

Living positive

in common language



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1. Everyone reacts differently

You know that you have HIV. Maybe you're able to stay relaxed. But you can also completely panic.





2. Anyone can get it

Nearly half of the people with HIV in the Netherlands are heterosexual. The other half is homosexual.

Half of the people with HIV in the Netherlands are natives. The rest is from other countries.

3. Healthy ageing

If you have HIV, healthy ageing is possible.

You must take your HIV medication every day. Sometimes one pill a day is enough. Sometimes you must take more pills. You should take medication for the rest of your life, every day, to stay healthy. When you get older, you are more likely to get other diseases. Just like people without HIV. Older people with HIV could have more specific diseases. Your doctor and nurse will monitor this closely.

HIV medication

In the past, there was no medication for HIV. In that time, many people died of AIDS. Nowadays, people with HIV only die when they don't take HIV medication. It happens especially in low-income countries short of HIV medication. In the Netherlands anyone who needs it gets HIV medication.

Virus

If you have HIV, you have a virus in your body. A virus is a tiny creature which can cause a disease. Influenza is also a virus. If you have the flu, you feel sick and after some time you feel better again. The flu virus is out of your body and you're cured. But flu is a different virus than HIV. If you have HIV, you don't necessarily feel sick. You may feel healthy and live a normal life, but you can still have the HIV virus. That virus always stays in your body. It cannot be cured.



Invisible

Many people with HIV look very healthy. You cannot see they are ill.

Very sick

If you have recently got HIV, you could get very sick. Your body must get used to the virus. It may also be that you are sick because you have had HIV for years. If you start taking HIV medication, it is likely that, after a while, you will feel healthy again.

AIDS

Having HIV is not the same as having AIDS. Your body has an immune system. It ensures that you don't get sick. The HIV virus attacks the immune system. If you do not take HIV medication, you become weaker because your immune system breaks down. You're no longer protected against diseases. You get all kinds of diseases and you end up dying. This is called AIDS. If you take HIV medication every day you will not get AIDS. The virus remains in your body, but you do not become ill.



4. A healthy baby

If you have HIV, you can have healthy babies.

When you want a baby, you can ensure that your baby is born without HIV. You can talk with your HIV doctor or HIV nurse for more advice about having a healthy baby. It is best to do so before you get pregnant.

Women with HIV

A pregnant woman with HIV needs to use HIV medication that is also good for the baby. If possible you get this medication from your doctor or nurse already before you conceive. After birth, you cannot breastfeed your baby. You have to give you baby HIV medication in the first four weeks. It takes a while before it is certain that your baby does not have HIV.

Man with HIV

For a man with HIV, there are two possibilities to ensure the mother and baby are healthy. The doctor or nurse will advice you:

1. You are advised to have sex with your wife or girlfriend without condom.
2. You are advised to inseminate your wife or girlfriend with your sperm in the hospital.



5. Your intimate partner

HIV can be difficult in your relationship.



If you do not have a partner

Are you afraid of not getting a partner because you have HIV? Do you prefer a partner with or without HIV? Or doesn't that matter to you?

If your partner does not have HIV

Is your partner supporting you? Do you feel guilty because you have HIV? Has your partner been at risk? Do you feel bad or ashamed? Do you feel more responsible for the health of your partner?

If your partner also has HIV

Sometimes it's difficult if a partner gets a virus from the other partner.

Talk

You can talk with your HIV nurse about these things. Through the Association of people living with HIV, you can talk with another person with HIV. If you need more help, your nurse can bring you into contact with other caregivers. They can talk with you about your problems and help to find a solution.



6. To tell or not to?

You are not obliged to tell people about your HIV status. You can tell if you want to a person you trust. When you do tell people, they usually respond well. Some people can react negatively. An unpleasant reaction can give you trouble. Some people do not talk or tell they have HIV because of shame or guilt, but other people do not have any problem with their HIV and see no reason why to tell.

No secret

After a while, some people tell more others about HIV and they feel free not walking with a secret anymore. They often say: “How nice it is to live without a secret and to get support from others”.

Tell doctors?

It is important to tell your doctor or specialist that you have HIV. A doctor is not allowed to tell anyone else.

Tell your dentist?

You can tell your dentist you have HIV, but it's not necessary. He must treat all patients carefully. For example, your dentist should wear plastic gloves and clean his hands and tools after treating every patient.

7. Talking with someone who also has HIV

It can be very good for you to share your story with someone who also has HIV.

With the help of your HIV nurse or the Association of people living with HIV, you can contact other people with HIV. You can talk to someone by phone or Internet, or you can go meet somewhere in person. There are activities where all people with HIV are welcome, but also special activities, for example for women, families with children, people from foreign origin or gay men. You may find it hard to visit such activities. But because most people there have HIV, you are no different from the others and you are not alone anymore.



8. The HIV doctor and HIV nurse

If you have recently heard that you have HIV, your doctor and nurse can help you. The doctor and nurse specialized in HIV treatment give you information and advice. There are 27 hospitals in the Netherlands with specialized doctors and nurses. At the place where your HIV test is done, they can tell you which hospital you can go to. But if you know another hospital with HIV doctors, you can also make an appointment there. You usually have your first call in a few days.

The doctor and nurse

The HIV doctor will examine you and advise you about the treatment. The HIV nurse tells you more about HIV and the medication to take. You can talk to them about your feelings and you can ask any question that you might have.

Immediately start taking HIV medication

It is best for your health to start taking medication immediately. And if you have used the medication for six months and all goes well, you cannot pass on HIV to another person anymore.

Every six months

If the medication works properly, you usually have appointments at the hospital every six months. Initially, you will have to be in the hospital more often.

In between

The nurse tells you what to do if you have a question between appointments. In one hospital, you can call all day or send an email, in another hospital you can call at certain hours.

General practitioner

If you are sick, you can visit the general practitioner.



9. Contact with your doctor and nurse

A good contact with your doctor and your nurse is important and useful for you.

Keep time

In the Netherlands, it is very important to arrive in time for your appointment. The appointment may start later because the person before you needs more time than expected.

Questions

You can listen what the doctor and nurse tell you. But you can also ask questions. It is good to write down your questions in advance and take the note with you. It helps you not to forget your questions.

Bring someone with you

You can bring a close friend or relative with you, someone who knows about your HIV and makes you feel relaxed. A doctor or nurse will often say a lot and the two of you hear more. Together you can talk about it later. People who do not understand or speak Dutch can bring a friend or family member to translate. They can also request an interpreter.

Shake hands

Most doctors and nurses shake hands. If you do not want this, tell your doctor or nurse. They will take this into account.

Do you understand the doctor and nurse?

Maybe you do not understand your doctor or nurse, because they use difficult words. Or because you do not understand the Dutch language. If you pretend you understand it will cause problems later. It's always better to say you do not understand!

Choose

Sometimes the doctor or nurse asks you to make a choice, for example: Do you want to continue taking the HIV medication you are using or would you like to change? This is not because they do not know, but because they respect the patient's view. You usually decide in consultation with your doctor.

Another HIV doctor

It may happen that you doubt your own doctor's advice. Then you can go to another HIV doctor to hear what he or she thinks about it. This visit and the explanation of another doctor is called a second opinion. Before you visit another doctor for advice, please inform your own doctor. The next time you go back to your own doctor.

If you are not satisfied with your HIV doctor, you can also change to another HIV doctor. That can be a doctor working in the same hospital or in another hospital. You can tell your HIV doctor you want to change, but if you find this difficult, you can also talk to your HIV nurse.

10. Other doctors

Some people also visit other doctors for HIV. For example, a naturopath or a traditional healer. This is fine, but you should keep going to the HIV doctor and keep taking your medication.

Do you have problems taking your medication? Consult your HIV doctor about this. You can probably start taking other medication. But if you just stop taking the HIV medication the HIV doctor gave you, you will certainly get very ill.



11. Blood test

The blood test measures your health.

Most people with HIV have their blood tested in the hospital every 6 months. Initially, they have multiple tests.

Normal

The nurses know about your HIV. You don't need to be ashamed. They don't tell others and they treat you normally.

Drawing blood

They take a few small tubes of blood. That seems like a lot, but it's only half a teacup. Your body makes blood very fast. At the end of the day your blood volume is normal again.

Anxious

Initially, a lot of people are anxious to hear the results of their blood test from the doctor or nurse. Usually, the results are good. Therefore, most people with HIV, after some time, are no longer nervous for the results.

Problems with medication?

The blood test checks if your medication causes problems. Sometimes your medication may cause problems you have already noticed. Sometimes you do not experience any problems, but the blood test still shows that the medication is not good for you. Then you get other medication.

How much virus

The blood test also measures how much HIV is in your blood. This is called your "viral load". If your medication does the job well, you'll have less and less virus in your blood until HIV is no longer found in your blood. In the hospital, they call it "undetectable viral load". Your viral load is sometimes higher, sometimes lower. This is normal and okay. If your viral load is getting higher after each blood test, there is something not going well. It's likely the medication may not work properly. Your doctor might give you other HIV medication.

Your body's army

Your immune cells protect your body, like soldiers. They ensure you don't get sick. But the HIV attacks your immune cells and enters those cells. These immune cells are called CD4. With the blood test, your doctor can see the quality of your defence, your body's army. For most people, the higher the CD4 counts, the better the immune system. HIV can make your immune system weak. Your risk of getting any other disease is getting larger. If you start taking HIV medication, your defence will improve. Every immune system changes, even with people without HIV. So, don't worry if your immune system is lower for a while.

Other blood tests

Sometimes they test other things in your blood. For example, if the medication is entering your blood. This is called the "blood level". If it's too low, you are probably not always taking your medication. Maybe you need more medication. Sometimes they test the working of your medication, whether they truly work against the HIV type in your body. This is called a "resistance assay".

Other viruses

Many people with HIV can also get other viruses in their body, for example Hepatitis A and B. Blood tests at the hospital show if you have had Hepatitis A and B. If you had these diseases in the past, you cannot get them again. If you have not had them yet, the nurse can tell you where you can get vaccinated to make sure you do not get this disease.

Hepatitis C

Hepatitis C is a serious disease of the liver. For example, you can get this disease if you have sex without a condom. If you have had Hepatitis C in the past, you can get it again. There is medication to cure Hepatitis C within a few months. There is no vaccine against Hepatitis C.



12. Take your pills

You can stay healthy during the rest of your life by taking one or a few pills every day. You must take your HIV medication at the same time every day. There are different types of medication. The HIV doctor and HIV nurse tell you what kind of medication you can take. Many people only need to take one pill a day. Other people take a few pills a day. Sometimes you can choose. The doctor or nurse tells you about the advantages and disadvantages of the medication.

Taking medication

You must take the medication at the same time every day. Do not vary between sometimes taking it in the morning and sometimes in the evening. Some medication requires you to eat something. But with most HIV medication it does not matter if you eat or not what time of the day you take a pill. You can talk with your nurse about the best time for you to take your medication. If you should take a few pills a day, the nurse tells you if you must take them at the same time or not.

Forgotten?

Did you forget to take your medication? Take the forgotten pill immediately. Call the HIV nurse to ask at what time you must take your next medication.

Vomiting or diarrhoea

You can ask your HIV nurse what to do with your medication if you vomit or have diarrhoea.

Stop for a while?

You should take your medication daily. It does not matter if you're at home, have the flu or going on a holiday, you always have to take the medication, every day. If you do not take your medication, initially you will not feel anything. But if you do not take your HIV medication more often or stop for a while, you may become sick.

Someone else's pill

If you do not have your medication with you, it is not good to take someone else's pill. It's only possible if you know for sure that it is the exact same pill.

Medication for family abroad?

It is not good to send your HIV medication to family abroad. Because you never know if that medication is right for your family member. You cannot provide for years the right daily HIV medication for your family abroad.

Research new medication

Sometimes the doctor asks people if they want to participate in a research. Then they can help to try out new HIV medication. The doctor tells you about the advantages and disadvantages. If the doctor asks you to participate, you can freely make your own choice. You can join, but you can also tell him you prefer to continue taking your regular medication.



13. The pharmacy

With your doctor or nurse's prescription you can collect your medication at the pharmacy. You can collect HIV medication at any pharmacy in the Netherlands. There are pharmacies that provide them immediately, in other pharmacies you can get within a few days. Get your new medication at the pharmacy in time. It's recommended to have enough medication for one week, because it is not good to stop taking your HIV medication for one day or longer. If you should take two or three HIV pills every day, it is also not good taking one pill and not taking the other pill(s).

You should take all your HIV medication daily. If you do not have any more HIV medication and the pharmacy cannot directly provide them, call your HIV nurse.

Note

If you get your medication in the pharmacy, there is a note with information in small print. This is called the "leaflet". In the pharmacy you often get another letter which is easier to read. Each pill can also cause some problems. This could be any problem: headache, nausea, diarrhoea, itching and so on. These are called side effects. The leaflet contains a listing of the side effects, including side effects almost nobody gets. Do not be scared by that long list. Usually, every HIV medication has a few common side effects.





14. Other medication

Tell your pharmacy, your HIV doctor or your nurse honestly about other medication and supplements you may use.

Be honest about medication without a prescription, herbal remedies, supplements and drugs. Not everything is a good combination with your HIV medication. You could become critically sick!

HIV medication may not work well when taken together with tablets prescribed by another doctor, or medication that you can buy without a prescription. HIV medication does not always go together well with drugs, such as XTC, or herbs such as St. John's Wort.

Several pharmacies

Maybe you don't want to collect your HIV medication at your own pharmacy. For example, because you do not want people of the pharmacy close to your home to know that you have HIV. Or because you get HIV medication from the pharmacy at the hospital. However, because some medication can not be taken together, it is important for you to get all your medication at the same pharmacy. They know exactly what kind of medication you use.

15. Problems with your HIV medication?

You may not have long term problems because of your HIV medication.

If you start HIV medication, you may have some problems. Problems with your stomach, insomnia, diarrhoea or other problems. Tell your doctor or nurse. Maybe they are caused by the medication. That is called a side effect.

Other HIV medication

Sometimes your doctor decides that you must immediately start taking another type of medication, because of the side effects. That other medication works just as well, but probably you don't have to suffer from side effects. Many side effects are lesser or completely gone after a few weeks. Are you still having problems after some time? Ask your doctor or nurse for other HIV medication.

Often tired

Some people with HIV feel tired, without working hard or practising sports. For example, because someone does not eat or sleep well, or worries a lot. Sometimes it's because of the medication. Discuss this with your doctor or nurse so they can help you.



16. Your belief

Your belief can support you. And you can get support from the people with the same belief. But sometimes people of your belief will not support you.

Fast

You should take your medication even if you want to fast. If you do not take your medication, you will not get sick right away, but it is possible that your medication does not work later. You must take medication with a glass of water and with some medication you should also eat something. Sick people do not have to fast.

Talk

You can talk to your nurse about HIV and your belief. You can also talk with him or her if it's difficult for you to take medication or blood tests during fasting.





17. Healthy living

Healthy living is good for everyone. If you have HIV and you stop smoking, it is the best!

You can become very sick from smoking. If you have HIV you have a bigger chance to get sick from smoking. If you stop smoking, it's very good for your health!

Many people with HIV try to live a healthy life: regular life, eat healthily, use less drugs and alcohol, do more exercise and stay away from stress.

18. No risk for other people

If the virus is not found in your blood, other people cannot get HIV from you. If you use HIV medication, the doctor and nurse tell you when the virus isn't found in your blood anymore. You then have an "undetectable viral load". At that time, there is almost no virus left in your blood. With an undetectable viral load, other people cannot get HIV from you. You cannot be cured from HIV, because there is always a little bit of virus somewhere in your body.

If the virus is still found in your blood, other people can get HIV from you in these ways:

- a sexual partner can get it from you by having sex without a condom
- someone who shares a needle with you can get HIV from you
- you can pass it on to your baby during pregnancy, during birth, or through breastfeeding



Other people cannot get HIV through your saliva and even not through your sweat, snot and tears. So, you don't have to worry about this at home with your kids, at school or at work. You can:

- kiss and French kiss
- sneeze, cough and sniffle
- shake hands
- massage
- get massaged
- use the same toilet
- sleep in the same bed
- share food
- drink together from the same glass
- hug





19. Sex

With HIV you can enjoy your sex life.

Not interested

If you recently know that you have HIV, you may not be interested in sex. Maybe you find it difficult to enjoy sex. This feeling is experienced by most people and will disappear by itself.

Undetectable

If your HIV can't be measured in your blood, it is not possible that other people get HIV from you. But of course, through sex you can pass on and get other diseases. These are "sexually transmitted diseases" mentioned (STDs). It is therefore recommended to use a condom when having sex with different partners.

Talk

You can always talk about your sex life with your nurse. You can also discuss with your nurse how often and where you can be tested for STDs (sexually transmitted diseases). If you experience many problems regarding your sex life, you can talk to an expert. Such a person is called a sexologist.

20. Work

When you apply for a job, or if you report sick, you do not have to tell anyone about your status.

Apply

An employer is not allowed to ask questions about your health, not even during a job interview. If he does so, you do not have to answer. But how do you react when someone asks you about this at your job interview? Your HIV nurse can tell you more about this. Discuss this with him or her before the job interview.

Work less

If you think you should reduce your working hours over the next six months because of your health situation, talk about that. But you do not have to tell anyone that it is because of HIV.

Examination

If you're examined by a doctor during your job application, the doctor is not allowed to ask you about your HIV status or to be tested for HIV.

Call in sick

When you call in sick at your work, you don't have to tell the reason to your employer. You don't need to explain if you are sick because of HIV. Your employer may ask you questions like: When do you expect to work again? Do you think you can work fulltime? Can you do everything? For more information about "calling in sick" please contact the Association of people living with HIV.

Company doctor

You are not required to tell the Company Doctor about your status, but it's often good to tell them about it. Company Doctors are not allowed to tell anyone, but sometimes this happens anyway. Therefore, always tell your Company Doctor you do not want him or her to tell anyone about it. You can also ask your HIV nurse for advice before you talk with the Company Doctor. He or she can give you good advice about what to do.





21. Travelling

With HIV you can travel without any problems, provided you arrange a few things in advance. You can ask your doctor for a letter for carrying medication.

Which country are you going to?

Some countries will not allow people with HIV to pass their border. You can read this on the English site www.hivtravel.org or ask your nurse or the Service-punt of the Association of people living with HIV.

Vaccination

For some countries you need a vaccination first, for example for Hepatitis A and B or yellow fever. Ask your HIV nurse for more information.

Bring extra medication

Bring extra medication in case of an unexpected longer stay. Make sure to bring extra medication, for example for one week.

Insurance

Make sure you are properly insured before you travel. You can then call your insurance company if you are abroad and unexpectedly short of medication. A good insurance is:

- Additional insurance for abroad with your health insurance; or a travel insurance with medical coverage.
- If you are traveling outside Europe, check if your insurance has world cover.

Fly

If you fly, put all your medication in your hand luggage. If you fly with someone else, then divide your medication in hand luggage. Even if a bag is stolen or lost, you will still have your medication.

Change time zones

If you travel and need to change time zones, you can keep taking your medication at the same time. For example, at breakfast. If there is a one or two-hour time difference, you can take your medication at your regular time without problem. But if you travel to America or Asia: what time you should take your medication during your trip? You can ask your nurse in advance.

Problems?

If you are abroad and having problems with your medication or your health, you can visit a hospital. But you can also call your nurse for advice. So, make sure to bring the phone number with you.



22. Money and Insurance

The basic insurance covers all HIV costs.

Every Dutchman and everyone who resides or works in the Netherlands requires a health insurance with basic insurance and must pay for it every month. The basic insurance pays your medication, your blood tests and your appointments in the hospital. Also if you have HIV, you pay the regular price for that insurance and you will not be denied. Every basic insurance has a deductible excess: every year you have to pay the first few hundred euro yourself.

Additional insurance

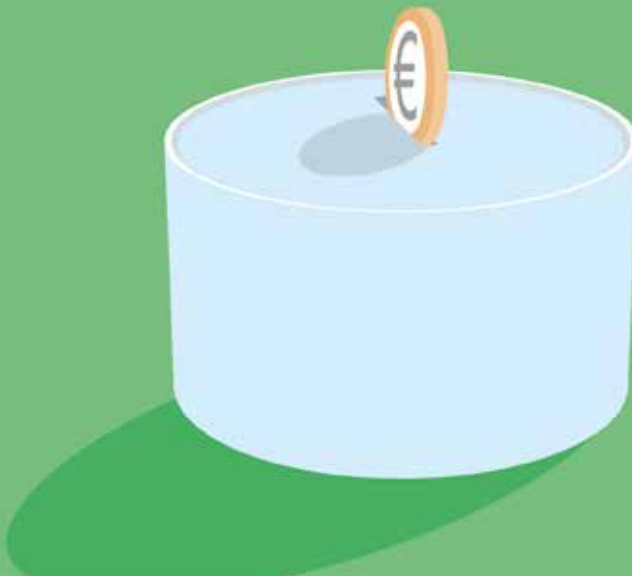
If you want, you can buy additional insurance, for example to visit the dentist or physical therapist. It's never happened that someone couldn't take such insurance because of having HIV.

Financial support from the Aidsfonds

If you have a low income, you may have problems with the extra costs related to HIV and staying healthy. You can contact the Aidsfonds (section individual assistance) and ask for financial support: 020 62 62 669. They only give money if you cannot get it from another organisation, for example your municipality, and only for specific purposes.

Insurances and taxes

You can read on the website www.hivvereniging.nl in Dutch about HIV and insurances and taxes. But if you want information in English, please call Servicepunt of the Association of people living with HIV.



23. Association of people living with HIV

The Association of people living with HIV helps you living with HIV. The association is not owned by the government; it is an independent organisation of members. The association is run by and for people living with HIV in the Netherlands and the people around them. The association provides good and actual information about living with HIV. They have made this booklet. They have a website with lots of information. The Association of people living with HIV stands up for your rights and can connect you with other people with HIV.

Talk

If you want to talk or if you want to ask something HIV related, you can call the Servicepunt of the Association. You do not have to provide your name if you do not want to. You can call on Monday, Tuesday and Thursday from 2 pm to 10 pm.

Become a member

You can support the Association through becoming a member. With more members, the association will be stronger. You can become a member by signing up via the website or by calling the Servicepunt.

Become a volunteer

You can support the Association of people living with HIV through becoming a volunteer. We like to talk about it with you.

How to reach us:

Phone Servicepunt: 020 689 25 77

Website: www.hivvereniging.nl

This booklet

This booklet is a gift from the Dutch Association of people living with HIV. It's made with money from Gilead, one of the creators of HIV medication and the Association of people living with HIV. The text is written by Fred Verdult, edited by Christine, Eid and Reina Foppen, the drawings were made by Richard Kleist and this booklet was printed by NPN Printers.

Colophon

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