

**Living with HIV**

Ready for  
therapy?

## Dear Reader

Being diagnosed with HIV is extremely unsettling. Suddenly, you are placed in a whole new situation. You may find yourself thinking about illness, death and pain. At the same time, you're facing urgent questions. What happens now? What are my chances? What are my options?

Let me give you an initial answer from the medical perspective right now: with today's HIV drugs, the chances are very high that you will live a long and healthy life. Thanks to HIV drugs, HIV is no longer terminal. Instead, it is a chronic disease comparable to diabetes, or high blood pressure.

That said, HIV therapy is demanding. It requires not only good medical support, but also personal discipline. At the beginning, it will feel like you've strayed into a medical jungle, but you will learn to find your way through it, just as you will learn to build your medication into your everyday life.

You will face challenging situations time and again. Even the question of when is the best time for you to begin therapy can be difficult. For many patients, however, the side-effects are the biggest worry. Side-effects can happen, but nowadays there are effective ways of dealing with them. The most important thing is to tell your doctor that you are experiencing them, so that they can adjust your treatment if necessary.

In addition to important information on HIV therapy, this booklet also gives you a whole range of tips on what you can do for yourself to support the success of your therapy programme – and how you can make sure that you get medical care that is tailored to you personally.



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A stylized, handwritten signature in black ink, consisting of a large, flowing 'J' followed by a horizontal line and a small dot.

**Dr. Jan Fehr**

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13 questions,  
13 answers

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## Why have HIV therapy?

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HIV is a virus that multiplies in the body and destroys its immune defences. It is able to do this unnoticed for a long time. From a certain point onwards, however, the body's defences are so weak that it can no longer fend off illness. That's when even harmless infections such as the common cold become dangerous. Once it has progressed this far, the virus is known as AIDS. Sooner or later, the person will die. HIV therapy can prevent things getting to this stage.



### Technical terms «ART»

HIV therapy is often known as ART for short. ART is the acronym for antiretroviral therapy: «antiretroviral» because HIV is one of a group of so-called retro-viruses.

You may also hear or see the term HAART. This stands for highly active antiretroviral therapy. ART and HAART refer to the same thing.

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## What does HIV therapy do?

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HIV drugs stop the virus spreading, so the amount of it present in the body falls. Once the virus can no longer be detected in the blood, the body's immune defences begin to recover. HIV therapy therefore allows you to live a long and healthy life. Many patients on HIV therapy even have so little of the virus in their body that they can no longer pass on HIV during sex – as long as they do not have any other sexually transmitted diseases. What's more, HIV therapy means that you can conceive and carry children, without passing the virus on to them.

### Technical terms

There are two important figures that show how far the HIV infection has progressed, and how much the immune system has been weakened. Both can be measured with a blood test.



#### «Viral load»

The viral load is the amount of HIV in a millilitre of blood.

#### «CD4 count»

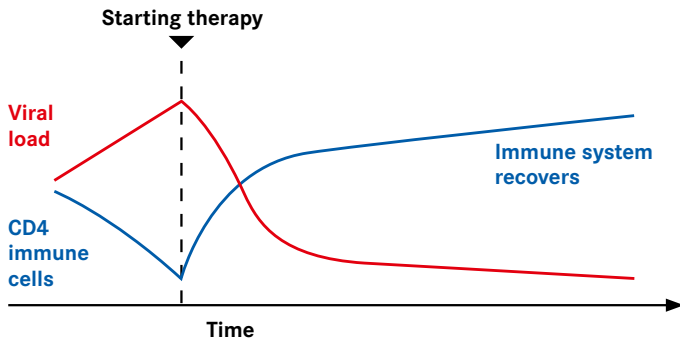
CD4 helper cells are immune cells that are responsible for the body's own defence against infection. HIV replicates primarily in these CD4 immune cells. In replicating, the virus destroys the cell, so that you have fewer and fewer CD4 immune cells in your bloodstream. The CD4 count gives the number of CD4 immune cells per microlitre of blood.

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## Is HIV therapy a cure?

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No. Unfortunately, it is not possible for therapy to cure HIV. It cannot remove the virus from the body completely. HIV drugs only continue to have an effect for as long as you take them. If you stop, HIV will begin to spread again. Controlled by drugs, an HIV infection is a chronic condition.



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## When should I start HIV therapy?

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There is no single answer to that. Most patients are able to choose a suitable time for themselves. You should, however, start taking the drugs before HIV has done too much damage to your immune defences. That is why doctors do regular blood tests – so that they can see in good time if the immune system is weakening. Many patients start therapy before this point for other reasons: because they want to stop being infectious if they have unprotected sex, or because they want to conceive and carry children without passing HIV on to the child.

### Technical term «CD4 threshold»

There are medical recommendations about the latest point at which you should start HIV therapy to avoid serious problems. This point comes when the number of CD4 immune cells per microlitre of blood falls below a certain level (see box above: CD4 count). Doctors work on the basis of this recommendation.



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## Does HIV therapy always work?

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Chosen properly, HIV therapy always works. You can tell that therapy is effective when the virus can no longer be detected in the blood. In some cases, however, the body's immune system will not recover completely, or will recover only very slowly. There may be two reasons for this: first, the patient was too late in beginning HIV therapy. Second, the level of drugs in the blood may be too low for a while, because they are not being taken properly, or regularly, for example.

### **Technical term «adherence»**

**«Adherence» describes the extent to which the patient is actually taking their HIV drugs in accordance with their doctor's recommendations. Good adherence means that they are taking the right quantity of the right drugs at the right time. This is crucial to HIV therapy, because the patient may otherwise develop resistance to the drugs (see next box, page 9).**



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## Are there any side effects to HIV therapy?

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As with all drugs, there may be side effects. Some people will not experience any at all, while others will have several at once. Some side effects occur mainly at the beginning of therapy, and stop after a time. The most common are headaches, nausea, diarrhoea and fatigue. These side effects aren't something that you just have to put up with – it's important to talk to your doctor about them. If necessary, they may be able to prescribe other HIV drugs.

A small number of long-term side effects are also possible. The main ones are osteoporosis (decrease in bone density), and impaired kidney function. Regular medical check-ups are an important part of HIV therapy to detect these problems at an early stage. It also goes without saying that you should tell your doctor if you notice something yourself.



**«HIV therapy isn't just about taking drugs.  
It affects all areas of your life.  
I had to change my diet, for example,  
because of the way my stomach reacted.»**

**Peter, 45,  
workshop employee**

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### **Is it a big problem if I forget to take the drugs?**

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It can happen – you forget to take your medication. If it's only rarely, you will be OK. The problems start if you often forget to take your HIV drugs. You will have the medication in your bloodstream, but not enough. This allows the virus to fight the drugs, and it starts to mutate so that, in the end, the drugs no longer work. This means you will have to change your HIV medication. If that happens several times, you may find that none of the drugs works any more, which lets the virus spread unchecked.



#### **Technical term «resistance»**

**Resistance is when HIV mutates so that certain HIV drugs are no longer effective. Resistance can happen if HIV therapy isn't taken according to the treatment plan.**

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## Are there different ways of treating HIV?

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At present, drug-based HIV therapy is the only way of stopping HIV replicating in the bloodstream. However, the overall therapy consists of a mix of different drugs, each of which works at different points to stop new viruses forming. There are now more than twenty drugs to combat HIV, and a whole variety of different combinations. As a rule, HIV therapy will consist of three different HIV drugs, as this is the safest and most effective way of tackling the virus. However, some drugs can only be combined with certain others.

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## What about complementary medicine?

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So far, alternative or complementary medicine has not been able to offer any effective therapy for HIV. That said, this form of medicine (such as acupuncture, or homeopathy) is often used to treat side effects and other symptoms, or to build up the body's own defences. If you want to take homeopathic remedies alongside your HIV drugs, it is essential that you discuss your plans with your doctor, because these remedies affect how the HIV drugs work in the body.

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## Where can I get treatment for HIV?

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Many larger hospitals have specialists in HIV, but there are also general practitioners who have chosen to focus on this field. To get the best HIV therapy for you, it makes sense to work with an expert. You can be referred by your GP, or you can go to a specialist independently. The regional AIDS support organisations will be happy to help (addresses on page 25).

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### **What does HIV therapy involve, apart from drugs?**

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When you start HIV therapy, you will have to go for check-ups with your doctor every couple of weeks at first. They will do a variety of tests to check that the drugs are working properly, and that your body is tolerating them well. For most patients, this is a relatively short phase lasting a few weeks. After that, you will generally have check-ups two to four times a year. Your viral load and CD4 count will be monitored on a regular basis (see box on page 6).

Outside of these regular check-ups, you should go to a doctor if you have any other problems with your health, or if you are planning a major event such as travel, sporting competitions or similar.

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### **What does HIV therapy cost?**

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The costs of HIV therapy are covered by compulsory health insurance. Everyone in Switzerland can (and must) take out this compulsory health insurance, even if they don't have a residence permit. In addition to their health insurance premiums, patients will pay the health insurance deductible and co-payment. If you have difficulty paying your premiums, contact social services where you live or at the hospital, or your local AIDS support organisation.

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### **How long does HIV therapy last?**

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Once you have started therapy, you must get used to the fact that you will be taking the drugs for a long time. As we've said: once you stop therapy, the virus will start spreading again. However, there may be times in your life when you decide to take a break from therapy, even if that doesn't make sense from the medical viewpoint. If you find yourself in such a situation, it is vital that you discuss your decision with your doctor.

You are the  
top priority

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## YOU ARE THE TOP PRIORITY

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### It's your decision

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Medically, it's very clear: HIV therapy enables people with HIV to live a normal life. By contrast, if you have HIV and aren't being treated, sooner or later you will develop a life-threatening disease. The decision about when to start therapy is ultimately yours.

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### HIV therapy is personal

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HIV therapy must be tailored precisely to the needs of each individual patient. Not everyone tolerates the drugs as well as others. And people have different daily routines. Some people prefer to take their medication in the morning, others in the evening. You'll get the best HIV therapy for you if you talk to your doctor openly about your needs and the structure of your daily life.

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### The success of HIV therapy is mainly up to you

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Once you have started, you should stick strictly to your HIV therapy schedule, otherwise the drugs will stop working. Your doctor might work with you to put together the very best HIV therapy, but it's up to you to take the drugs on a daily basis. If you find that difficult, there are plenty of practical things you can do to help. It's worth talking to your doctor or a healthcare professional about it. Many of them will be familiar with similar problems in other patients, and will be able to give you good advice.



**«I'm not always the most punctual or reliable of people. I found it difficult to take the drugs regularly, but I manage fine now thanks to the alarm I set on my phone.»**

**Andrea, 38,  
graphic designer**

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## TAKE CARE OF YOURSELF

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### Know your own needs

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A whole new phase of life begins when you have been diagnosed with HIV. You may not know right away how you will meet all the challenges that lie ahead. Sometimes, it can be difficult to know what you need. For example, many people want to be as open as possible about their infection, but still want to stop the news that they are HIV-positive reaching their workplace. You may be all about iron discipline one minute, but also want to continue living a relaxed sort of life the next.

There are no right or wrong answers here, but it is important to get to know your own needs. Once you do, you can work with your doctor and other experts to find the best solution for a therapy programme that is tailored to you personally. And if there are things you aren't sure of, or you feel that your needs are changing, don't be afraid to talk about it with your doctor.

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## Get support and take care of yourself

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HIV therapy takes up a lot of energy. In this situation, it helps to have someone you can trust and who can support you. It also makes sense to review important things like health insurance carefully, and to get everything in order. Experts at a regional AIDS support organisation are also on hand to provide advice if you need it.

Of course, it is also worth taking care of your body. This doesn't mean taking things to extremes – you don't have to become a great sportsman or woman, or a health fanatic – but it does make sense to look after yourself. That might mean that you give up smoking, take more exercise, or eat a more balanced diet. Your doctor will be able to help you here. What's more, your health insurance company may pay for a range of measures, to help you give up cigarettes or learn to relax, for example. You will generally need a prescription from your doctor for these things.



**«When someone comes to us at the hospital,  
they get all the medical information they need.  
But when deciding on therapy, it helps to  
talk to others who are HIV-positive, to understand  
that you can have a good life on therapy.»**

**Johannes, 54,  
study nurse**

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## Recognize the dangers early

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When HIV patients experience difficulties with therapy, it's generally the same problems that are to blame. There are a number of obstacles that might mean that drugs are no longer being taken properly – if at all. This can be avoided if the problems are recognized early on. The main ones are:

### **Poor mental health**

People with HIV tend to feel down, sad, or hopeless more often than those who do not have a chronic disease. When these feelings go on for a long time, you have no energy for everyday things. You lose motivation to follow your therapy programme, and stop taking care of yourself. In a situation like this it's important to get help in good time, whether it's professional psychotherapy, or just talking to others who are HIV-positive.

You should talk to your doctor if you

- have been feeling down, hopeless or depressed for several weeks
- have had no interest or enjoyment in life for several weeks
- have suicidal thoughts.

Your doctor will certainly be able to help, and can either refer you to a specialist, or put you in touch with organizations for those living with HIV.



**«You learn to listen to your body. I notice very fine changes such as signs of fatigue and the like. They're things you can feel, and give you a measure of your own health.»**

**Fabian, 42,  
computer scientist**

### **Excessive drug and alcohol consumption**

Taking drugs and drinking can have a negative effect on HIV therapy if it means that you're always missing doses, or not taking your drugs properly. They also weaken your immune system. Drinking and drugs are seen as a problem if

- you drink very large amounts several times a month
- or every couple of weeks you can't remember what happened the night before
- or other people (friends, professionals) try to talk to you about your excessive alcohol consumption more than once a year.

If this is the case, go to your doctor or to an alcohol advisory service in your region ([www.suchtindex.ch](http://www.suchtindex.ch)). They can advise you and help you to reduce your alcohol consumption.

### **Forgetfulness**

Being HIV-positive can affect the way your brain works. Often, it's a long time before you notice anything, but there are certain signs that you should tell your doctor about. They will then investigate whether medical intervention is necessary. Tell your doctor if you

- have trouble concentrating on daily tasks
- get the feeling that your thinking has slowed down
- are having problems with your memory.

How do you  
feel about  
HIV therapy?

**I want to start right away**

If you want to start HIV therapy now, it is certainly the right time. You can never begin too soon. Find out all you can about therapy. This also involves taking a critical look at yourself. Do you think that you'll be able to stick to your therapy programme once you've started? What stumbling blocks might you encounter?

Discuss these and other issues with your doctor:

- What can I do so that I don't forget a dose?
- What drug combinations are most likely to suit me, and what are the most common side effects of these drugs?
- What should I do if I experience side effects?

Sometimes, there are also very personal questions which are important to you. Don't be afraid of talking to your doctor about them. Good teamwork and mutual trust will make therapy easier.

**I'm torn**

Start now? Or wait a while? It's often a tough decision. Your mind turns over all the arguments for and against. In this situation, it helps to write down what the pros and cons are for you. You might see that you don't have important information on certain points, so you can fill in these gaps. Talking to other people – whether doctors, other experts, good friends or family – can also help to clarify things. The best people to talk to are those who are not too heavily biased towards one view, and those who you have been close to for a long time.

Sometimes, you may have a whole load of general information, but it doesn't relate to your specific circumstances. It's therefore worth discussing where you stand right now with your doctor. Here are some questions you can ask to get some insight:

- I'm thinking about therapy and feeling torn. Can we talk through the pros and cons together?
- With my HIV infection as it now stands, how long can I wait to start therapy before it gets dangerous, in your view?
- Which HIV drugs would be right for me, and what side effects should I expect?
- What else does HIV therapy involve, apart from drugs? How often would I have to go to the doctor, and what tests must I have?



### **I don't need therapy**

If you don't want to have HIV therapy for now, your doctor will accept your decision, even if treatment would be the right thing to do medically. Your doctor will certainly continue to work with you, because it is important to track the progression of an HIV infection closely, and to do something for your health if at all possible. You should therefore stay in touch, and ask questions if there is anything at all that you're unsure of. These, for example:

- I just don't want to do that right now. Do we still have to see each other?
- How long can I leave therapy, without having to worry?
- What about unprotected sex if I'm not having therapy?

Whatever  
your decision:  
teamwork  
is the way  
forward

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## Pick your team

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Whether you're starting HIV therapy immediately, or waiting a while, or you never do, it's important that you have good medical support. Have you already found an HIV specialist you feel comfortable with? If you haven't, your GP will be able to help. Alternatively, go to an AIDS support organization near you (all contact details can be found at [www.aids.ch](http://www.aids.ch)). In Switzerland, you can choose who you want to treat you, unless you have opted for a family doctor or HMO model of health insurance. Even if you have, that is something that you can change on an annual basis.

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## Expect a long-term partnership

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Your relationship with your HIV specialist will be a long-term one. You will go to them regularly for check-ups – around every three months if you are not having HIV therapy, and when you start. Once treatment is working well, you'll see them every six months. Sometimes it will be necessary to change your HIV therapy. Since little details can be important here, it's good if your doctor has known you for a while, and you trust each other.

You'll be in the best possible hands at a big hospital with an HIV treatment centre, but you may find that the person you see (your HIV doctor) changes regularly. If that bothers you, you can move to an HIV specialist with their own practice. Names and addresses are available from your regional AIDS support organization.

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## Get involved – or not

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Good teamwork has many faces. Some patients want to know exactly how the drugs and tests work. They want to have a say and make decisions for themselves. Other patients are the opposite. They don't want to know too many details, and usually leave everything to the doctor. The way you do things is up to you, but it's important to remember that you have the right to know everything, and you decide on things that affect you.



**«I always tell my patients: I'm the  
expert when it comes to picking the drugs,  
but you're the one who's the expert  
on living with therapy!»**

Annette, 52,  
HIV doctor

Help whatever  
your situation

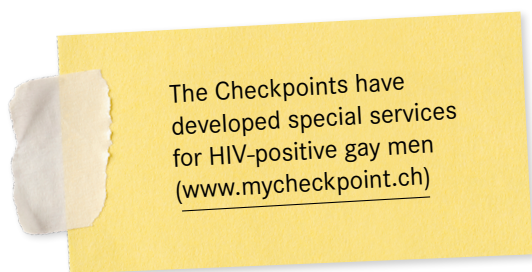
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## AIDS support organizations, Checkpoints

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If you need information, advice, support, a helping hand or the address of an HIV specialist, your AIDS support organization is there to help. In Zurich there are also pastoral HIV/AIDS support services available. Visit [www.aids.ch](http://www.aids.ch) or call 044 447 11 11 for contact details.

For men who have sex with men, there are Checkpoints in bigger cities, [www.mycheckpoint.ch](http://www.mycheckpoint.ch), for HIV tests, advice, treatment and much more.



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## Others living with HIV

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You may find it encouraging to talk to other people who are in the same situation as yourself. The AIDS support organization in your region can give you individual names, or tell you when meetings are held.

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## Legal advice from the Swiss AIDS Federation

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The Swiss AIDS Federation offers a free legal advice service for all questions connected with HIV and the law.

Our advisory team is available on the following days:

Tuesday 9 am–12 noon and 2–4 pm

Thursday 9 am–12 noon and 2–4 pm

044 447 11 11, [recht@aids.ch](mailto:recht@aids.ch)

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## Language problems

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It is very important that you and your doctor understand each other. If you have problems with the language, there are a number of options:

- You yourself can take someone with you to translate – but make sure that they are someone you trust.
- Ask for help at your HIV treatment centre or major hospital, where there are professional translation services.
- You can also look independently for someone to translate for you, but you will usually have to pay for this service yourself. Professional translation services are listed at [www.inter-pret.ch](http://www.inter-pret.ch), or ask a regional AIDS support organization.



The «Health Guide to Switzerland» booklet contains all the information you need about the Swiss health care system. For example, how and where you must insure yourself, where you can go if you're ill, and what you can do for your own health. The booklet is available in many languages. It can be ordered or read online at [www.migesplus.ch](http://www.migesplus.ch)

Employees of all of these organizations are subject to a duty of confidentiality. They are not permitted to pass on any information about you – not even to authorities or government offices. The fact that you have been diagnosed with HIV will be reported to the Federal Office for Public Health, as this is compulsory with HIV cases, but the report does not contain any information that might identify you personally.

More  
information

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## Publications

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«**Diagnosed with HIV? What you need to know**» – a brochure for everyone who has just found out that they are HIV-positive.

«**HIV drugs – what you need to know about therapy**» – (German/French) – contains basic information about the individual drugs used to treat HIV. Available as an online PDF only.

«**Drug table of antiretroviral substances**» – (German/French) – contains a list of all HIV drugs that are available in Switzerland, including dosages and principal side effects. Available as an online PDF only.

«**Relationship and sexuality**» – addresses the various questions and problems that arise in connection with relationships and sexuality, and provides reliable information as a basis for personal decisions.

«**Data protection – protecting your privacy**» – (German/French/Italian) – sets out the legal provisions which apply to handling information about you and your diagnosis, and explains the rights and options you have for protecting your privacy.

«**Job and HIV**» (German/French) – provides a summary of all the important information that you need at work and when looking for a job.

«**HIV – your legal advisor**» (German/French) – covers all fields of law that are connected with HIV. This legal advice publication is available online as a PDF at [www.aids.ch/rechtsratgeber](http://www.aids.ch/rechtsratgeber). You can also download all standard letters in Word format from this site

All publications are available in several languages and can be ordered from [shop@aids.ch](mailto:shop@aids.ch) or [www.shop.aids.ch](http://www.shop.aids.ch) (where you will find all publications online). All materials are sent out in neutral packaging.

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## Swiss Aids News

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Quarterly magazine featuring the latest news on the medical and legal fronts. An annual subscription costs CHF 40, although a discount may be given upon request.

### Address for orders

Swiss AIDS Federation, P.O. Box 1118, CH-8031 Zurich  
Tel. 044 447 11 13, fax 044 447 11 14

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### INTERNET

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- **[www.aids.ch](http://www.aids.ch)** – website of the Swiss AIDS Federation. This is where you'll find all information materials online.
- **[www.hiv.ch](http://www.hiv.ch)** – specialist articles and excellent selection of links.
- **[www.aidshilfe.de](http://www.aidshilfe.de)** – website of the German AIDS Service Organisation, featuring comprehensive information.
- **[www.infekt.ch](http://www.infekt.ch)** – website of the infectiology department at the Cantonal Hospital of St. Gallen, with useful current articles on HIV.
- **[www.bag.admin.ch/aids](http://www.bag.admin.ch/aids)** – website of the AIDS section of the Swiss Federal Office for Public Health.
- **[www.positivrat.ch](http://www.positivrat.ch)** – The Positive Council (Positivrat) is a specialist organisation which represents the interests of people with HIV.



## SUPPORT OUR WORK

With your donation, you are supporting our commitment to those living with HIV, specifically

- direct assistance with problems involving employers and insurance companies
- free legal advice
- financial support in emergencies
- advocacy for equal rights
- campaigns promoting greater solidarity in society, and combating prejudice and misinformation about HIV

**Thank you.**

Aids-Hilfe Schweiz, Zurich,  
PC 30-10900-5, or  
donate online at [www.aids.ch](http://www.aids.ch)

