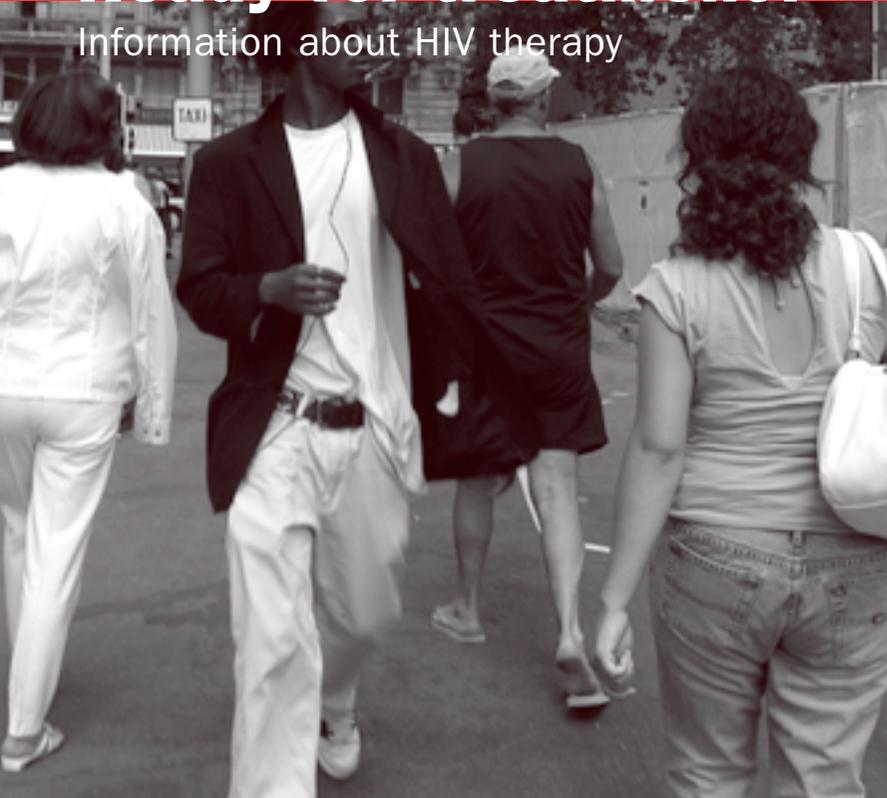


Ready for treatment?

Information about HIV therapy



The introduction of effective HIV drugs in the mid 1990s marked a breakthrough in the treatment of HIV infection. Since then, both the quality of life and the life expectancy of HIV-positive people have improved drastically. These drugs offer a genuine chance to maintain or recover medium and long-term life perspectives.

Despite these improvements, the downside of HIV infection and the limitations of the available treatments should not be forgotten: people are still dying of AIDS. Antiretroviral drugs are currently the only means of effectively combating HIV infection. This is why it is important for HIV-positive people to know more about HIV therapy.

The booklet 'Ready for treatment?' is intended to encourage all HIV-positive people to acquaint themselves with the complex subject of HIV therapy. There is no doubt about it: deciding for or against HIV therapy is difficult. Moreover, going on treatment requires commitment. But it is possible to learn how to cope with its requirements and integrate it into daily life. In most cases, well-adapted medical therapy for HIV makes it possible to live a long, rewarding life, despite HIV infection.

This booklet is meant mainly for HIV-positive people who are thinking about treatment, starting treatment or just looking for information. It is by no means an answer to all the questions that can arise. But it does offer an overview and provides assistance with making decisions on all aspects relating to HIV treatment.

Its aim is to help you make a clear decision: 'Yes, I'm going to start HIV treatment' or 'No, I'd rather wait'.

*Sincerely yours,
The Editorial Team*

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HIV-positive and still living well

I have taken control of my illness, I have started managing it. Not just surrendering. Not giving up.

*The most important thing for my health is not the diagnosis, but how I can join together with others to change my life situation. I want to be the master of my own fate as far as possible.**

** All quotations are taken from interviews with HIV-positive people.*

The diagnosis 'HIV-positive' is naturally a shock at first for those concerned and represents a decisive turning point in their life. The diagnosis usually ushers in a phase of intense personal coming to terms with the infection. A process that gives rise to many questions: How can life go on? What can I do? What does the infection mean for me?

Experience has shown that, with time, HIV-positive people find their own, creative way of coping with the infection. Some HIV-positive people change their life habits after the diagnosis – in their personal environment, at their workplace, in society generally. **They learn to live with their HIV infection.**

This does not mean one should simply gloss over the situation, nor does it mean one should be overhasty. One thing is certain: an HIV infection still can't be cured, and the health of HIV-positive people is in jeopardy. But this does not mean that HIV-positive people are completely at the mercy of the virus. On the contrary – they can assume responsibility for maintaining or improving their health and do something about it. It is important for HIV-positive people to react to the infection and take their future in their own hands.



HIV therapy

I have been doing very well with this therapy for six years. And I now think that life's worth living again. At some point I realised: yes, I'm regaining my strength.

Years ago, when I was told I was HIV-positive, I just drew a line under my life. With the new medications, all that has changed. I now have goals again. I have the confidence to do something again. I have regained my sense of self-worth.

Traditional medicine offers treatment for HIV infection which has been shown to help support health over the long term and significantly increase life expectancy.

When the medication is taken as directed, the virus cannot multiply any further, which allows the body's own powers of healing to recover to some extent. This results in a better general condition and less susceptibility to disease. Longer-term life perspectives can be maintained or recovered and quality of life can improve: living a fulfilled life with the virus is possible.

Today's HIV treatments are much easier than in the past. The amount of pills that have to be taken daily has now decreased drastically: instead of more than 20 tablets distributed throughout the entire day, most courses of treatment now involve taking only two to six tablets a day, either all at once or divided into two doses. A look at the side effects also shows that this aspect has also greatly improved.

But even today's HIV treatments do not cause the virus to disappear completely. Even if the viruses can no longer multiply during a successful therapy, the information that allows new viruses to form still remains inside the blood cells. Treatment is therefore only effective for as long as it is used. HIV therapy is a long-term treatment.

Important: during successful therapy for HIV the risk of transmitting HIV to the partner in unprotected sexual contacts (e.g. due to condom failure) is much lower than without therapy. However, scientific data are still insufficient to state with certainty that there is no risk of transmission. This is why it is recommended that people with HIV practise safer sex even while receiving treatment.



Should I start treatment now?

I did not just start when the doctors said I had to. I needed to discuss the whole thing quietly with my girlfriend and then with the doctors again and again. Only when I was really convinced that it was necessary did I begin taking the medication.

There is no cure for HIV infection at present; and no medical breakthrough seems to be in sight at the moment. But one thing is certain: without treatment HIV infection will gradually worsen. This is why sooner or later most people with HIV come to terms with the treatment that can halt the course of the disease. The decision not to begin treatment, however justified it may seem in individual cases, is usually of limited duration and has to be repeatedly reconsidered. The decisive factor is the course of the infection.

The course of an HIV infection

In general, an HIV infection proceeds in three phases:

- A phase directly after the infection, in which the number of viruses in the blood is very high for a short time.
- A phase in which there are hardly any symptoms; it lasts on average for eight to ten years.
- A phase of symptoms and serious diseases. If certain diseases occur, the person is said to have AIDS.

The course of an HIV infection is regularly monitored with two laboratory values:

CD4 cell count and **viral load**.

What is the CD4 cell count?

The CD4 cell count represents the number of CD4 cells per microlitre of blood. CD4 cells, also known as helper cells, play an important role in defence against diseases.

In order to multiply, HIV targets especially these cells and destroys them. Therefore, the number of CD4 cells shows the extent to which the immune system is damaged. The average CD4 cell count in healthy people is between 500 and 1500 per microlitre of blood; in people with HIV it can fall well below this range. With therapy, the CD4 cell count can improve and return to the normal level.

What is the viral load?

The viral load is the concentration of HIV in the blood, expressed as the number of viruses per millilitre of blood plasma (the liquid part of the blood without cells). The value reflects the number of viruses that are formed daily and therefore destroy CD4 cells. The more viruses are present in the blood plasma, the faster the CD4 value falls and the greater the probability that symptoms or AIDS-defining diseases will occur. During the course of an untreated infection, the viral load can reach several tens or even hundreds of thousands of viruses per millilitre of blood plasma. With effective therapy, it decreases towards zero.

For details on the course of HIV infection please see our booklet 'HIV-positive – what next?'. Order address p. 44.

From the medical perspective, it is clearly recommended to begin treatment:

- if infection-related symptoms develop or AIDS breaks out,
- if the CD4 value is between 200 and 300 cells per microlitre of blood.

Medical experts are in agreement regarding these guide values. CD4 cell counts below 200 mean that the immune system is affected and that there is a likelihood of serious diseases.

Differences of opinion do exist, however, about whether treatment is urgently needed or whether it is still possible to wait when the CD4 values are between 300 and 500. Start early or wait and see – there are medical arguments for both of these approaches.

Reasons for starting therapy early (with CD4 values above 300)

- An early start can strengthen and support the body's natural defences (= immune system) in the first stage of the infection. Diseases then occur much more rarely.
- The medications available today probably have a greater chance of reducing and controlling the viral load if this value is still low at the start of therapy.
- In some cases, treating HIV early in the infection could prevent the virus establishing itself in cells and tissues that are difficult for medications to reach.
- Side effects occur more rarely when treatment is started early.



Reasons for delaying therapy (not until the CD4 value is below 300)

- The long-term benefits of early treatment have not been conclusively demonstrated. No long-term data are yet available.
- There are justified concerns surrounding the long-term side effects of HIV treatment. It is now known, for example, that certain drugs may be associated with an increased risk of lipid metabolism disorders, cardiovascular diseases and diabetes. If therapy is not yet necessary, it appears advisable to wait in view of the possible side effects.
- Therapy commenced at a later date is also effective.

It is now common practice to delay therapy unless serious diseases have made it necessary or the immune system is in poor condition.

Therapy immediately after HIV infection

If an HIV infection is discovered during the first few weeks after transmission, a different situation applies regarding HIV treatment. Under these circumstances, when signs of disease showing the presence of an acute infection occur, some experts recommend starting therapy. The purpose of this early treatment is to protect the immune defence cells directed against HIV. However, there is a lack of controlled studies demonstrating the benefits of this approach. (See also our comments on this subject in 'HIV-positive – what next?', p. 30. Order address p. 44)

Whatever the case, the most important thing is to determine the best time for each person to start HIV therapy. To avoid missing this time point, the development of the HIV infection – regardless of whether a person has decided for or against being treated – should be regularly monitored by medical tests and starting the treatment should be discussed with the HIV specialist.

HIV drug classes

Today, people with HIV can use a entire range of medications to fight the virus. The various active drugs (and drug classes) contained in these medications have different sites of action from which they attack the multiplication and the activity of the virus. They prevent the viruses either docking onto cells, penetrating into them or multiplying inside them. Usually, HIV therapy combines drugs from different medication classes.

If you would like detailed information about the way HIV treatment works, please consult the binder 'Leben mit HIV und Aids' (available in German and French), a reference work about principles, health screening and daily therapy. Order address p. 44, or online at www.aids.ch / Für HIV-Positive.

Or ask your doctor.

Here we will give you just a brief survey of the different drug classes to familiarise you with the most important terms.

Reverse transcriptase inhibitors (abbreviations: NRTI / NNRTI)

The virus needs the enzyme reverse transcriptase to translate its genetic material into a different form. (Enzymes are proteins which accelerate chemical reactions in the cell.) Only the genetic material translated in this manner causes the infected cell to increase the number of viruses.

Reverse transcriptase inhibitors intervene in different ways in this translation process. Accordingly, there are also two classes of these inhibitors: the nucleoside-like reverse transcriptase inhibitors (abbreviation: NRTI) and the non-nucleoside-like reverse transcriptase inhibitors (abbreviation: NNRTI). Both interrupt the translation process.

Protease inhibitors (abbreviation: PI)

During the multiplication of viruses, various proteins are produced. From these, new viruses are formed. The enzyme protease is necessary for this process. The protease inhibitors (abbreviation: PI) block the activity of this enzyme.

Entry inhibitors (abbreviation: EI)

These drugs prevent the virus entering the cell and thereby protect the cell against infection.

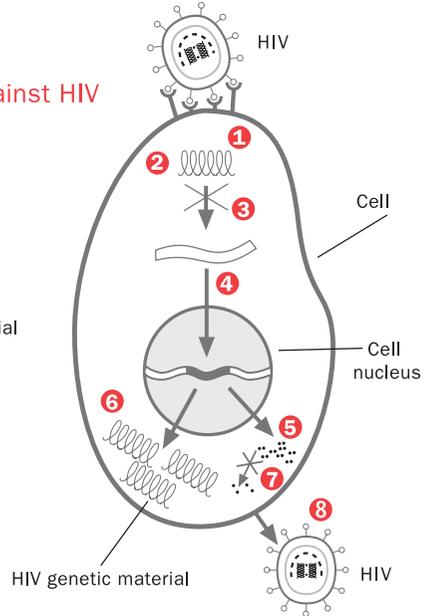


With the two types of reverse transcriptase inhibitors, protease inhibitors and entry inhibitors, four varieties or classes of drugs are therefore available for therapy.

At present about 20 different drugs are available to treat HIV. But they all work according to one of these four mechanisms. In therapy, three drugs belonging to two different drug classes are usually combined: for example two NRTI and one PI, or two NRTI and one NNRTI, etc. With this approach it should be possible to suppress the multiplication of the viruses after a few months.

How and where antiretroviral drugs work against HIV

- 1 Fusion: the virus locks itself in place (entry inhibitors can stop this)
- 2 The virus deposits its genetic material in the cell
- 3 The viral RNA is coded into DNA (reverse transcriptase inhibitors can stop this)
- 4 The viral DNA is integrated into the cell's genetic material
- 5 Proteins are produced
- 6 Viral RNA is produced
- 7 Proteins are assembled in the right order (protease inhibitors can stop this)
- 8 Viral particles are assembled into viruses and released from the host cell



What alternative medicine has to offer

I think it is important to consider all types of treatment options. Not when you are already in the midst of HIV treatment. You should consider all your options beforehand, especially alternative medicine.

Surveys show that many people with HIV in Switzerland use methods of alternative medicine. Dietary modification, homeopathy and plant extracts are the favourite choices. About half of HIV-positive people also undergo psychotherapy and make use of techniques of self-awareness.

Alternative medicine offers HIV-positive people a wide range of treatment methods. None of them, however, is capable of delaying the progress of HIV infection. Neither plant-based medicines nor diets, neither homeopathy nor traditional Chinese medicine can combat HIV as the cause of AIDS with proven efficacy. The benefits they provide derive from the fact that they supplement conventional medical treatments. This means that the resources of alternative medicine can strengthen the mind, maintain quality of life and alleviate some side effects of therapy.

Important: some alternative medical remedies (for example: St John's Wort) should not be taken with HIV medication due to the possibility of interactions. It is therefore essential for you to tell your doctor what alternative remedies you may be taking.

In the binder 'Leben mit HIV und Aids' (available in German and French) you will find detailed information about ten different kinds of alternative or complementary medicine and a chapter about psychotherapy. Order address p. 44. You can also find this information at www.aids.ch / Für HIV-Positive.

Important note: most health insurers (basic insurance) cover hardly any of the costs of alternative medical therapies.



Ready for HIV treatment?

It is important to come to terms with your own feelings, your fear, for example. What are you afraid of and what not? Sometimes the fear lessens when you face up to it.

Of course you can never be a hundred per cent certain that you have made the right decision, whether to start HIV treatment or not. But the biggest mistake of all is to just wriggle out of making any decision at all. We, my partner and I, discussed the matter for hours together.

Deciding for or against HIV treatment is not easy for many people. Ultimately, it is not just scientific and medical factors that are important. The decision affects you as a whole person, in your specific life situation, with your questions, fears, hopes and feelings.

Perhaps even more pressing issues overshadow the decision about treatment. The question of guilt, for example: 'I should have known better, I'm so ashamed or feel guilty.' Many HIV-positive people are familiar with these feelings linked to their HIV infection. HIV-positive people usually find an answer to them during the course of the infection.

Others struggle with their fate and ask themselves: 'Why did it have to be me?' Some search for a hidden meaning in the threat to their health.

It's worth paying attention to these feelings and taking them seriously.



Every person with HIV has to find their own way, accept the fact of being infected and integrate it into their life and self-image. There are no ready-made solutions and no predetermined answers. But this process of clarification can be useful as a means of dealing with the question of HIV treatment. It helps you define your position and come to terms with the infection step by step.

But perhaps the time is not yet right for you to address the question of HIV treatment. The important thing is for you not to allow the infection to progress untreated until it begins to pose a serious threat to your health. Regular check-ups are also important during this time.

Some people with HIV are so devastated by the threat to their health that they have no strength left and no longer see any point in being concerned about their well-being. 'HIV infection is incurable – what's the point of doing anything at all?' Please bear in mind that there are a variety of ways of treating the infection, and that thanks to today's treatments the life expectancy of people with HIV is much better than it used to be. There is a future worth living with HIV – countless people living with this infection experience this fact every day!

Attitudes towards treatment are often determined to some extent by the image one has of the infection. Perceiving the virus as an all-powerful, all-controlling enemy is an invitation to give up the fight without further effort. This can lead to loss of self-esteem. Don't give the virus so much importance and power. You – not the virus – have the power over your life.

Ideas and feelings about medication also play a major role in deciding whether to have therapy. Who would want to regularly swallow something they think is harmful? Finding a positive attitude towards the drugs is important. However, maintaining a positive and critical attitude at the same time is not a contradiction.



You're not alone!

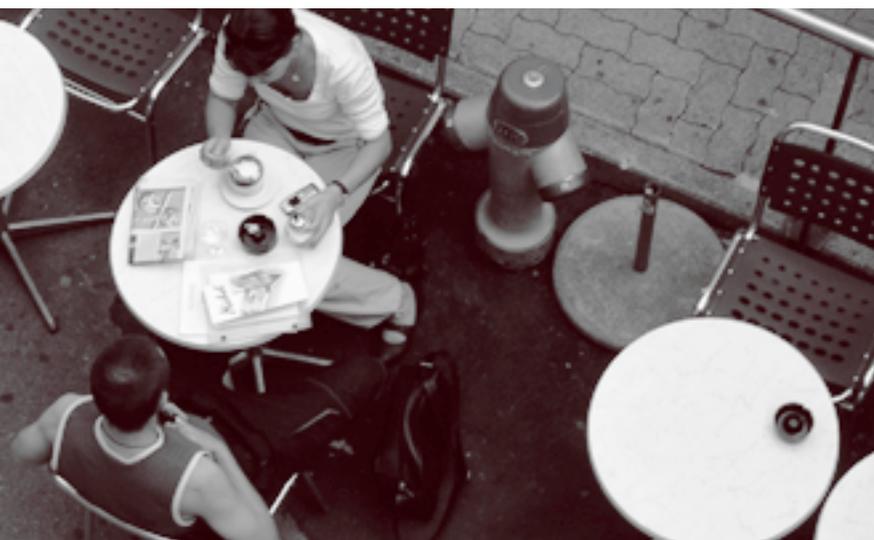
Among friends who also knew about my drug habit, there was no problem talking about the infection. And somehow there was always a good feeling, a sense of relief: I can trust them, they won't let me down.

What helped me was talking to the doctor.

It was very important for me to find someone I could talk to about everything. We support each other, discuss everything relating to HIV and the medication.

For me, the real experts are the people who actually have this condition. When it really comes down to deciding, I find it very helpful to talk to people who have already been through this experience themselves.

At the beginning of their infection, HIV-positive people often feel abandoned. In this situation it can be helpful to confide in people close to you or specialists (with regional AIDS service organisations, the hospital HIV clinic). Many of those affected also find it helpful to talk to other HIV-positive people (self-help groups, for example) and find out how others have coped with the difficult situation. The regional AIDS service organisations can establish suitable contacts.



Other people can support you in coming to terms with the infection and with the question of whether and when to start with treatment.

It is important for you to seek contact with specialists and other people. Do not be afraid to ask questions. Well informed and supported by other people, you will find it easier to decide what is best for you.

When approaching the question 'HIV treatment: yes or no?' it is also worth thinking about how you wish to make the decision. You can cooperate with your doctor in a form that suits your personal needs. Some people want to be informed in detail about the infection and its treatment as a basis for making their decision. Others prefer to leave the decision to the medical specialist. This person should then decide what steps are necessary. Another option is an open and frank discussion with specialist nurses at a hospital, not only during the course of HIV treatment, but also while you are still at the stage of considering whether a therapy is desirable or not.

Not only the medical aspects play an important role in making a decision. Your personal motivations, life circumstances and your fears must also be given equal priority. You are the expert in assessing your lifestyle and weighing up what you can and want to do.

Take the time you need. Do not be overhasty in deciding. Take advantage of the support offered by your private environment and healthcare professionals. And do not forget: you have the last word, after all it is your body and your life that are at stake.



Help for migrants

In Africa, the image of HIV is that you are either homosexual or a prostitute, or that you must have an alcohol problem. But none of that applied to me! This does not happen to people like me, or so I thought.

I thought I was the only African who has it. I thought that for a long time until I realised that I'm not alone.

Several thousand foreign nationals with HIV live in Switzerland. They face additional problems depending on their origin.

You have to try managing as an HIV-positive person in a foreign country and speaking a foreign language. For many people it is unusual to talk openly about HIV and sexuality; perhaps they feel that they are taboo subjects. Or they are worried about their family at home who could also be HIV-positive but have no access to medication. They are separated from their family, and getting their family members to join them is extremely difficult. Some have experienced racism and discrimination in their everyday life and this makes them afraid to talk about HIV.

If you experience such problems as a migrant, then it is important to know that help is close at hand! If you have any questions or are unsure about what to do, contact your regional AIDS support organisation, the AIDS clinic in hospitals or, regardless of your religion, churches (for addresses see pages 46/47). People who work in these institutions have experience with people living in a similar environment to yours and who are HIV-positive.



These specialists know that information about HIV is confidential. **The golden rule: No one is allowed to disclose your diagnosis without your consent.** Whatever you say at the AIDS support organisation, in the doctor's office or in a church remains confidential.

This confidentiality is also kept towards your partner, the aliens police, employees of asylum homes and your employer. Unless you give your consent to others being informed.

As a migrant you also have rights that protect you.

If you decide in favour of counselling, you have taken an important step forward.

It may be that further difficulties will arise. Perhaps you do not understand the language very well? Then inquire about the languages in which advice is offered. The larger hospitals with HIV treatment centres and regional offices of the Swiss AIDS federation can enlist the services of internal and external translators. Or you may be looking for a person in a position of trust who will translate for you. Someone from among your circle of acquaintances, from a relief organisation or independent, professional interpreters. It is important for you to make your concerns understood. Equally important is that you should understand exactly what is explained to you. Do not take for granted that someone will be provided to translate for you. Take the initiative and ask about it.

Perhaps you are unfamiliar with the foreign health care system and this unfamiliarity makes you feel insecure? The booklet 'Health Guide Switzerland' explains in 19 languages the most important things about the health system (order address p. 46). But do not hesitate to ask counsellors directly.

Important: Even without official papers, you must and can take out insurance against illness! Migration advice centres can explain to you how you should proceed.

Do not wait until health complaints occur. Seek assistance quickly. **Many HIV-positive people who speak a foreign tongue live in Switzerland and are successfully taking a combination therapy.** Do not miss this opportunity.



HIV treatment – yes or no?

For 30 years I rejected the idea of using chemical drugs and I was against HIV treatment for a long time. I took the view that I did not need it. And then the infection took such a rapid course that I did begin treatment.

I'm worth it. My life is worth it. I have something to offer society again.

Having to depend on the medications is hard for me to accept.

I never let the side effects hold me back.

I do not want to look on the dark side, but it is not as easy as is sometimes claimed today, when they say that side effects are not so much of a problem any more in the long term view. That is not the case for everyone.

As a human being I do not want to be reduced to laboratory values, even though they may be important. I am more than just CD4 cells and viral load.

I do not like suffering. That is motivation enough for me.

If you wait too long with starting therapy, then you can get other infections too, and they have to be treated with drugs as well. And so you have gained nothing.

It was really all about making this decision. For living or dying. And after a month I decided very definitely in favour of living.

I cost the health insurer an awful lot. It is not as if the costs do not matter to me.

That is another thing that motivated me to be on treatment at all: knowing that I can always stop if I really want to.

Should you say yes or no to HIV treatment? It is worthwhile taking a close look at its advantages and disadvantages. One well-proven method is to write down the advantages and disadvantages or your feelings about the subject and – if you wish – discuss them with someone who enjoys your confidence. The following table may be a help to you in this regard:

What are the advantages of the therapy?

What are the disadvantages of the therapy?

What advantages are there in not taking medications?

What disadvantages are there in not taking medications?

There are no clear-cut right or wrong answers to these questions.

This method can help you in making your decision.

But please remember that if your immune system is severely damaged, something should be done quickly, i.e. within a few weeks, to protect your health. In all other cases, there is usually sufficient time to ask oneself the questions.

If you or your partner have your own questions, just add them to the table. Take your time with writing down the answers. Sometimes it helps to wait a few days and then reconsider your answers.



As well as the medical facts, please also consider the emotional situation in which you currently find yourself. This can also influence the decision regarding treatment.

Perhaps you have just fallen in love and are enjoying time with your new partner. At last, a ray of light after a time full of uncertainties. Why should you spoil your new-found happiness with thoughts of medications and the infection? – Possibly this could be a reason to wait a while. But would not it also be reassuring to know that your health will remain stable in the long term thanks to treatment? And that the risk of HIV transmission, for example due to condom failure, is much smaller when you are on treatment?

Or a long-standing relationship on which you have firmly based your life breaks up. When a deep emotional bond comes to an end, it is a painful business for those involved. Often the basic question arises again. If it is all over anyway, what is the point of taking medication? – Please remember that stopping therapy jeopardises your health and can impose restrictions on your future life.

Are you exposed to particularly heavy demands in your occupation at the moment? Is your employment future uncertain? Are you planning to spend a lengthy period abroad?

There are **situations in your life which can fundamentally alter or influence your attitude to therapy**. Even when faced with such difficulties, it is important to keep a clear perspective and not to lose sight of the goal of leading a good life with HIV.



If you are already receiving HIV treatment, these or similar situations represent a renewed challenge. The point of being on treatment and the possibilities it offers may be called into question again. Do not make any overhasty decisions and be sure to discuss the situation with your doctor!

You decide in favour of the HIV treatment: If taken correctly and adjusted to your personal daily rhythm, treatment can dramatically improve the life expectancy and quality of life of HIV-positive people. The virus is no longer an all-determining factor. You are actively doing something for your health. You are supporting your immune system.

You decide against taking HIV treatment: Depending on the situation, there may be good reasons for deciding against taking HIV treatment. But it is still important for you to stay in touch with your doctor. Have your laboratory values checked at regular intervals and discuss the expected course of the disease with a healthcare professional so you do not miss the best time for beginning treatment later on. Because the decision against HIV treatment is usually a decision of limited duration.

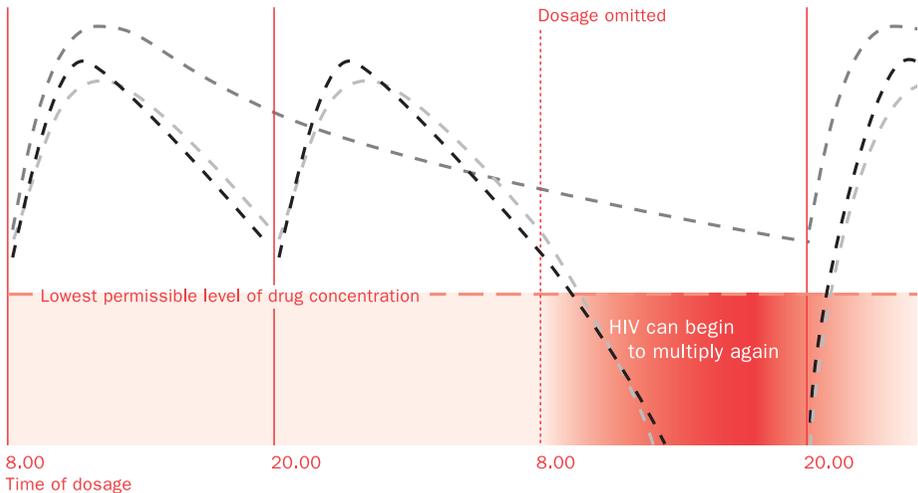


Sticking to the treatment

It takes a lot of discipline, but I have it. I have never yet missed a dose of my drugs.

I stick very faithfully to the treatment. It is simply important to know that the therapy is good, that it works. That makes you feel good, it motivates you.

Keeping closely to an established treatment schedule, also known as treatment compliance, is the key to effective HIV treatment. Especially in the first few weeks of therapy this is a very decisive factor. The medications only exert their desired effect if they are present in the blood continuously and in sufficient concentrations. The drug level must not fall below a certain value. Medications for the treatment of HIV therefore have to be taken at regular intervals, in the right dose and – depending on the medication – with or without meals. Every day, without exception. Tips and tricks for mastering this challenge can be found on page 34.



Course of drug levels in HIV treatment with three medications. Two of them are taken twice daily, one of them once daily. The example shows how the drug level of two medications falls below the minimum therapeutically effective concentration if a dose is left out. As a result, the entire combination is insufficiently effective.

In the treatment of HIV— unlike some other therapies — it is not enough to take the medications more or less as directed. Taking only half the drugs prescribed does not deliver half the effect, but actually does more harm than good.

The reason: If the drug level is too low, the viruses start multiplying again. As it multiplies, however, the virus keeps on making small errors; i.e. innumerable variations (or mutations) are produced. And suddenly there will be one mutation which is insensitive to HIV drugs (resistant). This variation can now multiply freely, even if you now continue taking your treatment exactly as directed. The therapy suppresses all the other viruses, but not this one, resistant variation.

Resistances are a problem because they can sometimes affect not only one drug but an entire class of drugs (see p. 9) (cross-resistance). This means that with one resistance you may end up missing out on an entire class of drugs. This greatly narrows the scope for a second effective course of treatment.

In fact, over time, resistances develop in a considerable percentage of patients and the therapy sometimes has to be changed.

The only preventive measure that can be taken against resistances is to consistently and constantly prevent the virus from multiplying on a large scale. And that means never letting the drug concentration fall below the required limit. And that is achieved by keeping closely to the treatment plan.

A good way of staying alert to possible difficulties with taking medication is to draw up a checklist (see next double page). This is a simple and fast way for you to get an overview of your lifestyle.



Checklist

You have to find out your own life rhythm. I think that is really important. You have to be aware when it is time to take your medication. It takes away a lot of the fear if you know you can adapt the therapy to suit your own life rhythm.

Answer the following questions for yourself. Make notes to prompt your memory and take your notes along with you to your next doctor's appointment. This will help you take your everyday living patterns suitably into account when making your treatment decision. **Probably you will also have other questions not included in the checklist. Consider the checklist as a useful foundation on which to build your own personal catalogue of questions.**

- Is my day rather regular or irregular?
- Do I live by the clock or rather spontaneously?
- Do I take regular and possibly scheduled breaks in my daily routine?
Or do I just take a break when I feel like it?
- Does the same apply to weekends?
- Do I find it easy or difficult to keep to scheduled times?
- Are there difficult phases during the course of the day in which I 'fall into a hole'? Does that tend to happen more in the morning, evening or at night?
- Do I find it easy to get to sleep again after I have been woken, or do I then stay lying awake for long periods?

- Can I breakfast immediately after getting up in the morning or do I need a little time before I can manage to eat anything?
- Do I take my meals at regular times or do I just eat when I feel hungry?
- Am I already taking other medications? If so: What is my experience with them so far?
- Do I consume recreational drugs such as alcohol, ecstasy, LSD, THC (pot, hashish) or heroin? If so: Do I take them rarely, occasionally or frequently? Can I decide myself when I do drugs or do I rather feel dependent?
- When talking to a doctor or another professional, do I find it easy to say what I honestly think, or do I find it difficult?
- Do I feel understood by a doctor or another professional when talking to them or do I rather have the feeling that I am not really 'getting the message across' as regards my thoughts and feelings?
- Have I enough people I can talk to about my situation and my decision regarding treatment, or do I lack people I can talk to in confidence?
- Am I ready to know about the advantages and disadvantages of medicinal therapy? If so, do I know enough or do I need more information?
- Am I aware of the possible side effects of the various treatment combinations I am considering, or do I still need to know more? Do I really want to know about all the possible side effects ahead of time?



Choosing your first HIV treatment

The best treatment combines maximum effectiveness with good tolerability. The treatment achieves these aims if it is in tune with your body and your life rhythm.

Life rhythm

With the aid of the checklist, you have already become aware of some aspects of your life rhythm: whether you have a regular daily routine or whether you are out and about a lot, about your eating habits and personal preferences.

Depending on how you organise your life, certain HIV drugs will be more suitable for you than others.

For example, if you are frequently out and about, it may be important to start a treatment that requires you to take the medication only once daily. You take the medication at a scheduled time and then forget about it. If you have a regular daily routine, you will find it easier to integrate a twice-daily dosage in your daily activities – which in turn has other advantages.

If you have difficulty keeping to scheduled times, it may be preferable for you to choose HIV drugs with a longer 'half-life'. This medication is metabolised more slowly by the body and thus remains for longer in sufficient concentrations in the blood. If you forget to take it at the usual time, this is less serious than when taking medications that have a shorter 'half-life'.

There is some scope when choosing the first therapy, although this may be more or less limited from case to case (see Resistances, p. 23).



Body weight

The standard dosage of medications is based on a person weighing about 70 kilograms. For someone who weighs considerably more or less, with some medication the dosage has to be adjusted accordingly. And with some medication, the drug level in the blood has to be checked at the start of treatment. Please do not forget to mention this to your doctor if the subject does not come up on its own.

Gender

Although there are (minor) differences between men and women as regards CD4 cell counts and viral load, it is known from studies that HIV treatment is approximately equally effective in both sexes.

There are some differences regarding side effects: for example, women develop skin rash more often than men when taking a certain medication.

Pregnancy

It is now possible for HIV-positive parents to fulfil their wish to have children if they meet certain requirements. As regards the possibility of becoming pregnant, however, HIV-positive women must be aware that – in order to protect the embryo – only certain HIV medications are approved for use during pregnancy.

For answers to specific questions, you should preferably consult the HIV treatment centres.

Diet

Certain HIV drugs may only be taken together with meals, others only on an empty stomach or with plenty of liquid. Depending on the medication, you should work out an appropriate schedule of meals.

It is important for your doctor to be familiar with your habits and plans. Only with this knowledge will it be possible to suggest a therapy for you that is ideally suited to your needs. You should therefore talk about your life rhythm, any recreational drugs you may be taking (see p. 39), whether you wish to have children and any other aspects that could influence the treatment.

Your doctor may also perform a resistance test to find out whether you have become infected with a virus that does not respond to certain drugs. This result could influence the choice of treatment.



What about side effects?

I was afraid that it would be the side effects that would really make me feel ill. But afterwards, when I had started the therapy, I found that things were different.

I deliberately stopped myself from looking up all the possible side effects. And anyway: statistics are statistics. Maybe I will be among the half that does not get this or that side effect.

It is important to know how to live with the drugs; but the side effects should be thoroughly explained as well.

Studies have shown that the fear of medication-related side effects is the reason that most often prevents HIV-positive people from starting HIV treatment. Treatment side effects are a problem to be taken seriously. There are cases in which side effects make it essential to discontinue a certain drug immediately and change the approach to treatment.

On the other hand, surveys have also shown that the fear of side effects is sometimes greater than the side effects themselves.

In many cases the side effects are tolerable even though, in some cases, they may be troublesome in the first few weeks. In the long term, however, no one would use a treatment causing severe side effects.



Side effects never occur to the same extent in everyone. The same medication may be very well tolerated by one person, while in someone else it may cause side effects that seriously affect one's daily life. If side effects occur, there are things that patients can learn or do to bring them under control. Since side effects show themselves in very different ways or may even not occur at all for many years, we cannot give any conclusive answers here but only provide general guidance.

In the initial phase after starting HIV treatment there are often so-called acute side effects; side effects that occur immediately and usually disappear again on their own after the first four to six weeks of treatment after the body has become used to the medication. The digestive system is particularly affected. Common symptoms are nausea, lower abdominal pain and diarrhoea.

Difficulties with digestion, nausea, loss of appetite

A balanced, healthy diet can greatly contribute to well-being. Experience has shown that diets which promise miracle cures, however, actually tend to be harmful. Certain diets lead to the risk of incorrect or inadequate nutrition. It is important to supply the body with sufficient amounts of all the substances it needs.

'Household remedies' are helpful for many digestive complaints. For diarrhoea, for example, crushed bananas, grated apples, black tea, oatmeal gruel, pretzel sticks. It is best to avoid alcohol, caffeine and nicotine, as well as high roughage foods. Be sure to drink enough! For persistent diarrhoea, nutritional supplements may be valuable which replace nutrient, mineral and vitamin losses.

An effective remedy for constipation is food with a high roughage content (muesli, whole-grain bread...), and lots of salad and vegetables. On the other hand, you should avoid eating chocolate. And for nausea, dry foods are better tolerated than others. Peppermint tea or peppermint sweets after meals are also helpful.

These are just a few tips. You probably know more, or if not, ask your doctor about them.



Alternative medical treatments are sometimes also effective against stomach and bowel complaints. It is important, however, that you should always keep your doctor informed about any remedies of this type you may be taking. Alternative medicines or non-prescription drugs can also have unwanted interactions with your HIV treatment!

And last but not least, there are also medications which are effective against nausea or diarrhoea.

Do not let yourself be discouraged by these initial difficulties. Have a talk with your doctor and bear in mind that these symptoms are only temporary. If they do not disappear, it is usually the time to change your course of treatment.

To be taken more seriously are possible long term effects that accompany the therapy, such as cardiovascular irregularities, elevated blood fats, disorders of fat tissue distribution (lipodystrophy) and diabetes. *Important:* side effects can be alleviated by suitable means and can be largely avoided by choosing the right medications.

Cardiovascular problems and smoking

Although the risk of cardiovascular problems occasionally increases with treatment, it does not do so to a serious extent. Much more important in this connection is smoking. Although it may not be easy, trying to quit can be really worthwhile. Look for a suitable form of assistance (counselling for example: telephone 0848 000 181 – then press number 1).



As regards cardiovascular complaints, good nutrition and sufficient exercise – sport and games – naturally play an important role.

If there are persistently increased **blood lipid or blood glucose values** that cannot be reduced despite sufficient exercise and suitable nutrition, additional medication can lower cholesterol and blood glucose.

For other side effects it may be helpful to plan the times at which you take your medication so that the side effects occur while you sleep and not while you are awake.

Sometimes the best solution is to switch treatment and use different medication. Whether and when a change in treatment would be beneficial has to be decided from case to case. *Important:* changing or discontinuing the treatment should never be done on your own initiative, but only after consulting your doctor.

This list shows you that you are not simply at the mercy of side effects. There are many ways of coping with this problem. If you have side effects, do not wait too long but seek informed advice and assistance. You know best which side effects should be treated and which you are likely to tolerate.

The fundamental goal is to find an HIV treatment which is effective for you personally, can be taken on a schedule acceptable to you and which you tolerate well! Today's HIV treatments are much better in terms of side effects than the treatments of the past.

Something you should know if you are worried about the side effects of HIV treatment: An untreated and progressive HIV infection leads to a large number of life-threatening complaints – from pneumonia through inflammations in the brain to tumours of the skin, etc. With successful HIV treatment, these complaints are prevented. In a nutshell: **Untreated HIV infection is the dangerous disease, not its medical treatment.**



Starting therapy: weighing the odds

At first I thought that when you take the tablets you feel ill. But that is absolutely wrong. In fact, you have the feeling that every day you can do something towards getting better.

With each pill I'm strengthening my immune system, as if I would go training daily to build up the strength of my muscles. Sometimes I have the impression that I'm living more healthily now than before.

I tell myself: I have an advantage over my friends in Africa. I have the medication and can talk to my doctor about things. Maybe there are differences in how Swiss women are treated, but it is not noticeable.

For a long time I was against having therapy. But then I realised that the combination of nature and chemistry is not so bad after all.



Many people feel unhappy about having to take medication. This is especially true for HIV treatment which – based on existing knowledge – has to be taken for the rest of your life. Questions arise: ‘Don’t the drugs do more harm than good?’ ‘What risks am I taking?’

Some patients may see taking medication as a defeat, ‘It means admitting that my body has failed in its fight against the virus’.

Taking medication can give rise to a feeling of being controlled from outside and dependent on others. The medication is a constant reminder that you can not live in quite as carefree a manner as before the infection.

But despite all these reservations: HIV treatment is a great chance and the only method that has been proven to help maintain health! It gives HIV-positive people the possibility to actively make a positive and valuable contribution to maintaining their health.

Studies have shown that a positive attitude towards HIV treatment can have a beneficial effect on the course of the infection. The vital energy that returns after the diseases have receded in response to treatment and the first physical proof that the medications are actually working naturally make it easier to adopt a positive attitude towards HIV treatment.

Someone who only takes medication reluctantly will probably not go on doing so for long. Saying yes to HIV drugs also means saying yes to lifelong medical treatment. This need not be seen as a defeat, in fact it can be a definite gain.

I’m actively doing something against my HIV infection.
I have deliberately decided in favour of it.
I know the advantages and the possible disadvantages.

Taking a positive attitude towards HIV treatment also has a positive effect on keeping to the treatment plan.



Tips and tricks for taking medication

Always take the medication immediately after getting dressed: This ritual is important for me so I do not forget anything.

I help myself by always eating a piece of chocolate after taking the medication. Even while taking them I concentrate on the taste of the chocolate. That is a great help for me and a kind of reward.

There are many tips and tricks that can help make it easier to take medication, some of them are based on the wealth of experience gathered by HIV-positive people who have been taking HIV drugs successfully for a long time.

Someone starting HIV treatment for the first time may perhaps find it hard to imagine how taking medication regularly could cause difficulties. It can be very useful to simulate the treatment schedule in a one-week 'trial run' with vitamin tablets or jelly babies, in other words pretending you are taking the therapy. This trial run shows where problems and hindrances occur in daily life or the opposite, when taking medication regularly causes no problems at all.

Many people find it helpful linking the times for taking their medication to some of their regular activities. This may be brushing their teeth in the morning and evening. Or reading the newspaper, locking the front door late in the evening, starting the computer, stopping work for the day or similar daily milestones. Every life has such recurring activities. It is important to identify and name them – and to closely consider whether they take place in the same way



on all seven days of the week. In this way, taking medication can be coordinated with the daily routine and the intake schedule followed more easily.

Another strategy consists in keeping a supply of medication in places where they are easy and convenient to take. The first daily ration, for example, beside the alarm clock, the coffee machine or the toothbrush.

It may be helpful to keep a reserve supply of medication at hand, for example at the workplace.

Counting the pills for each day of the week once weekly and placing the amounts for each dosing time in advance in pill boxes or containers may also make taking the medication easier. In this way, you can then always see if you have already taken a ration.

Calendars, either paper or electronic, offer a good way of keeping a medication diary and keeping track of what you have taken. Reminder notes placed in different spots may also be helpful.

Many hospitals, pharmacies and health insurers also offer their patients special services. For example a text message service that sends you a warning to remind you to take your medication. Inquire what type of support health care professionals can provide to enhance therapy compliance.

Memory aids have also proved successful. Be creative: there is no such thing as the right way of remembering – only one, the one that works for you.

Keeping closely and accurately to the treatment schedule is not always easy. Side effects can make life difficult and daily life has its fair share of unexpected events. If support from the people around you is lacking, motivation to continue taking your medication can soon evaporate and therapy compliance may be at risk.

The doctor-patient relationship is also an important factor: Look for healthcare professionals in whom you have trust. Together with them you can draw up a dosing schedule that suits your life habits better.

Very many people with HIV receiving successful treatment show that the demands of therapy compliance can be met. You will manage it too.



Forgot to take the medication?

Life is so interesting, you can not always be thinking about your medication.

Sometimes I'm just leaving the building and realise: Damn, I have forgotten my meds! How troublesome therapy can sometimes be! But so far I have always decided in favour of treatment.

Despite the best therapy compliance, it is only human and understandable to occasionally forget to take a dose of medication. This can happen easily, especially on weekends, or when you are off on vacation, going on a business trip, changing jobs or when a relationship is breaking up or just starting.

If you ever do forget to take a dose of medication, please follow these rules:

If you forget a dose of medication that has to be taken once daily – e.g. in the morning – you can make up for it by taking it later in the day.

But what to do with a medication that has to be taken twice daily if you realise you have forgotten the morning dose? Try to make up for the missed dose by taking it as soon as possible afterwards. If possible, also put off taking the next dose for a short while. If you were supposed to take the medication with a meal, however, take the dose with your next meal rather than putting it off until later.

What is the best course of action if you find you have to throw up after taking your drugs? If it happens within one hour after taking the medication, you should take the medication again because the body did not have sufficient time to absorb it completely. But if it does not happen until after an hour has passed, you do not need to take the medication again.

If you are in doubt, it is essential for you to ask your doctor or pharmacist because the effects can vary for different medications.

HIV treatment and my life

Thank heavens for the treatment. A real piece of luck in our misfortune, and one that allows us to live. Allows us to work and lead a balanced family life.

Today's methods of treatment have dramatically improved the quality of life of people with HIV over the last few years. Medium and long-term life perspectives remain possible. There is not only a life, but also a future with HIV.

Therapy and family planning

I did not know that you can have a healthy child. But they explained to me that it is possible with the treatment and a caesarean section. My son is completely healthy.

It is no longer impossible for couples with HIV to want to have children, whether the woman, the man or both are infected. Besides effective HIV treatment, there are also special techniques of assisted reproduction that help couples with HIV to fulfil their wish to have children without putting the health of either partner or child at risk. These techniques have been used successfully for years. If a couple with HIV decides to have a child, they should seek specialised counselling at a hospital. Here they are also supported and accompanied during pregnancy and childbirth. *Important:* determine beforehand what services your health insurer will reimburse.

HIV Treatment and sexuality

A successful treatment drastically reduces the viral load. A low viral load, however, not only shows that the treatment is working and that your immune system can recover. A very low viral load also has an influence on how infectious you are, i.e. how great the risk is of you passing on the virus to a partner, for example in the event of condom failure. With a viral load below the limit of detection (see p. 40) this risk is very much smaller than with a high viral load. Nevertheless, you should still continue using condoms, especially for casual sexual contacts.



HIV treatment and travel

For many people, travel is part of leading a fulfilled life. Meeting new people, visiting friends, cultivating relationships, all these can be things of great value in peoples' lives. With effective HIV treatment, travel is no longer a problem for HIV-positive people in good health.

But please remember that certain countries have special entry requirements. Before every journey, make sure whether you as an HIV-positive person are allowed to enter the country – for example, HIV-positive persons are officially not allowed to enter the USA. The easiest course of action is to inquire at the diplomatic representations of the various countries about what entry regulations are currently in force. Or get information from the relevant consulates on the Internet.

Every journey should be well planned, together with your doctor – especially if you need certain vaccinations for your chosen destination (see www.safe-travel.ch). You should also make sure that you have packed a sufficient supply of medication for the total duration of the journey. Make arrangements to ensure that you can also take the medication regularly during your journey. (Assistance is also offered in the leaflet 'Reisen mit HIV' [available in German and French], obtainable from the Swiss AIDS Federation, order address p. 44.)



HIV treatment and other medication

People receiving HIV treatment – just like everyone else – sometimes become ill and have to take other medications in addition to their HIV medication. When taking other medication there is always a risk of interactions between them which could favourably or unfavourably influence the active drug concentration. It is therefore important for you to discuss this aspect with your doctor. It is recommended to keep the user information leaflets of all your medications and take them with you to your doctor's appointment. As already mentioned, this also applies to 'harmless', non-prescription drugs such as St John's Wort for depression or other medications like antihistamines (e.g. for asthma or allergies) and medicines to treat hyperacidity of the stomach.

HIV treatment and recreational drugs/substitution medications

Several thousand people with HIV in Switzerland have become infected during the intravenous use of recreational drugs; many of them continue to use these substances or are undergoing substitution therapy (methadone). A large number of former or existing illicit drug users with HIV are also suffering additionally from chronic infection with the hepatitis C virus. If you also use recreational drugs – whether on a regular basis or only occasionally – it is very important for you to tell your doctor about it: the use of illicit drugs or substitution drugs and hepatitis infection and its treatment must be taken into account when establishing your HIV treatment plan. Some of the medications used to treat HIV, for example, influence the effect of methadone; depending on the treatment course chosen, a different, usually higher dose of methadone may have to be given. Moreover, when simultaneously treating hepatitis infection and an HIV infection it is important to consider the possible interactions very closely.

Effective and well tolerated treatment of HIV infection is also possible for illicit drug users. But this demands specialised knowledge. It is therefore advisable to contact a specialist in this situation.



First shot – best shot!

Your first HIV treatment is your best chance of preventing the virus from multiplying over the long term and guaranteeing lasting success. Because in this first treatment you can be treated with any of the available HIV drugs – unless you are infected with a resistant virus and your therapy has to be adjusted accordingly. An effective, well tolerated and correctly used first treatment can prevent the virus developing resistances to medication.

How do you know if the treatment is effective? The success of treatment can be measured from the viral load. This value is therefore checked one month after starting therapy and every three months throughout the treatment programme. If the medication is working, the viral load should already have decreased significantly four to six weeks after starting treatment. Depending on the pre-treatment viral load, after three to six months the viral load falls below the limit of detection of the most sensitive tests (which is currently about 50 viruses per millilitre of blood plasma) – always presuming that you are taking the medication in the prescribed dosage and at the scheduled times and they are having the anticipated effects.

Correspondingly, the number of CD4 cells will slowly increase. This value is also checked at regular intervals, i.e. every three months.



Even under the most favourable conditions it can happen that unforeseen events in your life may cause your discipline to weaken. This need not always be side effects. Stressful life situations can throw people off course – this also applies for HIV-positive people who were highly motivated when they began treatment.

It is only natural and fully understandable that under such circumstances there is a wish to leave out the medication, to live daily life again without the burden of medical treatment – or perhaps only to reduce the dose.

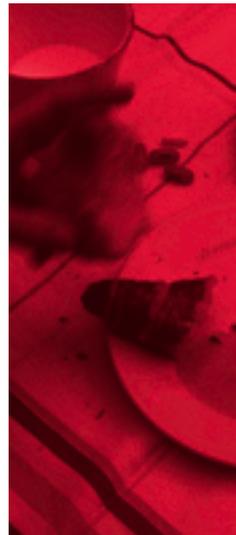
Before you decide to take such a step, it is essential that you should inform your doctor or other healthcare professional. Try to talk as openly as possible about your attitude to the treatment or any difficulties you are having. Usually, it is possible to work out some good solutions together. Take advantage of your first and best shot!

If you insist on discontinuing HIV treatment, your doctor can explain to you how you should proceed to avoid unwanted consequences of this decision as far as possible. In such cases it is important to stop taking all HIV medications. To allow the effectiveness of the treatment to be checked later on, whenever treatment is terminated or interrupted it is desirable to check the HIV viral load or to freeze a blood sample for later testing.

Why this precaution? As you know, only complete adherence to the treatment programme can keep the active drug levels in the blood high enough to prevent the viruses from multiplying. This protects your immune system adequately and can prevent resistant viruses from developing.

Important: Inadequately practised therapy is more hazardous in this respect than no therapy at all! Reducing the dose without first seeking medical advice can have worse consequences than stopping the therapy completely.

Maybe after a pause you will recover the motivation to start the therapy again. New studies have shown that regularly making pauses in the course of treatment is not medically advantageous.



More chances down the road!

At some point I was told that this drug was my last chance. But there is always another new 'last chance'.

It sometimes happens that even the best HIV treatment fails. In about one fifth of patients whose treatment is initially effective, the viral load starts increasing again, or cannot even be reduced to below the limit of detection in the first place.

Many HIV-positive people are understandably very concerned that if the first therapy fails they will have no further chances. This is not the case. There are more chances down the road because it is possible to continue treatment with other medication.

There are several possibilities:

- Current treatment can – for example because of resistances or side effects – be switched to a different course of treatment which is more effective or better tolerated.
- The number of medications can be increased to bring the virus under control again.
- People for whom these two strategies are no longer possible may benefit from new medications which, although not yet officially approved, can already be administered in clinical trials.

Even if the first therapy fails, nothing is lost yet. It is important, however, to approach the individual treatment opportunities with the right attitude and use them exactly as instructed, because the number of new chances is not unlimited!

Tip: It may be helpful to keep a personal treatment diary in which you record the CD4 value, the viral load, the results of resistance tests, medications already used, side effects and allergies. Your doctor will of course also enter this information in your medical record. But if you are personally well informed, you will be able to competently discuss with your doctor any required changes in the therapy on the basis of your personal experience.

A final note

We hope this booklet has given you a good overview of the important topics that are relevant for deciding for or against HIV treatment. The booklet cannot give any specific recommendations, and that is not its purpose. But if it has made you aware of some important aspects and questions, then it has fulfilled some important aims.

The booklet also shows that HIV-positive people facing decisions regarding treatment have a great responsibility. Deciding for or against HIV treatment isn't easy. It is necessary to consider a large number of questions, a lot of information and impressions and weigh them all against each other. And ultimately, the decision is yours alone to make. No one can relieve you of this responsibility: not your doctor, nor your specialised nurses, nor your family or your friends.

But there is also much to be gained from making this decision. With HIV treatment, you are doing something for your health because you yourself consider it worthwhile. And if, after talking to your doctor, you decide that HIV treatment is not yet necessary at the present time, then that is your decision. By regularly monitoring the course of the infection you assume responsibility for maintaining your health.

It is essential to deal openly and confidently with this subject. Even though this may not always be easy.

And a very final note: If you have any suggestions for improving our booklet – please let us know. We will be pleased to hear your comments.



Further information

In addition to this booklet there are other information publications dealing with the different aspects of living with HIV.

Order address

Swiss AIDS Federation, P.O. Box 1118, 8031 Zurich

Telephone +41(0)44 447 11 13, fax +41(0)44 447 11 14

shop@aids.ch; www.shop.aids.ch (here you can find all our publications online)

All requested materials will be sent to you under plain cover. This means that the contents of the mailing is not apparent from the wrapper and the sender (Swiss AIDS Federation) is not shown.

Further booklets from this series for HIV-positive people (all free of charge)

Available in English

'HIV-positive – what next?' – addresses all questions relating to HIV infection – medicine, law, occupation, relationship, etc. – and provides initial answers. It is a basic guide for people who have recently been informed of their infection. (48 pages, also available in German, French, Italian, Spanish and Portuguese)

Other titles available only in German, French and Italian

'Beziehung & Sexualität' – addresses the various questions and problems arising regarding relationships and sexuality and provides reliable information as a basis for taking your own decisions. (48 pages)

'Datenschutz – Schutz der Privatsphäre' – shows the legal regulations for handling information about your personal identity and diagnosis, and explains the rights and options you have for protecting your privacy. (32 pages)

'Recht haben – Recht bekommen' – explains what steps are necessary in the procedural jungle to ensure that you really obtain your rights. (32 pages)

'Job und HIV' – a compilation of all the important information you need in your working world and when looking for employment (48 pages)

**More detailed medical and legal information
(available in German and French)**

‘Leben mit HIV und Aids’ – Detailed binder with the chapters ‘Principles’, ‘Medicinal treatment of HIV’, ‘New approaches to combating HIV’, ‘Treatment of acute diseases’, ‘Special aspects’ (including HIV in children, HIV in women), ‘Methods of complementary medicine’, ‘Psychological and psychotherapeutic treatment’, ‘HIV/AIDS and law in Switzerland’.

About 300 pages, 80 Swiss francs – price reduction possible by arrangement.

‘Swiss AIDS News’ – Bi-monthly journal with new information from the areas medicine, law and society. Annual subscription 40 Swiss francs – price reduction possible by arrangement.

Guide to the Health Care System in Switzerland

(available in 19 languages – German, French, Italian, English, Spanish, Portuguese, Albanian, Arabic, Bosnian, Farsi, Croatian, Russian, Serbian, Somali, Tamil, Thai, Turkish, Urdu, Vietnamese)

‘Health Guide Switzerland’, Published by: Swiss Federal Office of Public Health, Swiss Red Cross, Caritas Switzerland.

Useful Internet Sites

www.aids.ch – Homepage of the Swiss AIDS Federation (German, French, Italian, English). Here you will find all the information online.

www.bag.admin.ch/aids – Homepage of the AIDS Section of the Swiss Federal Office of Public Health. Here you will also find epidemiological data (German, French, Italian, English).

www.workpositive.ch – Job exchange of the Swiss AIDS Federation: Acts as an agency between HIV-positive people looking for employment and employers who recruit HIV-positive people. (German/French)

www.chat.aids.ch – Forum and discussion page of the Swiss AIDS Federation (German/French)

www.aegis.com – Independent site with a wide range of detailed information

www.aidsmap.com – Site of an NGO network in the United Kingdom with current information

www.infekt.ch – The German-language site of the Infectious Diseases Department of Saint Gall Cantonal Hospital with useful, up-to-date articles on HIV (click on ‘Infectious diseases’ and then on ‘HIV’) Responsible: Prof. P. Verazza, MD



Useful addresses

Employees of all the institutions and organisations listed below are bound by a professional duty to preserve their clients' confidentiality. They are not allowed to disclose your personal information – even to public authorities and departments.

Information about the following and other addresses

Swiss AIDS Federation, Telephone 044 447 11 11
aids@aids.ch, www.aids.ch

Emergency outreach service 24/7

Dargebotene Hand [The Outstretched Hand], Telephone 143

Regional AIDS service organisations

Regional AIDS service organisations as recognised specialist agencies can be found in almost all the Swiss Cantons. They offer

- information about physicians in the region who have experience supporting HIV-positive people;
- individual counselling (e.g. about treatment decisions, sexuality, etc.);
- long-term support (if required);
- Information and advice about other services offered in the region;
 - Discussion groups and meetings of HIV-positive people
 - Suitable psychotherapists
 - Organisations of/for migrants, etc.

If you prefer, you can take advantage of these offers anonymously – i.e. without ever giving your name. Your particulars will be treated confidentially. The AIDS service organisations are not allowed to inform any governmental or non-governmental departments.

You can find their addresses in the telephone book, on the Internet under www.aids.ch or can inquire about them at the Swiss AIDS Federation under 044 447 11 11.

HIV treatment centres in Switzerland

Aarau: HIV-Sprechstunde, Ambulatorium Medizin, Haus 7, Kantonsspital, 5000 Aarau Tel. 062 838 68 12

Baden: Sprechstunde für Infektionskrankheiten, Kantonsspital, 5404 Baden Tel. 056 486 25 84

Basel: Medizinische Poliklinik, Universitätsspital, 4031 Basel Tel. 061 265 50 05

Bern: HIV-Sprechstunde, Klinik + Poliklinik für Infektiologie, Inselspital, 3010 Bern Tel. 031 632 25 25

Geneva: Division des maladies infectieuses, HCUG, 1211 Genève	Tél. 022 372 96 17
Lausanne: Division des maladies infectieuses, CHUV, 1011 Lausanne	Tél. 021 314 10 23
Lugano: Servizio malattia infettiva, Ospedale Civico, 6900 Lugano	Tel. 091 811 60 21
Sion: Institut Central des Hôpitaux Valaisans, Consultation de maladies infectieuses, 1950 Sion	Tel. 027/603 47 80
Saint Gall: Infektiologische Sprechstunde, Kantonsspital, 9007 St. Gallen	Tel. 071 494 10 28
Zurich: Abteilung Infektionskrankheiten und Spitalhygiene, Universitätsspital, 8091 Zürich	Tel. 044 255 33 22
Zurich: Zentrum für Infektionskrankheiten, Klinik im Park, 8038 Zürich	Tel. 044 209 20 60

Legal advice

Swiss AIDS Federation, Monday mornings, Tuesday and Thursday – telephone 044 447 11 11

Advice from lawyers and other persons qualified to give advice on legal matters relating to HIV/AIDS.

Information about organisations for sub-Saharan migrants

Berne Canton – Multicolore Project of AIDS-Hilfe Bern, telephone 031 390 36 36.

Geneva, Vaud and Zurich Cantons – Afrimedia Project, in close cooperation with the corresponding regional AIDS service organisations. Coordination: telephone 044 447 11 11.

In all other cantons, please contact the local AIDS service organisation for further information.

Organisation of HIV-positive African Women

ASFAG Association Solidarité Femmes Africaines de Genève
20, rue du Clos, 1207 Genève, telephone 022 786 00 76; www.asfag.org
The women at ASFAG also advise HIV-positive men from Africa on request.

Suitable interpreters

You can find suitable interpreters on the Internet at www.eka-cfe.ch/d/Doku/vermittlungstellen.pdf, or inquire at the local AIDS service organisation.

There are many other services on offer besides those listed here: Church offices for AIDS, advice centres for AIDS and children, organisations in the substance abuse field, for homo- and bisexual people, for sex workers, etc. Your local AIDS service organisation or the Swiss AIDS Federation can provide you with all the useful addresses. You can also find some of them under the heading 'Addresses' at www.aids.ch.



Today things are different compared to 12 years ago. Then I used to think: I hope I will still live to be 50. My priority was living as well as possible for the few years I still had left. Now, thanks to HIV treatment, all that has changed.

Before, my life just revolved completely around the medication. Now I say, it's Smarties time again, they've got really nice colours, haven't they? I'm trying to treat it all with humour.

Swiss AIDS Federation, Konradstrasse 20, P.O. Box 1118, 8031 Zurich

For orders: telephone 044 447 11 13, fax 044 447 11 14

shop@aids.ch, www.shop.aids.ch

For further information: telephone 044 447 11 11, fax 044 447 11 12

aids@aids.ch, www.aids.ch

Donations account: Swiss AIDS Federation, Zurich, 80-23678-6



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