

# Living with HIV



**This guide gives answers to some of your questions**

# Knowledge of your own infection

**In this guide you will find answers to some questions related to HIV infection.** Different types of medication that are able to influence the quality and continuity of life have been developed to treat the infection. At the moment, however, there is no treatment available that would fully remove the virus from the human system or cure the disease. If you have questions to which you do not find answers here, you may contact your own health care centre or an organisation conducting HIV and AIDS work. You will find information on different organisations at the end of the guide.

# HIV and AIDS

**HIV infection is a long-term disease, which progressed stage is called AIDS.** HIV is an abbreviation of the words Human Immunodeficiency Virus. The virus weakens the defense system by destroying the helper cells (CD4 lymphocytes). These helper cells are in a key position when the system fights against HIV. If the level of your helper cells decreases, you may more easily contract an opportunistic infection typical to HIV infection. This stage of the disease is called AIDS, which is an abbreviation of the words Acquired Immune Deficiency Syndrome. The word 'acquired' indicates the immune deficiency acquired as a result of a weakened defense system, as a contrast to an inherent weakening of a defense system. The time from contracting the infection to a diagnosis of AIDS varies individually. The better you take care of your health, the higher is the probability that you will remain healthy in spite of the infection.

# Ways of contracting HIV

**HIV infection is transferred only from human to human.** The virus does not choose its target based on skin colour, religion, sex or sexual orientation. A person who has contracted the virus has it in his / her blood and other secretions of the body. HIV may be infectious from a person to another through blood, vaginal secretion, semen and man's pre-ejaculation fluid.

During the years HIV infection has developed several subtypes. It is possible that two persons, who have contracted the virus, exchange their viruses either through sexual contact or in connection with the use of intravenous drugs. A person may have more than one HIV infection at the same time. Your own infection, therefore, does not protect you from getting another one.

**HIV infection may be contracted in the following ways:**

- through unprotected sexual contact where partner's secretions (vaginal secretion, man's pre-ejaculation fluid, sperm or blood) come into contact with the mucous membrane
- through unprotected oral sex

- through blood contact, such as
  - through needles and syringes, which have been shared
  - through piercing and tattooing tools, which have not been properly cleaned
- from an HIV positive mother to a baby during pregnancy, childbirth or breast feeding

In Finland donated blood is examined. However, if you suspect to be HIV positive, do not donate blood before a potential infection has been ruled out.

# HIV is not infectious in day-to-day situations

**HIV is not easily infectious.** Outside the human body it does not live very long. In order to live, HIV needs humans and human cells inside of which it multiplies into more and more viruses. HIV cannot be contracted through air or by touching. In order for it to be contracted, the virus requires a mucous membrane or a blood contact. In practice, the virus must get inside a human body either through sexual contact or directly through blood contact.

The virus cannot be contracted for example through towels or bedclothes, and it is not infectious either through a touch or a kiss. If you are HIV positive, cooking is also 100 % safe. You can still go to work or study without being afraid that you will infect the people around you. You can still enjoy the hobbies you have. If you sweat a lot during a physical exercise, you do not have to worry about the sweat getting into contact with someone else, because HIV is not infectious through sweat. Having sauna with others is also safe.

You need to be careful and protect your partner when having sex, as well as in situations where there is any kind of blood contact. When you use protection during sex, you also take care of your own safety and avoid other infections. Additionally, all skin piercing tools (for example insulin needles and needles or syringes for other medication) that come into contact with blood must be disposable. You must dispose of these types of tools immediately after use so that others do not come into contact with them, and also so that you do not use the same tools again. In this way you avoid getting impurities into your own system and manage to avoid infections.

## Instructions to day-to-day situations

- Take care of your health, because other infectious diseases weaken your resistance against the virus.
- Tell your partner about the infection. If you have had unprotected sexual intercourses, suggest that he / she should take an HIV test.
- Follow the rules of safer sex. Use a condom during sex, including oral sex.
- If you get cuts or areas of damaged skin, cover them with a band-aid.
- If your blood or other secretions come into contact with another person's cut, or on a mucous membrane, instruct the person to wash them away immediately with plenty of water.
- Do not let others use your personal hygiene belongings, such as your toothbrush or a razor.
- Do not let others use your needles or syringes.
- You may wash your bed linen and other laundry the way you wash your normal laundry. Clothes stained with blood or bodily secretions may be washed in a washing machine using detergent.
- Do not donate blood, sperm or breast milk. Unfortunately so, you cannot become an organ donator either.

- Tell the health care professional treating you about your infection so that the HIV infection may be taken into consideration when planning your treatment. Health care professionals are bound by confidentiality.



## The infection progresses by stages

**After the initial infection the body develops antibodies against the pathogens of the disease.** In HIV tests antibodies of the virus have been found in your blood. This is a sign of the infection. The progression of the infection depends, for example, on what type of virus you have contracted as well as what condition your own health is in. Additionally, other simultaneous infectious diseases, such as other sexually transmitted diseases, weaken your resistance against HIV.

After the infection you may have developed some flu-like symptoms. For some, this early stage is symptomless, and some may become ill with symptoms of a normal virus disease (fever, sore throat, articular pain). For others the early disease requires even hospital treatment. Usually a symptomless period, which may last for years, starts after the early disease.

If the disease progresses, enlarged lymph nodes (diameter of over 1 cm) appear as the first symptoms at least in two areas outside of the groin. However, your general condition still remains good, and you can continue your daily life normally.

If the disease progresses and your resistance against it gets weaker, more symptoms start to appear. The first symptoms often appear on the skin and the mucous membranes with different types of bacterial and virus infections. As the resistance against the disease further decreases, your condition weakens, and you may get general symptoms, such as fever, weight loss, diarrhea and a feeling of illness. When a person, who has contracted an HIV infection, becomes ill with an opportunist disease, this is called AIDS. Opportunist diseases can be rejected with a healthy resistance, but a weakened resistance cannot reject them.

## Treatment and follow-up

**Both treatment and medication for an HIV infection are free of charge for patients in Finland.** It depends on your condition and the results of laboratory tests used in the monitoring of the infection, when your medication starts. In most cases the starting of the medication is not urgent. Antiretroviral medication slows down the multiplication of the virus, and in that way prevents healthy cells becoming infected with the virus. The regularly taken medication will help the weakened resistance to get stronger. In this way the progression of the disease can be stopped. However, the virus cannot be completely destroyed from the body with the medication currently available. The effectiveness of the medication and the duration of the effectiveness vary from person to person. Therefore, do not compare your own medication with the medication of others who have contracted the disease.

Follow-up of the HIV infection is carried out in an outpatient department. If you take care of regular visits, the staff of the outpatient department can intervene more speedily in the problems caused by the HIV infection. The visits will be planned individually taking your health into consideration. Blood tests, X-ray examinations, as well as other required examinations

will be carried out on you. CD4 cells and the virus load in blood reveal the progression of the HIV infection the best. When your health and your blood count are good, you will visit the doctor at 4-6 month intervals, or, if the situation so requires, more often. In the beginning, when you start your medication against the HIV infection there will be more frequent visits. At the outpatient department you will meet a doctor and a nurse. If you want, you can also meet a psychiatric nurse and a social worker. In a problematic situation you may always contact your own HIV doctor or HIV nurse.

You may require in-patient treatment, if your health weakens for some reason and you need more specific examinations. If you become ill with an opportunist disease related to the HIV infection, for example a pneumonia requiring intravenous antibiotic treatment, it will be treated in an in-patient ward.

Your resistance against infections may weaken as your blood's CD4 helper cell count decreases and your virus load increases. For this reason you may need to start medication against the

virus. The aim of the medicine is to improve your resistance to diseases by increasing your helper cell count and decreasing the virus quantity. According to the current information, the medical treatment has been designed to last for the rest of your life.

So it is good for you to consider in advance, if you are ready to follow it through. Consider whether the time is suitable for you, and whether you are able to commit yourself to a demanding medical treatment.



When starting the medication, temporary side effects may occur, such as nausea. Some of the medications also have serious side effects, which are not all yet well known. The most important thing is that you take the medication regularly, because in this way the development of the virus to become resistant to your medication is prevented. The medication will be planned for you individually as a combination treatment of several medicines. Sometimes your medical treatment may need to be discontinued or the medicines changed to other antiretroviral medicines due to the side effects. If you decide to discontinue your medication, you should at first discuss it with your doctor. You will receive support for the starting and implementation of your medication from your doctor and the outpatient department's HIV nurse.

## Patient representative

If you feel that you do not receive the treatment you require, discuss it first with your doctor and nurse. If required, contact your treatment place's patient representative, who will help you with your problems.

**The knowledge of your own HIV infection will stir your emotions.** An acknowledgement of a disease is always a crisis. Generally, a crisis progresses through certain stages. However, remember that each one of us is an individual, and the emotions or crises do not progress in the same way.

The first stage of a crisis, an initial shock, may last from a short moment to a few days. In this shock stage your emotions may fluctuate between numb and confused. After the initial shock, follows a reaction stage when strong feelings may overwhelm you. These types of feelings may include anger, guilt, anxiety, fear and grief. It may feel unfair and unreasonable that you have become infected. Anger may be directed at the virus itself or your sexual partner. Sometimes the anger may be directed at a third person who is an outsider, such as a doctor or another professional. At the correction stage thoughts and emotions are directed at the future again. You can actually live with the infection for years and you can continue your work or your studies. Perhaps you cannot control the virus, but you can control your own life.

## Talking about it helps

**In connection with finding out about the disease some of your emotions may come out in a form of different somatic symptoms: headaches or stomachaches.** As the disease progresses, also new crises may come along. Letting go and grief may become emotions controlling your life. Thinking about death causes fear and anxiety in most of us. It helps to talk about it.

A panic disorder and a depression are a reality for many. Depression may also be caused by HIV medication, other medications used for the treatment of infections, or the use of alcohol. Also the effects of the HIV infection in the central nervous system may cause depression. However, even a chronic depression may be treated. The most common treatment for depression is a combination of therapy and medicine. Discuss your emotions with your doctor or a nurse, and ask for help as soon as you feel you need it. You will find contact information of organizations offering support and opportunities for discussions at the end of this brochure.

Our situations in life and past experiences influence how we will face becoming ill, and how

the knowledge of the infection will affect us. Our life experience and personality will also influence the means of coping. Receiving support and sharing your own feelings with someone have proved to be useful methods in coping. Every person should have someone they can talk to about difficult matters in life. However, you should consider to whom you want to tell about your infection. It is good to remember that the news of your infection may be a shock to the people close to you. They too need to deal with the matter in their own ways. You do not have to tell your employer about your infection. The infection does not have to stop you from working, studying and from having hobbies.

It is good for you to be aware of the fact that HIV and AIDS arouse different feelings in people and reveal our society's attitudes towards sexuality, disease and death. Some people may still, but incorrectly so, think about the infection as a disease of certain groups. It is good to remember, though, that HIV touches all societies and all groups of people. The virus does not discriminate, people do.

**Health is a resource, which helps us to cope in different situations in life.** Physical, psychological and social capacities are a part of our health. Several factors influence health, such as the way of life, environment, stress, relationships or an actual physical disease. Taking care of your health means you have to make choices. Each one of us has an opportunity to take care of one's own health through the right choices. Everyone chooses for oneself.

As an HIV positive it is important for you to take care of your health. Although you may have earlier taken some risks regarding your health, it is now worthwhile to choose differently. Being HIV positive does not necessarily mean that you are ill, because with the right choices you can remain healthy for a long time.

**A wrong type of strain or stress is one factor that influences our health by weakening it. Our natural defense system is weakened by:**

- unbalanced nutrition
- lack of sleep

- stress
- too much work
- lack of free time and relaxation
- lack of exercise
- feeling down or depressed
- smoking, certain medicine, drugs and alcohol

A continuous strain exceeding our resources is dangerous for the health. It may be difficult to notice your own stress. The symptoms may include depression, irritability, sleep disorders, headache or an increased blood pressure. Remember to rest and exercise enough, give time for yourself and do things that you enjoy. If it feels difficult to cope with it alone, seek help from a peer group or a support person.

**We need different types of nutrients every day: carbohydrates, proteins, fats, minerals, vitamins, fiber and water.** With their help our bodies produce heat and energy, and on the other hand prevent onsets of diseases. A balanced diet is essential for our health. You will get carbohydrates, which the body uses to produce energy, as well as vitamins from whole grain crop, root crop, fruits and vegetables. Proteins needed for the growth and renewal of cells can be found, for example, in meat, fresh fish, cheeses and beans. Good sources of fiber are whole grain bread, muesli, nuts and brans. A healthy nutrition is natural, fresh and do not include additives. Try to drink plenty of water. Because of your medication your doctor may recommend you plenty of drinks containing energy. You can obtain additional instructions and advice from a nutritional therapist or a nurse. You will find the most suitable diet by experimenting.

Hygiene is as important in eating as nutrients. Always clean fresh food so that you will not contract any infectious diseases through it. Always wash your hands before preparing the food. The hygiene of your hands is especially important when processing raw meat, beef, pork, chicken or fish.

If you use HIV medication, discuss with your own doctor or nurse, whether the medication needs to be taken with food.

## Exercise

**Exercise improves your blood circulation and also the oxygen intake.** With the help of exercise you prevent yourself becoming overweight and on the other hand you prevent your bones becoming prematurely brittle. Additionally, with exercise your mood will become happy and your stress level will decrease. Choose your own type of exercise according to your preferences. Exercise does not need to be trendy or performed with top gear. Walking, swimming and biking are all excellent ways to keep in a good condition.



## Intoxicants and dental care

**Smoking weakens our bodies' natural defense system against different diseases.**

Additionally, it increases nervousness, weakens the surface blood circulation, impairs the oxygen intake of our bodies, and as a result causes tiredness. If you feel that your alcohol or other intoxicant use is not in control, you can contact your local substance abuse services where you will receive help for your situation. Munkkisaari Service Centre operating in Helsinki provides its services nationwide for drug users who have contracted an HIV infection. There you will receive counselling and advice related to both HIV and safer use of drugs. You will find contact information of the Munkkisaari Service Centre at the end of the brochure.

**Remember to take care of your oral health too.** Careful oral hygiene prevents infections that you may contract more easily than others, because of your HIV infection. Have the condition of your teeth examined annually. At the same time the dentist will also examine the condition of your oral mucous membranes. Dental care staff as well as other health care staff is bound by confidentiality.

**Menstrual disruptions, such as irregular menstruation, are common with women who have contracted the infection.** Your menstruation may stop completely as the disease progresses. With women some gynecological diseases are related to HIV infection. Vagina's yeast infections are common with women who have been infected. Yeast infections may also occur in the mouth or in the esophagus. Pay more attention than normally to your personal hygiene, if you notice that you have recurrent yeast infections. Cotton and other natural fiber clothes as well as consumption of lactic acid bacteria help to prevent yeast infections.

Cancer of the uterine cervix develops normally over a long period. With the help of regular follow-up examinations the incidence of the cancer has decreased. More cell mutations than usual and pre-stages of cancer in the uterine cervix, vagina and the anal area occur in women who have contracted an HIV infection. The risk increases in connection with sexually transmitted diseases and the lowering of the body's natural defense system. Because of this you should take Pap tests frequently. It is recommended to have a test every 6 months to 1 year.

**Knowledge of your own HIV infection may also influence your sexual appetite.** Interest in sex may at first disappear. In most cases sexual appetite and the need for closeness reappear as time passes. Be brave to talk about sex with your partner. When both of you know what the other one wants and does not want, sex will be more enjoyable and safer. Safer sex is practiced when secretions (semen, vaginal secretion, blood or urine) do not enter the partner's body, mucous membranes and cuts.

Not everyone likes to be told what can be done and what cannot be done especially when this advice concerns sex. Sex may be playful and satisfying, but it may also involve a risk, especially when you do not know your partner. If you know about the risks concerning sex and you are able to take them into consideration, you will enjoy your sexuality more. Taking risks means always making choices. Remember that it is important for you to protect yourself both from new HIV infections as well as other sexually transmitted diseases. Your own infection does not protect you from getting a new virus, because HIV has different subtypes. An overlapping infection will weaken your physical condition, and will be more difficult to treat

with medication. When you protect your partner, you also protect yourself.

All of us, and not only those who have contracted the infection, have the responsibility of preventing the spread of HIV. Always use a condom during an intercourse. Take care that the condom is of good quality and the right size, and that it is not outdated. If a condom breaks during an intercourse, contact your doctor.

**Safer sex can be practiced in the following ways:**

- hugging, touching, massaging
- masturbating you and your partner
- kissing
- fantasizing
- using personal sex toys

**Sex that contains a risk of an infection:**

- intercourse without a condom
- oral sex (blow job) without a condom both with a woman or a man
- anal sex or caressing the anal area
- sex with a blood contact
- sharing of sex toys



# Use of condom

**Using a condom is the easiest way to protect oneself from sexually transmitted infections.**

Normally a condom breaks, because it has not been used in a correct way.

**When using a condom, follow carefully the instructions below:**

- store condoms in a dry and cool place
- use a condom always during an intercourse and oral sex (when caressing a woman you can use plastic wrap or a condom that has been cut open)
- open the package of a condom carefully; nails or rings may break the condom
- roll the condom open slightly so that you can see which way it should be placed
- empty the air from the tip of the condom carefully pressing with your fingers
- before you roll the condom over an erect penis pull the foreskin back
- roll the condom all the way to the base of the penis and make sure there is no air left at the tip of the condom (air left at the tip of a condom is the most common reason for a condom to break)
- if necessary, use a water-based lubricant (especially during an anal intercourse)

- after ejaculation hold on to the base of the condom and pull the penis out of your partner
- tie up the end of the condom and dispose of it with other waste
- always use a new condom during each intercourse

Femidom, a condom for women, is a pre-lubricated condom made out of polyurethane and it is to be placed in the vagina. It is suitable also to persons allergic to rubber and it gives women the opportunity to take care of their own protection. It can be placed in the vagina well before an intercourse. The condom is not dependent on erection and, therefore, there is no hurry after an intercourse to pull the penis out in the same way as with the men's condom. You can use both water-based and oil-based lubricants with the women's condom.

Another condom that is suitable for persons allergic to rubber is called 'Avanti'. It is made out of polyurethane and does not contain elements originating from animals. A condom called 'Vegaani' can be found from a pharmacy. It does not contain casein originating from animals. Additionally, this condom is cheaper than the others.

## Organizations that offer support

### **Finnish Body Positive Association (Positiiviset ry) / [www.positiiviset.fi](http://www.positiiviset.fi)**

Finnish Body Positive Association promotes the welfare of persons who have contracted an HIV infection by supporting them and the people close to them. The association's important goal is to fight against discrimination, to prevent the spreading of HIV infection, as well as to inform of HIV and AIDS.

In Finnish Body Positive Association people who have contracted an HIV infection help themselves and others. This is the fundamental idea of similar peer support groups all over the world. The association welcomes everyone, who wants to fight for the rights of HIV positive persons, as its member.

In the association the infected and the people close to them can meet others who are in the same life situation. The premises in Helsinki are open for spending time together and finding activities for six hours per each weekday. Additionally, a lunch is offered on Saturdays. Also training, seminars and evening gatherings are organised in the premises. The importance of confidentiality is emphasized in all the activities of the association.

## **Finnish Aids Council (Aids-tukikeskus) / [www.aidstukikeskus.fi](http://www.aidstukikeskus.fi)**

Finnish Aids Council is an organisation, which offers services for HIV positive, people close to them, as well as persons who suspect they have contracted an HIV infection. Council has offices in Helsinki, Tampere, Turku and Oulu.

Finnish AIDS Council provides following services: HIV Hotline from Monday to Friday at 10 a.m.-3.30 p.m, counselling, therapy services, social work, day centre activities, group and recreational activities, resource courses and group activities for immigrants. Additionally, there is an opportunity to take an anonymous and free of charge HIV antibody test. AIDS Council also offers training services.

## **The Finnish Red Cross (Suomen Punainen Risti) / [www.redcross.fi](http://www.redcross.fi)**

HIV Hotline service answers your queries related to HIV with the cost of a local telephone call, from Monday to Thursday at 5 p.m.-9 p.m. You can also ask for a support person. Pluspiste offices provide local support activities in Joensuu, Kuopio, Jyväskylä and Seinäjoki. In Pluspiste there is also an opportunity to take an anonymous HIV antibody test.

**Your own nurse** \_\_\_\_\_

**Outpatient department** \_\_\_\_\_

**Dental clinic** \_\_\_\_\_

**HUS / Aurora Hospital** (infection outpatient department) 09 - 471 75930

**HUS / Infection control unit** (infection control nurse) 050 - 427 1660

**HIV nurse** 09 - 471 75930

**Finnish Body Positive Association** 09 - 692 5441

**Finnish Aids Council / HIV Hotline** 0207 465 705

**The Finnish Red Cross / HIV Hotline** 0203 27000

**Prostitute Counselling Centre** 09 - 726 2877

**Munkkisaari Service Centre** (HIV Positive Drug Abusers) 09 - 775 04050

**Other important telephone numbers:**

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# Living with HIV

**How to protect yourself and others?**

**How to cope with it rest of your life?**

**How to continue meaningful life in spite of your infection?**

**Finnish Association for Nurses in AIDS Care, registered organization©**

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