

**Deutsch: HIV-positiv – was tun?**

**Français: Séropositif – et maintenant ?**

**Español: VIH-positivo – ¿y ahora qué?**

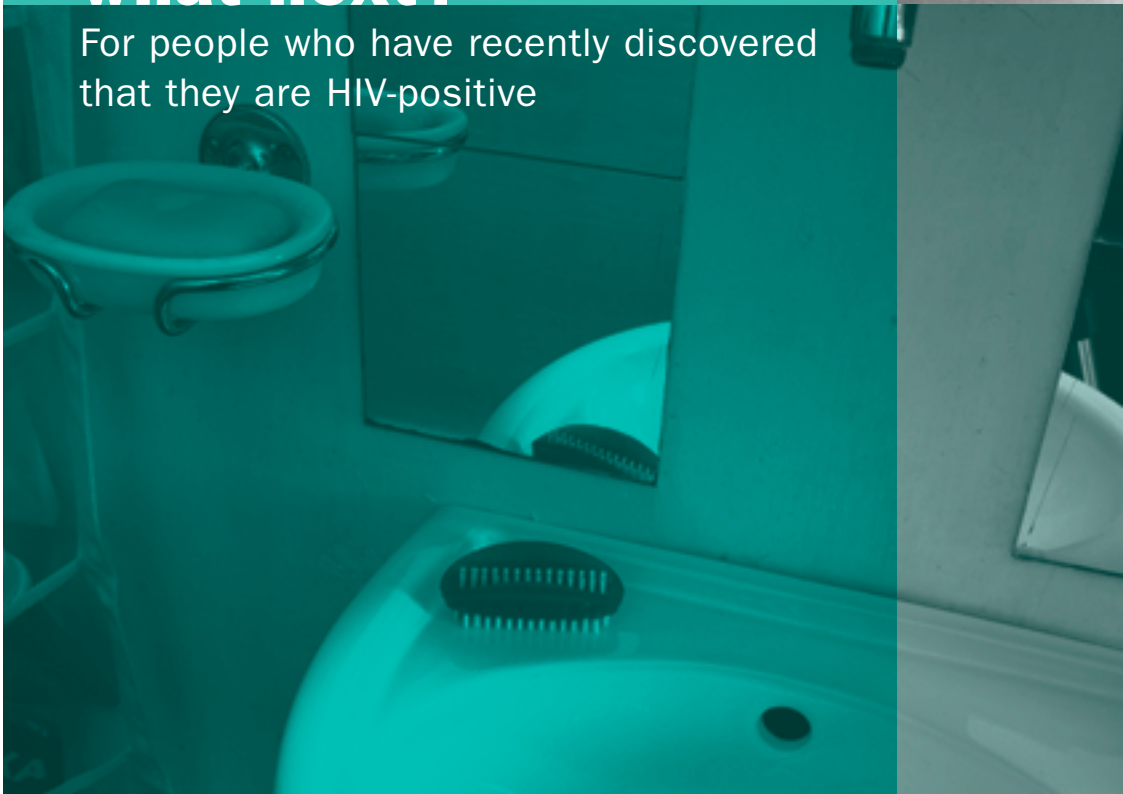
**Português: Infectado pelo VIH – o que fazer?**

**Italiano: Esito positivo – che fare?**

Bestelltalon in dieser Broschüre / Bulletin de commande à l'intérieur /  
Order form inside / Talón de pedido en el interior / Talão de encomenda  
no interior / Tagliando di ordinazione all'interno

## **HIV-positive – what next?**

For people who have recently discovered  
that they are HIV-positive



*You have just found out that your HIV test was confirmed positive, which means you have been infected with the HI virus. This is, of course, very serious news.*

*But having an HIV infection does not mean that you are under immediate threat of death. Thanks to the medical therapies and procedures available today, it is possible to live with HIV just as with any chronic disease. There is a strong chance you have many good years ahead of you. But today's medicine cannot cure HIV.*

*As long as you are living in Switzerland, you have the right to appropriate medical care and modern and effective therapies, regardless of your nationality or residence status.*

*Most people find the initial period after diagnosis very hard. Countless questions need to be answered. Why me? Can I live with this diagnosis? What does it mean in practice? For me? For my future? For my partner? For my children? For friends and relatives? Who can or must I tell, or who do I want to tell – and how?*

*Don't make hasty decisions in this situation. Weigh up who you want to trust with your result. The information and stories of people's experience in this brochure will help you to find your feet again. It will give you a clearer picture of exactly what the diagnosis means, and what HIV infection is. And it explains what therapies are now available and what they can do. People who have been in the same situation as you share the experiences they had and what was important for them. The brochure also provides information about what HIV infection means in terms of sexuality, your job, insurance, etc. At the end you will find details of where to get further information and useful addresses.*

*Make use of the diversity of information, advice and support that is available, according to your own needs.*

*The editorial team*

**Bestelltalon / Bulletin de commande / Order form / Talón para su pedido /  
Talão de encomenda / Tagliando di ordinazione**

Die gewünschte Broschüre wird Ihnen **kostenlos** und in **neutraler Verpackung** zugestellt. Das heisst, der Postsendung ist von aussen der Inhalt nicht anzusehen und der Absender (Aids-Hilfe Schweiz) steht nicht drauf.

*La brochure vous sera envoyée **gratuitement** et sous **pli discret**, c'est-à-dire que l'enveloppe ne donne aucune indication sur son contenu et ne mentionne pas le nom de l'expéditeur (Aide Suisse contre le Sida).*

The requested brochure will be sent to you **free of charge** and in a **plain envelope**. It is impossible to see what is in the packet and the identity of the sender (Swiss AIDS Federation) will not be on it.

*El folleto deseado le será enviado **gratis** y dentro de un **sobre neutro**. Es decir que no se verá lo que contiene y además, el nombre del remitente (Aids-Hilfe Schweiz) no aparecerá en el sobre.*

A brochura desejada ser-lhe-á enviada **gratuitamente** e num **pacote neutro**. Isto significa que não será possível, pelo lado de fora, reconhecer o conteúdo do pacote. Também não constará o nome do remetente (Aids-Hilfe Schweiz).

*L'opuscolo desiderato vi verrà rimesso **gratuitamente** e in **imballaggio neutrale**. Vuol dire che il contenuto dell'invio postale non si vede dall'esterno, e il mittente (Aiuto Aids Svizzero) non figura sulla busta.*

Falten und zusammenkleben / Plier et coller / Fold and stick together /  
Doblar y pegar / Dobrar e colar / Piegarlo e chiuderlo incollandolo

\_\_\_\_\_ Ex. Deutsch: HIV-positiv – was tun?  
\_\_\_\_\_ ex. en français: Séropositif – et maintenant ?  
\_\_\_\_\_ copies English: HIV-positive – what next?  
\_\_\_\_\_ ejemp. en español: VIH-positivo – ¿y ahora qué?  
\_\_\_\_\_ Ex. português: Infectado pelo VIH – o que fazer?  
\_\_\_\_\_ cop. italiano: Esito positivo – che fare?

Ihre Adresse: / Votre adresse: / Your address: / Sus señas: / O seu endereço: / Il vostro indirizzo:

Name \_\_\_\_\_

Street \_\_\_\_\_

Zip code / Town \_\_\_\_\_

Bestellen per Telefon, Fax oder E-Mail: / Commande par téléphone, fax ou courriel: / Ordering by telephone, fax or e-mail: / Pedido telefónico, por fax o e-mail: / Encomenda por telefone, fax ou e-mail: / Ordinanze telefoniche, per fax o e-mail:

Tel. 044 447 11 13  
Fax 044 447 11 14  
shop@aids.ch  
www.shop.aids.ch

Hier anfeuchten und zukleben / Humidifier et coller ici / Moisten here and seal /  
Humedezca aquí y pegue / Umidecer aquí e colar / Bagnare leggermente qui e chiudere

Bitte frankieren  
Prière d'affranchir  
Please affix stamp  
Franquear por favor  
Affrancare p.f.

Aids-Hilfe Schweiz  
Postfach 1118  
8031 Zürich

# Contents

- 4 HIV-positive!?**
- 6 Who should I tell?**
- 8 How contagious am I?**
  
- 10 HI virus infection: the most important points**
- 12 HIV-positive: what exactly does that mean?**
- 15 Medical treatment: the most important points**
- 18 What if I'm a foreigner?**
  
- 22 Finding the right doctor**
- 24 The next appointment**
- 26 What do I want to sort out at the next appointment?**
- 28 Therapy now or later?**
  
- 31 Sexuality: what now?**
- 34 What about at work?**
- 36 What about my insurance policies?**
- 38 Herbs, diet, alcohol, smoking and sport ...**
  
- 40 Further information**
- 44 Useful addresses**

## *Published by*

Swiss AIDS Federation, Swiss Federal Office of Public Health

## *Authors*

Lukas Meyer, lic. phil I, Swiss AIDS Federation, and Andreas Loh, dipl. Psych.  
with Isabella Kehrl, Zürcher Aids-Hilfe

## *Editor*

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

## *Scientific assistants*

PD Dr. med. P. Vernazza, lic. iur. Catherine Jobin

## *Translator / Language assistant*

Jackie Leach Scully / Chinwe Ifejika Speranza

Special thanks to all those people with HIV and AIDS who have contributed so much to the writing of this brochure with their statements, suggestions and criticisms, and to the doctors we consulted.

We do not know whether any of the people in the photographs are HIV-positive or HIV-negative.

## *This brochure was financed by*

Swiss Federal Office of Public Health; Abbott AG; Bristol-Myers Squibb AG;  
GlaxoSmithKline AG; Merck Sharp & Dohme-Chibret AG.

# HIV-positive!!?

Even if you were already apprehensive about the result, the certainty of infection usually comes as a heavy blow. Some people are overwhelmed with fear or despair, others feel completely powerless or wounded. A maelstrom of different emotions may dominate the initial period after receiving a positive test result.

*It was such a shock, I felt totally helpless, didn't know how, what or where. I felt a huge pressure inside me, came over all hot and cold, I wanted to run away from it all – and at work I had to carry on as if nothing was the matter.*

Christa\*, 55 years old

These are understandable and predictable reactions to receiving the positive test result, as HIV infection poses a serious threat to your health.

And yet, even if it seems unimaginable at first, experience shows that HIV-positive people can, over time, find a way of coping with the fact of being infected.

At the beginning, it can sometimes be a good idea just to let your feelings overwhelm you and to accept the fact that you will slump.

After a few days of sleeplessness or brooding, many people turn to whatever has helped them in difficult situations in the past: some seek solitude, others

*\* All names and details of nationality have been changed to protect the people concerned.*



confide in close friends, yet others assemble information or organise their daily routine in a new way ...

*I fell into a pit, I must have felt terrible for about a week, I shut myself away, felt so isolated. Why me, why me, why me? At the same time I thought, I've got to be strong.*

Daniel, 37 years old

In the early days it is important to know that the terrible emotions of the first phase will pass, that the HIV infection can in most cases be kept at bay with the drugs available today, and that as a rule there is enough time to discuss the necessary measures calmly with your doctor.

It is worth not making any drastic decisions in the period just after you get the positive test result. The more you know about HIV, and particularly about what effects the infection and treatment could have on your daily life, the better you can take concrete steps towards coping with your situation. This knowledge will help you to manage the paralysing fear. Repressing the fact of the HIV infection, on the other hand, generally just makes the fear worse by forcing it underground.

Make use of the various opportunities to get advice, even if you have little energy for it at the moment. Information will give you more room to manoeuvre later on. Ask all the questions that come to mind and that bother you.

HIV-positive people with long experience of being infected advise that you quickly make contact with a doctor whom you trust and who can offer you enough support.

*It would have been very helpful for me to know that I'm not alone, there are many others who are in the same boat as me.*

Natalie, 26 years old

*At the beginning I was in a dreadful state psychologically. I was admitted to hospital for three weeks. Now I am full of plans and ideas ...*

Sofia, woman from Mali who has lived in Switzerland for eight years, 29 years old



## Who should I tell?

Right after receiving the diagnosis, it may be a good idea to confide in someone close to you for the support you need during the acute crisis.

*I phoned up two friends at once and told them to come round straightaway. I was in such shock.*

Christa, 55 years old

*I came out of the practice. I tried to contact my partner immediately. We looked at the situation. He helped me a lot.*

Martin, 40 years old

But sharing the news may also lead to uncomfortable situations; some people may disappoint you, and once you have told them you cannot get the information back. While you are still unsure what this news means for you, it is best if you talk about it only with people whom you really trust and whose support you can rely on. Once you know where you yourself stand in terms of your infection, it will be easier to talk about it in less close relationships as well – if you want to.

Take your time, and use the available advice or support as you need.

*Right at the beginning I had a need to tell lots of people. To diffuse the pain and the fear. But later I didn't do that. Not even my mother knows. I was in an HIV-positive self-help group, and they all said they would no longer tell so many people. It changes everything in a single instant, especially at work, where you're not so emotionally close. Many people feel*





*rejected there. – Then I found a psychotherapist, right at the beginning. I wanted to be able to talk to someone, all the same. That's good. It takes away the pressure of needing to talk to others about it.*

Thomas, 34 years old

*I went around outing myself, that was my way of dealing with it. In gay circles I soon outed myself, but it took another quarter or half a year to tell my parents.*

Daniel, 37 years old

*Even if you aren't going to tell your family anything, don't cut yourself off. That's what I advise everybody. It's possible your husband will reject you, or your family. Then we are here to help.*

Aisha, member of the Association Solidarité Femmes Africaines de Genève (address on p. 45)

**Please note:** The information that you are HIV-positive is subject to the rules on data protection. This means that no one is allowed to pass this fact on without your permission. It might be helpful to tell the person you are talking to that your privacy is protected by law.

Doctors will keep this information confidential. They are subject to the rules of medical confidentiality. More details on this are given on p. 19 and in the brochure **'Datenschutz – Schutz der Privatsphäre'** (available in German, French and Italian).

If you are in a relationship, you have to decide how you will prevent transmitting HIV to your partner (safer sex or no sex). You can find the most important points about this on page 31 of this brochure. The brochure **'Beziehung & Sexualität'** gives more information (ordering address on p 40).

If talking with your partner about this is difficult or impossible, you can also get support from your doctor or regional AIDS counselling service.

*I first thought about not telling my wife immediately. But we had slept together since then. So I told her just like that, when she came in.*

Thomas, 34 years old



# How contagious am I?

*When I got the test result, I froze – I just froze in that instant. And thoughts raced through my head: who can love me now? Who can touch me now? Who will stand by me now? – And then I started crying.*

Silvia, 38 years old, positive HIV test 1999, now with a new boyfriend

*If I hurt myself, I always tell my little son to go away – don't lick the wound. I explained to him about transmission. And now he understands.*

Agnes, 40 years old, positive HIV test 1988; 11-year-old HIV-negative son

*At the time, I just broke off my sex life, I didn't even know if you could eat from the same fork, let alone have sex.*

Christa, 55 years old, positive HIV test 1993

**There is no risk of transmitting HIV in day-to-day situations, or through physical closeness or tender physical contact.** The HI virus is **not** passed on through

- shaking hands or dancing;
- cuddling, flirting;
- massage;
- hugging, kissing, stroking;
- petting (mutual masturbation);
- eating from the same pot or bowl, or drinking from the same glass;
- coughing or sneezing, or through tears;
- handling small children (changing nappies, feeding, etc.);



- walking arm-in-arm by the lake and looking at the sunset, camping, gardening, etc.;
- participation in all kinds of sport (but it might be sensible to be cautious about telling people about your infection, because of prejudice in this area).

An HIV infection does not mean you have to keep a distance from others. The virus will not shut you out of life. Many, many things will still be possible.

Only in the following situations is there a risk of the HI virus being passed on:

- **Sexual intercourse without a condom**

Safer sex (see page 31.) will prevent you infecting someone during sex. **Always use a condom during penetrative sex.**

- **High-risk drug taking**

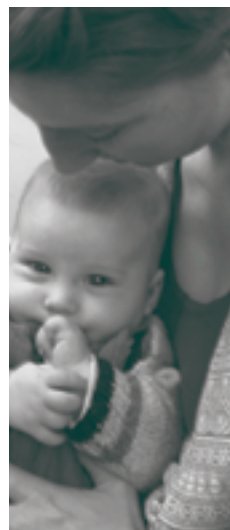
Safer use, i.e. only using your own syringe and needle, and only your own gear (spoon, filter, cotton wool, water), will prevent you passing on the virus this way, or becoming infected with other pathogens.

- Mother-child transmission **during pregnancy, while giving birth or through breastfeeding**

Medical interventions available in Switzerland today can almost eliminate this route of transmission. Therefore, tell your doctor if you are pregnant or would like to become pregnant.

**In situations like these where there is a risk of passing on HIV, you can and must protect yourself and others (see p. 32 and 33).**

- In many migrants' countries of origin, other transmission routes are possible: for example, via uncontrolled blood products or non-sterile needles during medical treatment, or through the use of non-sterile instruments during circumcision of males or females, tattooing or scarification.



# HI virus infection: the most important points

People are exposed to pathogens every day: bacteria, fungi, viruses, and so on. This is why the body has a **defence or immune system**. Our defence system fights off invaders and renders them harmless. This protects us from many diseases and, for example, is what makes a cold get better.

One important defensive function is performed by special cells, which move around in the body and regulate the defences. They are called helper cells or **CD4 cells**.

**Infection with the HI virus (HIV)** weakens the immune system over years, until it can no longer carry out its tasks adequately. HI stands for **H**uman **I**mmuno-deficiency.

Viruses are microscopic pathogens. They cannot reproduce on their own, but have to use human cells to replicate. The HI virus specifically uses the CD4 cells of the immune system for this. So it attacks and destroys precisely those cells that are so important for defence against pathogens.

The body fights for years against the HI virus, continually forming new CD4 cells. But the HI virus carries on destroying these newly formed CD4 cells too. A person who is affected may well not notice any sign of this battle between CD4 cells and HI viruses, as the immune system continues to function adequately for a long time.

*Finding out my seropositive status was pure coincidence. When I applied for a job in healthcare, I was advised to take an HIV test, which I did. I was quite relaxed, no fears or anything. Then: 'Yes, you're positive.'*

Alexej, Russian man who has lived in Switzerland for 12 years, 35 years old

*It did not occur to me that I might have it. I was a devout Muslim, young, healthy and a virgin – and in Africa, HIV-positive people looked liked skeletons.*

Aisha, woman from Zanzibar who has lived in Switzerland for 13 years, 38 years old

In only a tiny proportion of cases do HIV-positive people show any sign of their infection.

**Over the years**, the continual destruction of CD4 cells increases; the cells become less able to recover, and function progressively less well.

**The medical therapies available today stop the virus from replicating itself in the CD4 cells. They cannot make the virus itself disappear, but they can slow down or stop the destruction of the immune system.** (More on pages 15-17 and 28-29.)

Once the immune system is significantly weakened, the body is no longer able to defend itself against other pathogens. Now various diseases that do not occur, or only rarely occur, unless the immune system is weakened, can break out: e.g. fungal infections of the mouth and throat, tuberculosis, a special kind of pneumonia, and many others.

*I had such extreme problems with my gums that I had to be admitted as an emergency to the dental clinic at the university hospital. The consultant said immediately that I was either HIV-positive or that I had already developed AIDS. It was a fungal infection that occurs in this extreme form only in people with HIV or AIDS.*

Adrian, 26 years old

These diseases are called **opportunistic infections**, because the pathogens causing them exploit the opportunity that the weakened immune system presents. Only when one of these diseases has occurred do we start talking about AIDS. A person with **AIDS** is thus someone who is infected with the HI virus and in whom a disease occurs because of the weakened immune system. Some of these diseases can be fatal.

So AIDS is not an independent disease, but the late stage of an HIV infection that is not being treated successfully.

**There are medical therapies that are effective against many of the opportunistic diseases too. And even at this point (i.e. if someone has AIDS) anti-HIV therapy can still help.**

# HIV-positive: what exactly does that mean?

*Being positive does not mean all is lost. Your whole life is turned upside down. But you have to be brave. It's not the end of the world.*

Francis, man from Nigeria who has lived in Switzerland for two years, 34 years old

## Has the positive HIV test result been confirmed?

'Confirmed positive' means that you have taken a first test that raised the suspicion of your being HIV-positive. This result was confirmed through a second blood sample and a second test. – **If you have only the result of the first test, remember: false positives can occur! Always have yourself tested a second time.** Only a confirmed HIV-positive result means that you are really infected with HIV.

## What does HIV-positive mean?

If someone has been infected with the HI virus, the body begins to form defences that target precisely these pathogens. An HIV test examines the blood for the presence of these specific defences, or **antibodies**.

If the test is positive, it means the antibodies that fight the HI virus have been found in the blood. So although the HIV test does not show the HI virus directly, it is a very reliable method of detecting infection by the HI virus.

**An HIV infection that has been determined and confirmed does not – according to current knowledge – get healed. But**



**a diagnosis of being HIV-positive gives no indication of how long someone has already carried the HI virus, or how far advanced the infection is.** The diagnosis indicates only that someone has at some point become infected with HIV and now carries the virus.

## **HIV infection has three phases**

- 1)** A few weeks after infection with HIV, most infected people have a brief, flu-like illness. This is called the **primary HIV infection**. In this phase the immune system is not yet prepared for the invader and the viruses can replicate intensively. However, the body soon forms defences that turn against the virus.
- 2)** After the immune system has adjusted itself to the invader, there follows a phase that usually lasts **several years**, in which the immune system and the virus are in a constant stand-off. The affected person often does not notice any sign of this; symptoms are rare, even without medical therapy.
- 3)** This phase ends when the immune system is significantly weakened, and the **first diseases** appear as a result. This phase is called AIDS.

**So being HIV-positive and having AIDS is not the same thing.**

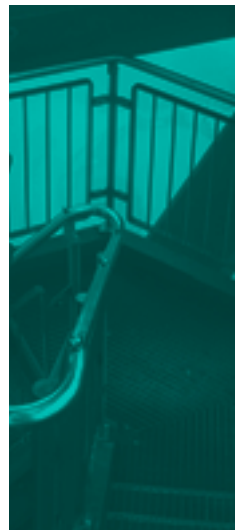
*You have to make an effort to be very, very well informed. About the difference between HIV and AIDS, for instance. People only ever talk about AIDS! I haven't got AIDS! I am HIV-positive; so that's how I refer to it. That gives me hope, strength.*

Martin, 40 years old

*I have learnt that you don't just go off and die of it. You have to go on. You have to carry on living, making plans. I think about work, about further training, about getting a residence permit.*

Sofia, in Switzerland as a 'sans-papier' since 1995, 29 years old

Many people find out about their HIV infection relatively late, perhaps only when the first opportunistic diseases (see p. 11) occur. In other people, the infection is identified right at the start, very shortly after they have become infected.



Your doctor can tell you at what stage your infection is at your next appointment (see page 24 - 25). This is important for planning your future and for making a decision about whether you should consider a therapy at the moment.

*For now, starting a therapy is not under discussion, not yet. My values are constant ...*

Thomas, 34 years old, married, three children

A few people have been living with HIV infection for more than 15 years, have never had a therapy and yet have not developed AIDS. We do not currently understand exactly why the virus does not destroy their immune system as it does in other people.





# Medical treatment: the most important points

*I actually live quite a normal life now! With a few exceptions. I have altered my goals. And I take medications twice a day – so it's always present.*

Martin, positive HIV test in February 2001, started treatment in October 2001

*HIV combination therapies give me the opportunity to help a patient get this deadly disease under control and have a largely normal life. – I find the development of HIV combination therapies to be one of the most remarkable things that I have experienced in my career as a doctor.*

S. N., doctor

The medicines used today against HIV are available as tablets, capsules, syrup or powder, which have to be taken once, twice or three times a day. Only the combination of different medicines is adequately effective. We thus speak of **HIV combination therapy** or Highly Active Antiretroviral Therapy (**HAART**).

The drugs used in HIV combination therapy hinder the replication of the virus in the cells of the immune system. But they cannot drive the HI virus out of the body. That means that they cannot cure the HIV infection once and for all.

However, the medicines decisively delay the progress of an HIV infection. They keep the virus at bay.

Thus, at best they can halt the continued weakening of the immune system and may even help an already weakened immune system to recover. Thanks to these therapies, the life expectancy of people with an HIV infection may be similar to or the same as people without HIV.

Nevertheless, these therapies must not be taken lightly. Here are a few important points that you should know now about these HIV combination therapies.

**1)** According to current knowledge, HIV combination therapy is a **long-term treatment**. An HIV combination therapy works only as long as you take the medicines regularly. You will probably have to take the medication for the rest of your life.



2) Generally, a HIV combination therapy becomes necessary only when the immune system is already weakened – i.e. usually **a few years after becoming infected with the virus**. It is therefore important that you first find out what your current state of health is, and how it is developing (see pages 24-25 and 28-30). You can find this out through regular consultations with your doctor.

3) The success of an HIV combination therapy depends on you taking the medicines exactly according to the schedule you are given. You must not forget any dose – once, twice or three times a day, seven days a week, and in the holidays too. **Otherwise, there is a real danger that the HI virus will no longer react to the drugs and the therapy will not work any more.** So before you start a therapy, ask yourself whether you are properly prepared for it, whether you want and are able to keep the rules of the therapy. When you are ready, discuss with your doctor what the best plan is for you. Your personal needs are just as important as the scientific and medical recommendations.

4) Like other strong medicines, HIV combination therapy often has **side effects** (such as nausea, diarrhoea, tiredness, rashes, or sleep disturbances). Some of these side effects appear immediately after the start of the therapy and disappear again after a couple of weeks. Other side effects (e.g. disturbances of fat distribution, neuralgia) only become noticeable after a while. As a rule these side effects can now be prevented. Get advice on the possible side effects well before starting a therapy. The objective should be for you not to notice any side effects of the therapy in the long term.



**5) The therapies do not work to the same extent for everyone.** It may be that you have become infected with strains of virus for which certain drugs are no longer effective. If there is any indication of this, resistance tests will provide information about what possibilities there are for you.

Further information is given on pages 28-30.

The brochure **'Bereit für die Therapie?'** (in German, French or Italian) may also help you in making a decision for or against treatment. Ordering address on page 40.

**Alternative or traditional treatments** may help improve your quality of life; but no scientific study yet has been able to prove the effectiveness of any of these treatments against the HI virus itself (see also page 38-39)!



# What if I'm a foreigner?

Everyone who lives in Switzerland – regardless of residence status – has a right to medical care, and should be able to benefit equally from up-to-date medical treatment.

Every year a couple of hundred people in Switzerland discover they have been infected with the HI virus. One in five comes from an African country, one in ten from other European countries. There are people from Asia, North, Central and South America, the Caribbean, etc., who live in Switzerland and are HIV-positive.

Whatever your nationality, other people from your country of origin are in the same situation as you are.

*They drummed it into us that AIDS is a punishment. People have accepted cancer, but HIV .... There are families that don't talk about it. – HIV has nothing to do with religion: it can strike anyone, regardless of their sex or age – just anyone. There is no reason to be ashamed.*

Aisha, woman from Zanzibar, 38 years old, in Switzerland since 1990



## 1.

### **No one can find out about your infection without your permission!**

The information that someone is HIV-positive is confidential. No one is allowed to give your diagnosis to a third party without your permission.

**Doctors are bound by the rules of medical confidentiality.** Whatever you say at the doctor's practice or in hospital, and whatever your tests show, your doctors or their assistants are not allowed to tell anyone else – not your partner, not the immigration police, not the staff of refugee centres, not your employer or anyone else – unless you give your permission.

*There are people that I know must not meet in the waiting room. We can take care of that. And I treat many migrants, not just because of HIV. If someone is in my waiting room, no one knows why he or she is here.*

P. G., doctor

The rules of professional confidentiality also apply to practice **assistants, pharmacists and their assistants, interpreters, and everyone involved in advice and counselling** – counsellors at the Aids-Hilfe, social workers, organisations for migrants, etc. – as well as people employed by the health insurance companies.

Your diagnosis is well protected by professional confidentiality. Knowledge of your diagnosis will not spread if you make use of these services. (**For exceptions to this rule, see p. 33.**)

You can find more detailed information in the brochure **'Datenschutz – Schutz der Privatsphäre'** (ordering address on p. 40 – in German, French and Italian).

## 2.

### **The costs of the necessary medical treatment will be covered during your stay in Switzerland**

Medical care for an HIV infection costs a lot of money. But you don't have to pay these costs yourself – whatever your residence status in Switzerland.

Everyone who lives in Switzerland can – and must – have health insurance. This applies regardless of residence status: even 'sans-papiers' must get health insurance (instructions from the Swiss Federal Social Insurance Office regarding mandatory insurance for 'sans-papiers,' *Kreisschreiben* 02/10 of 19 December 2002). Take out health insurance if you do not already have it.

For people who live in Switzerland but do not have a place of residence (e.g. people who have been sent to prison straight after entering the country), other



institutions take on the costs of necessary medical treatment during their stay. (This does not, however, apply to holiday visits!)

If you have questions regarding health insurance or who bears the costs, the **legal service of the Swiss AIDS Federation** is happy to advise you: 044 447 11 11. In emergencies the Swiss AIDS Federation can also provide grants from its Solidarity Fund, if for example you cannot otherwise pay the flat rate ('Franchise') or excess ('Selbstbehalt'). Contact the AIDS counselling service in your canton.

### **3. What if you have difficulties with language or making yourself understood?**

*I usually talk to black Africans in French or English. That works pretty well. Only one came with an interpreter from Caritas, a woman from Angola. She spoke only Portuguese and a local language. She spoke Portuguese with the interpreter.*

P G., doctor

It is very important that you can make yourself understood to your doctor, and vice versa. If you have difficulties, you should make use of the help available. You can always take someone with you to interpret for you. If you don't know anyone who can translate or if you would rather not have anyone who knows you as an interpreter, there are other options.

If you are being treated in an HIV treatment centre at one of the larger hospitals, a solution can usually be found in-house as the hospitals have lists of



employees who can act as interpreters. Your doctor will – with your permission – find a suitable person.

If you would rather bring your own professional interpreter, get in touch with a counselling centre (addresses in the brochure **'Health Guide Switzerland,'** ordering address on p. 40). In this case, however, you will often have to pay the costs yourself.

#### 4.

**If you are facing expulsion from Switzerland** we advise you to make contact immediately with the AIDS counselling service in your region, or directly with the legal advice service of the Swiss AIDS Federation.

#### 5.

##### **Have the courage to look for support**

There are many organisations in Switzerland of and for migrants. These can provide a home from home, offer you support, and give you advice in difficulties of all kinds – legal problems, trouble in your marriage, etc.

*Here at the Association Solidarité Femmes Africaines de Genève we can talk to each other. If someone has to go back, they won't have the medications in their bag, but they can take their experience in the group with them. That gives them hope. – That's the reason for our organisation. And to keep our culture alive. We share the beautiful and the sad moments together. Here we can live our own culture.*

Aisha, positive HIV test 1990

On pages 44-45 you will find addresses where you can get information about existing organisations for migrants.

Most of these organisations do not specialise in healthcare issues or HIV. Your doctor will generally be able to advise you better on these topics. For questions about the healthcare system or insurance, and for information about other organisations, counsellors at the Aids-Hilfe can also help you.

In addition, the brochure **'Health Guide Switzerland'** helps people who live in Switzerland to find their way around our healthcare system. It provides information about medical care and explains important laws and rules such as those on health or invalidity insurance.



# Finding the right doctor

*I tell them all at the first appointment that they should think about who will provide the medical care. It should be carried out the way they want. We are talking about long-term care, after all. If you don't get on with your doctor, things won't turn out well.*

S. N., doctor with a practice specialising in HIV

*My doctor then sent me to the university hospital. He didn't want to do it himself. He said the university hospital was the best place. – At first I had difficulties there, having a different doctor every year. Now I have a super doctor.*

Martin, positive HIV test 2001

Everyone who lives in Switzerland must take out compulsory health insurance. The law on health insurance ensures that everyone has the right to find a doctor of their choice.

*Insured persons may choose freely among approved service providers who are suitable for the treatment of their illness.*

Swiss Federal Law on Health Insurance, Art. 41, para. 1

The only case where this does not apply is if you have voluntarily renounced this right and agreed with your health insurance company to a GP (general practitioner) or HMO model. (These models oblige you – in return for discounted premiums – always to go to the same practice, from where any necessary referrals to a specialist are made.) However, you can cancel this agreement – if you want – in the next contractual period.





**Make use of your right to a free choice of doctor.** Many people with an HIV infection have found that it is enormously important to find a doctor with whom one feels comfortable and who has good professional knowledge of HIV.

Treating an HIV infection requires special expertise. Most GPs are unfamiliar with the rapidly changing anti-HIV therapies. Therefore your GP will generally work with an HIV treatment centre or an experienced doctor. This way, you will have an optimum treatment team of one doctor who knows you well, and an HIV specialist who knows about HIV infection.

And how can you find suitable specialists by yourself – if you do not have a GP or if he or she cannot help you further? You will not find information on who specialises in treating HIV in the telephone book. But you have two other possibilities:

- In Basel, Bern, Geneva, Lausanne, Lugano, St. Gall and Zurich there are HIV treatment centres located in hospitals. The addresses are on page 45. You can get in touch with one of these centres yourself and ask for an appointment.
- You can ask the regional AIDS counselling service for the names of GPs with practices that specialise in HIV. Swiss AIDS Federation will be happy to give you the address of the nearest AIDS counselling service, without you having to give your name (telephone 044 447 11 11).

Choose a doctor that is just right for you. This is all about your health and your well-being.

*What's really important in a doctor: that he or she listens properly, takes me seriously, and has enough time.*

Doris, positive HIV test 1986, HIV combination therapy since 1996

*By the end of the fourth month after the diagnosis I decided to change my doctor. The new one listens really well and explains things. Since then I have felt much better and I am starting to feel hopeful again.*

Eric, positive HIV test 2002



# The next appointment

*It is ultimately the patient who determines when the next appointment will be. Some ask: 'Have you got time tomorrow?' Then they can come again tomorrow, sure. Others don't want to know anything at that point. So then I make a suggestion.*

S. N., doctor

*I repressed it completely. Looked for a job. Lived like I always had. I didn't want to know anything about all that HIV stuff. I wanted to be the same as the others. Although really I knew: I'm not the same any more.*

Tanja, 35 years old

You are free to choose when next to go to a doctor. But it is better not to wait more than one to three months before your next examination. This is important: the doctor can answer any questions you still have. Above all, it is useful to take stock of your current position: is my general health good? Is my immune system intact or are weaknesses already showing? You should find that out now, so that you have a baseline for comparison later on. It provides a good basis for estimating the state and progress of the HIV infection.

Concretely, it is the question of whether treatment is already recommendable or whether you can still wait without risk. A timely start to HIV therapy can spare you from serious illnesses.



## Exceptions

- If there is a suspicion that you have become infected within the last couple of weeks, specialists recommend that you return for re-examination very soon. In this case it can be considered whether the very fresh infection, the so-called primary HIV infection, should be treated (see pages 13 and 30).
- If you are already suffering from a disease that is probably a result of the HIV infection, you should, for the benefit of your health, take the next steps as soon as possible.

At the next appointment your doctor will give you a detailed physical examination, and with your help try to reconstruct the story of the infection as accurately as possible. He or she will also take blood for testing. It is particularly important to determine the number of CD4 cells and the amount of virus in the blood (see pages 28 - 29). Additionally, further blood tests are also a good idea – with a view to diagnosing possible accompanying diseases. In some cases, X-rays will also be taken, or you may be given an ultrasound examination.

This next appointment and the blood tests are also important because – in very rare cases – it turns out that the initial diagnosis was incorrect! This would be shown by these follow-up tests.

After this, it is a good idea to see your doctor about every three months as a general rule. If you are thinking of starting a therapy, or if problems arise with a therapy, you may need more frequent consultations. But as long as you remain well, your appointments might be less frequent.

Try to see your doctor with an open mind and to describe your situation as you really experience it. This gives him or her the opportunity to get to know you as a whole person. And this is the basis for better communication between you and your doctor.



## What do I want to sort out at the next appointment?

*My strategy, which I developed gradually, is: I observe myself. I go to the doctor with written notes. Otherwise you forget half of it. Then I go home, and my boyfriend asks: Did you ask such and such?! I don't want that any more.*

Martin, 40 years old, under medical treatment for HIV since 2001

*At the beginning I always wrote down the questions that came to mind. I found things out on the Internet. Got information about things that I should really have known before. I also ordered the treatment file from Swiss AIDS Federation. Now I go to the doctor every week. There I can ask things directly. And of course I also ask the patient representative in the clinical trial in which I am participating. I knew very little about the subject. And I had to start treatment right away.*

Adrian, 26 years old, receiving medical care for HIV since 2001

Don't feel awkward about asking lots of questions. You have a right to know

- what HIV infection is;
- what tests are proposed and why;
- what your values are and what that means;
- why you are being advised right now to have treatment;
- what alternatives to therapy are open to you;
- how the HIV drugs work, what side effects may occur;
- why you should take which drugs and when, and so on.



**But you need not restrict yourself just to medical questions. Talk about every thing that bothers you – issues of sexuality, protection from transmission, quality of life, etc. – or what you observe in yourself.** Don't be shy of telling your doctor your fears and worries as well. It might help you if you make brief notes of the answers and information.

*It took all my courage to say what I wanted. That I was not satisfied, was so down. – Now I have quite different medicines. And now the values are good.*

Martin, positive HIV test spring 2001, started therapy autumn 2001

Look on your doctor as a medically trained advisor and counsellor. Cooperate with him or her, according to your needs, to achieve what is best for you.

After the consultation you will decide what you do and do not want. Even if your doctor urges you to start a therapy, it is entirely up to you whether to accept this advice or not. After all, it is you who will then have to take the medicines, who will have to cope with the therapy – and it is your life that will be affected if you still want to wait.

Develop a cooperative alliance with your doctor. The more precisely you make your needs clear to him or her, the better you will be able to agree on decisions for or against a therapy.

*The HIV infection changed my relationship to doctors. I was brought up to have respect for them. But now I think: they're only people too. But I still find it hard to accept when they then reach the limits of their knowledge.*

Agnes, positive HIV test 1988, started treatment 1997

*I usually do it like this: if I go to the doctor, they take blood. I don't then wait until the next consultation, I ring up beforehand to ask what the values are. Depending on that, I know what I have to ask next time.*

Doris, positive HIV test 1986, started treatment 1996



# Therapy now or later?

*When I was very ill, I was having a really bad time. But I didn't want to be pressured into having treatment. I waited a long time before I finally started.*

Yves, 46 years old, positive HIV test 1983, started treatment 1998

*It's really great that there is HIV combination therapy. Not panicking every day: when am I going to get ill? Am I going to die soon? Thanks to the medicines I have a pretty good quality of life.*

Tanja, 35 years old, positive HIV test 1989, started treatment 1996

To get an idea of the prognosis and to judge whether a therapy is recommendable at this point, it is important to find out how far advanced the HIV infection is. Two values give information about this:

**1) The number of CD4 cells, also called CD4 values.** In a healthy state, a person has about 500 or more CD4 cells per microlitre of blood. In the course of the HIV infection this number decreases. Starting a HIV combination therapy is recommended once the CD4 value has sunk below 350 to 200 cells, because the risk of getting opportunistic infections then rises steeply (see p. 11). Without treatment, the number of CD4 cells may approach zero.



**2) The quantity of virus in the blood, also called viral load.** With very effective treatment, the viruses replicate to such a minute extent that they can no longer be detected in the blood. Without treatment the quantity of virus can range from a few thousand per millilitre of blood plasma to over a million.

### **No therapy – for the moment?**

Take the time that you need to decide whether or not to have a therapy. Perhaps this is all happening too fast for you. Then just wait a bit. Or perhaps you need more information. So ask your doctor to explain whatever you need to know.

It is your decision to begin a therapy or not. This is all about your health. Nobody can take this responsibility from you, nobody can force you to have a therapy – and nobody can refuse to give you a therapy if it is medically appropriate and you want it. Discuss your concerns and worries about treatment with your doctor – several times, if you want.

Don't rush into making a decision just so that you don't have to think about it any more. And remember: even if you decide against a therapy for the time being, your doctor will continue to give you the best medical care possible.

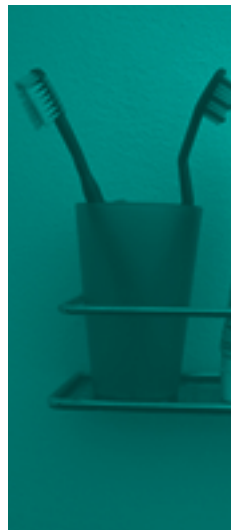
### **Treatment of an advanced infection**

From a medical point of view, treatment of advanced HIV infection is definitely recommended. And many people with HIV who have already become severely ill have experienced starting HIV combination therapy – despite the problems associated with it – as like a rebirth. You are nevertheless free to do without a therapy if you don't want to start one.

Important: **the first treatment for HIV is the one most likely to work. So make sure you have all the information you need and want before you start a therapy, and be sure you feel ready within yourself for a therapy. Only you can decide if this is the case.**

*It's now been 17 days since I started with the therapy. Apart from minimal side effects at the moment – headaches ... or is that the weather ... the 'Geneva breeze'? – I can't say more than that I hope with all my heart that I can tolerate the therapy. Because I love life and I'm rather afraid of dying...*

Jean-Pierre, 28 years old



### **Treatment of the primary infection**

A diagnosis of HIV is rarely made during the primary infection (see p. 13), i.e. in the first few weeks after HIV transmission. If you became infected only a few weeks ago, there might still be a reason for starting a therapy immediately. But the grounds for recommending this are not as good as for recommending a therapy for an advanced infection.

In any case, an HIV treatment centre should be involved in treating a primary infection. And if you want to opt for this, you must act very quickly – in the coming week. Important: you can reverse your decision and stop the treatment – if you have changed your mind – without further ado. If, on the other hand, you decide later on that you wish you had got treatment, you will already have missed the most important phase. In this situation you have to decide quickly – but don't let yourself be coerced into something you don't really want.





# Sexuality: what now?

*After I found out about my HIV infection, in the beginning I just lost all desire for sex. As the shock ebbed away, desire came back as well.*

Jan, 45 years old, HIV-positive since 1986

*In terms of sex, I don't actually find anything particularly difficult or different because of my HIV infection.*

Tanja, 35 years old, HIV-positive since 1989

*I protect others from transmission by using a condom – but I don't have to tell them that I am HIV-positive.*

Josianne, woman from Angola who has lived in Switzerland for three years

*Really I just wanted to screw like crazy, while I could – you know, do it today, you might not be here tomorrow.*

Stefan, 33 years old

Many people who find out that they are HIV-positive react at first by losing all appetite for sex. They can't imagine experiencing sexual desire or being desired by someone ever again.

After the initial shock, desire generally comes back. And many people with HIV or AIDS confirm that after the initial shock they have found their way back to living a sexuality that is just as enjoyable as before.

But remember: **HIV is a sexually transmitted disease** – even if you yourself feel well or are having an effective medical therapy. It is therefore important that you only practise **safer sex**. Safer sex means:

- use a condom for all sex that involves penetration (vaginal or anal);
- take care that no semen or menstrual blood gets into your partner's mouth during oral sex. You yourself should also follow this rule if you stimulate your partner with your mouth.

These rules still apply even if you assume or are sure that your partner is also HIV-positive.

You can become infected a second time with the HI virus. And you might become infected with a strain of virus that is resistant to certain medicines. This would drastically diminish your chances of responding well to therapy.

In addition, other diseases are also transmitted sexually (e.g. syphilis, hepatitis B, herpes). People with a less robust immune system should do all they can to avoid further infections. You have a greater risk of complications, and possibly additional infections may also accelerate the progress of the HIV infection.



Important:

- If you don't mention your HIV infection and do not use a condom during intercourse, you can be prosecuted. If you pass on HIV, you risk several years in prison! In law, you cannot count on protection from HIV infection being considered the responsibility of both of the above-age partners involved.
- If you protect your partner from transmission of HIV (i.e. using a condom and taking care that he or she does not get semen or menstrual blood in his/her mouth), you are not legally obliged to tell them your diagnosis. But if the condom tears or slips off, you must tell them your diagnosis. Your partner then has the opportunity of undergoing Post Exposure Prophylaxis (or PEP), which may be able to prevent transmission. Your partner must in this case go to an HIV treatment centre as soon as possible, at the latest on the following day (addresses on p. 45).
- **It is only decent and fair to be open about your diagnosis with your long-term partner.** This gives him or her the option of getting tested for HIV, and if necessary making use of medical care. You can then also discuss together how to deal with the situation.



**In these situations there are also two exceptions to the rule that your diagnosis may not be told to anyone without your permission:**

- If you knowingly pass on the virus to your partner, it is treated under criminal law as grievous bodily harm. According to the cantonal legislation, in this case – and only in this case – your doctor is allowed, but not obligated, to report it to the police, or to give evidence in a court case.
- If your doctor is convinced that your sexual partner should be informed of your disease, and you do not agree, he or she may submit an application to the supervisory authority to be released from medical confidentiality. – Ask your doctor about his or her procedure if you are in this situation.

More information on this topic is available in the brochure **‘Beziehung & Sexualität’** (in German, French or Italian, ordering address on p. 40). Among other things it explains in greater detail which situations present a risk of HIV transmission and which do not. It explains PEP and makes recommendations on the circumstances in which two HIV-positive partners face a tolerable risk and as such need not use a condom. The brochure explains the effects that the HIV infection or its treatment could have on your sex life and how this can be dealt with. What do you have to consider if you want to have children? At what physical signs, indicating a sexually transmitted disease other than HIV, do you have to go to a doctor? These and other questions are answered in the brochure.



## What about at work?

*On the Monday after the test I went to work again. Work did me good, actually. I'm really not a workaholic. But work gave me a bit of a break. At first I'm sure I worked a bit harder, buried myself in it. But the routine, the constant activity, just gave me a break.*

Thomas

*Nobody knows at work, and I don't want them to know either. We had a meeting once about the question of whether you had to tell the boss if you had an infectious disease. I work in catering. The answer was a clear yes. Then I asked: 'HIV too?' They said, of course you would have to inform the boss then. I contradicted that and asked them what they would do if I were HIV-positive. One woman said: 'I wouldn't shake hands with you any more.' They said terrible things. Well, she is a very nervous person, she's afraid even if someone has a cold. Some reacted very well, others indicated that they would then rather not get too close to me. – There's just a lack of information.*

Andreas, HIV-negative partner of an HIV-positive woman

There are no circumstances in which you are obliged to inform your employer or the personnel department that you have tested HIV-positive. This is true irrespective of your profession. In everyday activities, and if you keep the hygiene rules that apply to the various professions, there is no risk that you could infect someone with HIV. Even if you are a butcher, a nurse, or work in catering, there is still no obligation to tell!



Whatever your employer insurance – mandatory insurance or with supplementary benefits – it will continue as agreed. With regard to your existing insurance, you are also under no obligation to give information.

**Experience has shown that in the immediate aftermath of your diagnosis it is generally wise to be very cautious about telling people at work that you are HIV-positive.** When you are more comfortable with the diagnosis yourself, you will be better able to decide who you want to tell and who not.

### **Looking for a job**

When looking for a job, you are also not under any obligation to reveal your diagnosis either in your application or in an interview. You only have to say if your ability to work within the agreed working hours is limited – but without saying what disease is responsible for any limitation.

But there can still be obstacles: in taking out an insurance policy with supplementary benefits, or in undergoing medical examination, for example. **It is therefore recommended that you prepare yourself well for situations you might encounter in your job search.**

The brochures **‘Job und HIV’** and **‘Datenschutz – Schutz der Privatsphäre’** (in German, French or Italian) give you all the information you might need at work. You will find the ordering address on p. 40.



# What about my insurance policies?

*I would like to be better insured. Take out life insurance. Or insurance for dental treatment. Or private health insurance. But I don't know where. You have to fill out all those questionnaires, answer those questions about AIDS. That bothers me. Then I don't get the insurance coverage, that's difficult.*

Alexej

A diagnosis of HIV changes nothing in terms of all forms of compulsory insurance in Switzerland:

- Mandatory health insurance
- Old-age and survivors' insurance (AHV)
- Invalidity insurance
- Mandatory occupational pension
- Unemployment insurance, etc.

Any further insurance policies, including those offering supplementary benefits, that you took out voluntarily **before** you were diagnosed HIV-positive are not under threat because of the diagnosis. This might include an existing loss of income insurance, or if you have insured yourself for private hospital care.

In none of these cases are you required to provide information. Furthermore, you can, for example, change the health insurance company with which you have taken out your basic policy. But if you have taken out **optional extra insurance, don't cancel it!** You are likely to face major difficulties if, after the diagnosis, you want to take out new supplementary insurance to cover yourself



better (for example, for private healthcare). When taking out the policy, the insurers are allowed to ask about existing illnesses, and you are required to give information that is accurate and true to the best of your knowledge. The insurers will either refuse to insure you on the grounds of the details you give, or put in a condition to exclude your HIV infection from coverage.

If you say nothing about your HIV infection when taking out the insurance contract, you are committing the offence of concealment. The insurers are then not obliged to provide their services and can withdraw from the contract. The premiums you have paid so far will not be refunded either.

You will find the situation covered in detail in the insurance sector of the file **'Leben mit HIV/AIDS'** (in German or French, ordering address on p. 40) or at [www.aids.ch](http://www.aids.ch) (click on 'Für HIV-Positive', then on 'Recht'). You can also have a personal consultation at your regional AIDS counselling service, or ask for legal advice from the Swiss AIDS Federation directly (addresses on p. 44-45).

**Important:** if you have so far only had an anonymous HIV test in a laboratory or hospital, make the most of this opportunity and – before your next appointment! – get advice from a cantonal AIDS counselling service about the best possible ways to proceed (addresses on p. 44).



## Herbs, diet, alcohol, smoking and sport ...

*After the initial shock I did everything I could to strengthen my immune system. When I stopped taking drugs, I tipped right to the opposite extreme: no headache pills any more, no medication, nothing. Instead I took high-dose vitamin C and St John's Wort. – Sometimes I want to laugh about it now: trying to cure AIDS with green tea and vitamin C ...*

Doris, 40 years old, positive HIV test 1986, started therapy in 1996

*At the beginning you have such fatalistic thoughts. What the hell, why should I care about my health now? It won't make any difference any more. But now I'm planning to stop smoking. In future I'm going to think much more about myself. The business will have to take a back seat.*

Martin, 40 years old, positive HIV test 2001

The HIV-positive diagnosis does not require an immediate radical change in your lifestyle, except in one area: your sexual behaviour. So it is not necessary to 'punish' or restrict yourself by doing without your favourite things. With time however, living rather healthier in all areas is good for your long-term prognosis and quality of life. Treat yourself to a better life!

### **Here are a few suggestions:**

Studies show that eight years after starting certain anti-HIV medication, the risk of heart attack as a side effect is increased by 3%. But this is negligible and, particularly compared to smoking, irrelevant.





As for wine, beer and spirits, the same conditions apply to people with HIV as to everybody else. Moderate alcohol consumption is not harmful (as long as you have no simultaneous infection with hepatitis viruses).

Getting adequate exercise – games, dancing, cycling, athletics – does your heart good and improves the circulation; exercise also helps against depression and promotes general well-being. But don't overdo it. It should feel good and do you good!

A varied diet with a lot of fruit and vegetables is more fun and better for you than a diet of processed ready meals or junk food. And it helps your body and your immune system. Extreme diets or a specialised diet based on different ideologies cause more harm than good because of the imbalance of the nutrients. And continue to give yourself a treat now and then: the seven-layer cream cake, the Sunday morning bacon and fried egg, the pizza in front of the TV ... Here, the HIV infection plays less of a role than the question of what really makes you feel good, what you can really enjoy.

In an advanced HIV infection or if you are having HIV combination therapy, targeted changes in your diet may sometimes be necessary. Your doctor can give you advice on this (see also the brochure 'Rund um die Ernährung' – in German, ordering address on p. 40).

According to current scientific and medical knowledge, there are no **vitamins, herbs or alternative or traditional medicines** that can cure HIV infection or have a noticeable effect on it. Traditional, alternative or complementary medicines may however help to improve your quality of life.

If you use other methods than conventional medicine, it is very important that you keep your doctor informed about it too. **In some cases there can be undesired interactions between the active ingredients of conventional medications and those of traditional or alternative medicine!**

If you find **spirituality or religion** meaningful, it may also contribute to your quality of life if you spend some time tending your spiritual side or developing it further.



# Further information

## Ordering address

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

Telephone 044 447 11 13, fax 044 447 11 14

shop@aids.ch; www.shop.aids.ch (You can also find all publications online here.)

**All the materials you order will be sent to you in a plain envelope. This means that it is impossible to see what is in the packet, and the identity of the sender (Swiss AIDS Federation) will not be written on it.**

Further brochures in this series for HIV-positive people  
(available in German, French and Italian)

**‘Bereit für die Therapie?’** – explains in simple language why sticking faithfully to your therapy is vital and gives tips and suggestions on how to achieve this. (24 pages)

**‘Beziehung & Sexualität’** – addresses the various issues and problems that arise in relationships and sexuality, and provides reliable information as a basis for your own decisions. (48 pages)

**‘Datenschutz – Schutz der Privatsphäre’** – gives the legal provisions on the handling of information about yourself and your diagnosis, and explains your rights and the opportunities you have to protect your privacy. (32 pages)

**‘Recht haben – Recht bekommen’** – explains the necessary steps to take in the legal jungle, so that you really do get what you’re entitled to. (32 pages)

**‘Job und HIV’** – contains all the important pieces of information you will need in the world of work and job seeking. (approx. 32 pages)

**‘Rund um die Ernährung’** – shows you how to improve your quality of life with a targeted diet, and gives concrete tips on what to do in difficulty (e.g. diarrhoea, constipation ...). (72 pages, available in German only)

In-depth specialist medical and legal information  
(available in German and French)

**‘Leben mit HIV und Aids’** – detailed file with the chapters ‘Grundlagen’, ‘Medikamentöse Behandlung gegen HIV’, ‘Neue Ansätze zur Bekämpfung von HIV’, ‘Behandlung akuter Erkrankungen’, ‘Besondere Aspekte’ (including HIV in children or women), ‘Methoden der Komplementärmedizin’, ‘Psychologische und psychotherapeutische Behandlung’, ‘HIV/AIDS und Recht in der Schweiz’. Approx. 300 pages, CHF 80 – price reduction possible on request.

**‘Swiss AIDS News’** – bi-monthly magazine with news on medicine and law. Annual subscription CHF 40 – price reduction possible on request.

### Guideline on the Swiss healthcare system

(available in 19 languages: English, German, French, Italian, 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 Schweiz.

## Useful websites

### Sites of the publishers of this brochure

**www.aids.ch** – homepage of the Swiss AIDS Federation (English, German, French, Italian). Here you can find all the information materials online.

**www.bag.admin.ch/aids** – homepage of the AIDS section of the Swiss Federal Office of Public Health. Here you can find facts and figures about epidemiology, etc. (English, German, French, Italian).

**www.workpositive.ch** – job exchange of the Swiss AIDS Federation: mediates between HIV-positive people who are looking for jobs and employers who give work to HIV-positive people (German, French).

**www.chat.aids.ch** – forums and discussion pages of the Swiss AIDS Federation (German, French).

### International sites

**www.who.int** – homepage of the World Health Organization (English, French, Spanish).

**www.unaids.org** – homepage of the UN AIDS programme.

### Sites in German

**www.hiv.ch** – specialist articles and excellent list of links to further sites. Person responsible: Dr M. Flepp.

**www.infekt.ch** – the site of the Fachbereich Infektiologie at the Kantonsspital St. Gall, with useful, up-to-date articles about HIV (click on ‘Infektionskrankheiten’, then on ‘HIV’).

**www.aidshilfe.de** – the site of the German AIDS-Hilfe, with wide-ranging information.

### Sites in French

**www.groupesida.ch** – homepage of Groupe sida Genève, the main AIDS service organisation in Geneva and local branch of the Swiss AIDS Federation. Basic information on HIV/AIDS, prevention, positive living, etc.

**www.sida-info-service.org** – site of the French Ligne d'écoute, with 24-hour telephone advice line, many links and much information.

### Sites in English

**www.aegis.com** – independent site with the most varied, in-depth information.

**www.aidsmap.com** – site of a network of NGOs in Great Britain with up-to-date information (versions also in French, Spanish and Portuguese).



## Sites in Spanish

**www.fase.es** – site of the Fundación anti-sida española, with information on the HI virus and treatments, online advice, etc.

**www.huesped.org.ar** – site of the Argentinian Fundación Huésped, with excellent information for HIV-positive people.

**www.vihpositivo.com** – information website, produced in Spain for Spanish and Latin American users. Daily news summaries and essential information for people living with HIV. Operated by HIV-positive people and updated daily.

## Sites in Portuguese

**www.aids.gov.br** – site of Brazil's national HIV/AIDS programme, wealth of information.

**www.aidsportugal.com** – site with chat and forum possibilities as well as a wide-ranging list of links.

**abraco.esoterica.pt** – (access only without preceding www) site of the most important NGO in the HIV/AIDS sector in Portugal.

## Site in Italian

**www.anlaids.it** – Site of the Italian Associazione Nazionale per la Lotta contro l'AIDS; includes a forum and the option to ask specialists questions via electronic media.

## Warning: there is a lot of misleading and inaccurate information on the Internet!

*It's understandable that you grasp at anything that promises a cure. But often, I have to say, what's offered on the Internet is just quackery.*

A. F., doctor

*At the weekend I searched the Internet – and there I found old stuff as well, about 'useless therapies', and so on. That made me feel pretty bad.*

Thomas, positive HIV test 2001



# Useful addresses

*There are many sources of information. You just have to have the courage to get in touch with the different institutions. I have not had any bad experiences when looking for info. Everyone was very willing to help.*

Franziska, 34 years old

**Staff of all the institutions and organisations listed below are subject to the rules on professional confidentiality. They are not allowed to pass on information about you to third parties, including government authorities and their officials.**

## **Further information and addresses**

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

## **Round-the-clock helpline (Samaritans)**

Dargebotene Hand, telephone 143

## **Regional AIDS counselling services**

Almost all the cantons in Switzerland have recognised regional AIDS counselling services. They offer

- information on doctors in the region who have experience in the care of HIV-positive people;
- individual counselling (e.g. on therapy decisions, on sexuality, etc.);
- information and advice on further services in the region;
- self-help groups and meetings of HIV-positive people;
- suitable psychotherapists;
- organisations of/for migrants, etc.

If you wish, you can make use of these services anonymously – i.e. without having to give your name. Your details will be treated confidentially. The regional AIDS counselling services are not allowed to pass information on to governmental or nongovernmental agencies.

You will find their addresses in the telephone book, on the Internet under www.aids.ch, or by phoning the Swiss AIDS Federation on 044 447 11 11.

## **HIV treatment centres in Switzerland**

*Basel:* Medizinische Poliklinik, Kantonsspital, 4031 Basel,  
tel. 061 265 50 05

*Bern:* HIV-Sprechstunde, Medizinische Poliklinik, Inselspital, 3010 Bern,  
tel. 031 632 25 25

*Geneva:* Division des Maladies Infectieuses, HCUg, 1211 Geneva,  
tel. 022 372 96 17

*Lausanne:* Division des Maladies Infectieuses, CHUV, 1011 Lausanne,  
tel. 021 314 10 22

*Lugano:* Ambulatorio di malattie infettive, Ospedale Civico, 6900 Lugano,  
tel. 091 805 60 21

*St. Gall:* Infektiologische Sprechstunde, Kantonsspital, 9007 St. Gall,  
tel. 071 494 10 28

*Zurich:* Abteilung für Infektionskrankheiten und Spitalhygiene,  
Universitätsspital, 8091 Zurich, tel. 01 255 33 22

## **Legal advice**

Swiss AIDS Federation, Monday to Thursday – telephone 044 447 11 11  
Advice from lawyers and other experts on legal issues to do with HIV/AIDS.

## **Information on organisations for Sub-Saharan migrants**

Canton Bern – project 'Multicolore' of the Aids-Hilfe Bern,  
tel. 031 390 36 36

Canton Geneva, Vaud and Zurich – project of the Swiss Red Cross and the Swiss Tropical Institute, in close cooperation with the regional AIDS counselling services. Coordination: 031 387 73 38.

In other cantons you should preferably contact the local AIDS counselling services for more information.

## **Organisation of HIV-positive Africans**

ASFAG Association Solidarité Femmes Africaines de Genève,  
case postale 2753 – 1211 Geneva 2,  
tel. 079 726 61 89; [www.asfag.org](http://www.asfag.org)

The women of the ASFAG also provide advice for HIV-positive men from Africa, if requested.

In addition to the services listed here, there are many more: AIDS chaplaincies, counselling on children and AIDS, organisations in the drugs sector, for homosexual or bisexual people, for sex workers, etc. The AIDS counselling services in your region or the Swiss AIDS Federation can give you all the useful addresses. You will also find some of them under 'Adressen' at [www.aids.ch](http://www.aids.ch).

*I sat there with my mouth dry and my heart pounding, and I didn't know what to say. I didn't know very much then. That was on a Friday. With the knowledge of my diagnosis and a piece of paper I went home and thought about what I could say to my wife.*

*What do I recommend? Go to a good doctor as soon as possible. Don't wait and try to cope with it alone. Just that one weekend seemed to last for years. So: find a doctor immediately and ask. You won't get anywhere by yourself.*

Thomas, 35 years old, positive HIV test three years ago

*I was shocked and for a month, three months, I lost all hope. But the doctor told me: You aren't going to die! You aren't going to die if you have treatment!*

Francis, Nigerian, 34 years old, has been in Switzerland for two years

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



ZEWO, trademark for charitable organisations

Account for donations

Swiss AIDS Federation, Zurich, 80-23678-6

