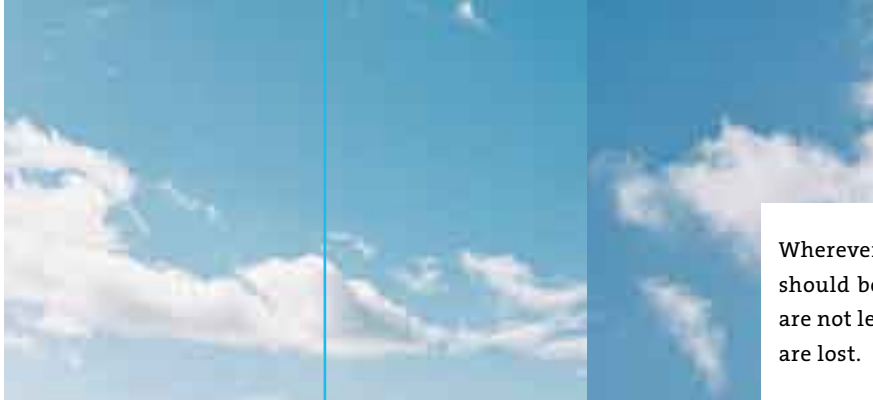
The risk of HIV transmission from the mother to her baby can be lowered to below 2 % if the woman has a caesarean section before labour starts, takes anti-HIV drugs in the last few weeks of pregnancy, and does not breastfeed, and if the baby receives preventive treatment with anti-HIV drugs. For women who are already receiving combination therapy, checks are made in the first few weeks of pregnancy to see whether any anti-HIV drugs need to be replaced by others in order to protect the child.

HIV-positive men cannot pass the virus on to a child during conception, but they can infect the woman; this can be prevented by “sperm washing”. As far as we know at present, it does not harm the child if the father has taken medication.

Dangerous interactions can occur between HIV medication, other medicines, alcohol and illicit drugs. For example, some HIV drugs slow down the breakdown of drugs in the body, which means that the drugs act for longer and have a stronger effect. Some 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 which allows 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.

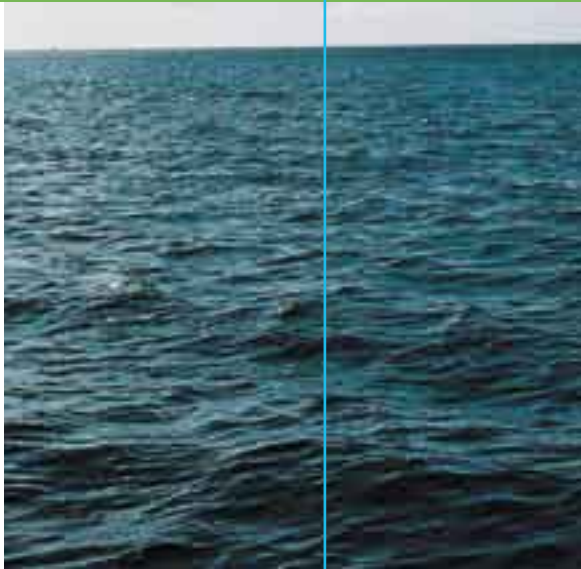


**What about other medicines,
alcohol and illicit drugs?**



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.

What about travel?



Only a very few countries have travel restrictions on HIV positive tourists entering the country (e.g. USA, China, Saudi Arabia, Iraq). But in many countries there might be problems if you are planning a longer stay. More detailed information on entering countries, staying there and on treatment options in other countries you can get from the AIDS service organisations (Aidshilfen) or at www.hiv-wechselwirkungen.de > Broschüren > Einreisebestimmungen. The Aidshilfen also offer counseling and tips on how you can stay mobile in spite of these travel restrictions.

Vaccinations (e.g. against hepatitis A and B, influenza or pneumococcal pneumonia) are especially important for people with HIV. In the case of a functioning immune system, the success of vaccinations is higher and you are better protected from disease.

In the course of HIV 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 due to HIV therapy, it should be checked whether vaccinations (hepatitis A/B, tetanus, diphtheria, polio, ...) need to be boosted.

What about vaccinations?

Sources of information

Booklets

HIV and AIDS (order number: 020111)

Basic information about HIV and AIDS and how to protect oneself and others against infection. The booklet also informs about health insurance, AIDS service organisations (Aidshilfen) and other agencies which provide help and advice.

Positively pregnant (order number: 020064)

Information for pregnant women with HIV about protective measures for the health of mother and child from the very beginning of the pregnancy (e.g. HIV treatment, examinations, planned caesarean section, HIV prophylaxis for the newborn baby).

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, telephone (030) 69 00 87-43, fax (030) 69 04 13 00 internet: www.aidshilfe.de e-mail: versand@dah.aidshilfe.de.

Information on the internet

www.aegis.org
www.thebody.org
www.poz.com
www.aidsmap.com

Personal counselling ...

... is offered by the AIDS service organisations (Aidshilfen; for addresses see www.aidshilfe.de). They can also tell you the names of doctors who are experienced in HIV treatment, and will be pleased to put you in touch with other people with HIV and AIDS.

Online counselling service of the Aidshilfe (also in English): www.aidshilfe-beratung.de.

Impressum

Herausgeberin:

Deutsche AIDS-Hilfe e.V., Berlin

Tel.: 030 / 69 00 87-0

www.aidshilfe.de,

E-Mail: dah@aidshilfe.de

2007 (aktualisierter Nachdruck der 2. Auflage [2005])

Bestellnummer: 020118

Textgrundlage: Peter Wießner

Redaktion: Karl Lemmen, Armin Schafberger,

Uli Sporleder, Holger Sweers, Achim Weber

Herzlichen Dank an: Götz Bähr, Dr. Christiane

Cordes, Harald Hägele, Helmut Hartl, Hermann

Jansen, Dr. Christoph Mayr, Clemens Sindelar,

Carlos Stemmerich und Engelbert Zankl

Bearbeitung: Holger Sweers

Gestaltung: Paul Bieri, dia* netzwerk für

visuelle kommunikation, Berlin

Fotos: Marcel Steger

Druck: Druckerei Conrad, Berlin