



HIV in the family





To the reader

The brochure is targeted at families with children in which a parent, a child or a teenager is HIV positive. The brochure instructs on how to tell about HIV and talk about the infection. This brochure has been created in cooperation with HUS Children's Hospital and the Finnish AIDS Council.



HIV INFECTIONS IN FAMILIES

Usually, the parent in a family has the infection. There are only a few HIV positive children and teenagers in Finland. In Finland, HIV is mainly transmitted via sex but, globally, in addition to sex, transmissions and infections caused by drug syringes, HIV can sometimes be transmitted via blood transfusion or from mother to child during pregnancy, delivery or breastfeeding. Foreigners moving into Finland often come from areas where HIV is common and the probability to get infected is also greater.

With improved medical treatment, those infected with HIV live longer and healthier than before. In Finland, the life expectancy of an HIV positive person is nearly the same as a person without HIV. Many of them settle down and have children. When the HIV infection of a mother or a father is known, transmission to the child can be prevented with medication during pregnancy and delivery.

Support from family members and loved ones helps with living with a chronic disease. Therefore, it is important that families can talk about HIV openly and that accurate and necessary information is available to everyone. Social and healthcare professionals can support families by providing information about HIV and its treatment as well as contemplating together with the families how and what to discuss about HIV in different phases of life.



WHAT DOES HIV INFECTION REFER TO?

HIV, or the Human Immunodeficiency Virus, is a virus that damages the immune system of the infected person. The virus attacks certain white blood cells and destroys them. It can easily transform itself, which makes it difficult to destroy with medication. The immune system of HIV positive persons weakens little by little, and without proper medication they will be exposed to numerous different illnesses.

Without medication, the HIV infection can develop into AIDS (Acquired Immunodeficiency Syndrome). HIV and AIDS are not the same thing, and not everyone with HIV progresses to AIDS. A person with AIDS has a

significantly weakened immune system and contracts one of the opportunistic infections related to HIV, for instance, pneumonia, meningitis, brain fever, salivary gland infection or a fungal infection of the esophagus. The development of HIV into AIDS can be prevented with proper medication.



HOW IS HIV TRANSMITTED?

HIV does not spread easily. The virus does not spread through air or surface contact: it requires contact of mucous membranes or blood to be transmitted.

Routes of HIV transmission include:

- unprotected vaginal or anal intercourse with an HIV positive person
- unprotected oral sex with an HIV positive person (a person who gets vaginal discharge, semen or pre-seminal fluid in their mouth has the highest risk)
- blood transfusion or organ transplant from an HIV-infected person
- use of drug injection equipment containing HIV
- from mother to child during pregnancy, delivery or breastfeeding



DIAGNOSING HIV

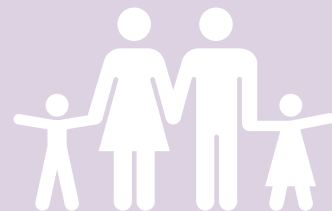
The infection is diagnosed with an HIV antibody test. HIV can be detected in the test one to three months after contracting the infection. The test can be performed as a rapid test through a blood sample taken from either your fingertip or your arm. In Finland, the test can be taken in any healthcare unit, at the Finnish AIDS Council and at the Finnish Red Cross (SPR).

Diagnosing infection as soon as possible after acquiring it offers a good possibility to take care of your own health and to protect others.

Diagnosis can trigger fears of death, childlessness, abandonment both in the family and the community or of losing a residence permit. A person who has just moved into Finland may have to adapt to a new culture and,

at the same time, process the knowledge that they have HIV.

Being HIV positive will not affect your possibilities of acquiring a residence permit in Finland.



TELLING ABOUT HIV INFECTION IN THE FAMILY



WHEN A PARENT IS HIV POSITIVE

HIV positive parents wonder whether they should tell their children about the infection and when would be the best time to tell. Most parents want to secure a carefree and safe childhood and adolescence to their children. Parents may think that their health condition is not their children's concern and do not want to burden their children with sad and difficult issues. Parents may want to avoid the potentially difficult questions their children may have: How were you infected? Are you going to die? Am I infected? Children may notice that their parents have something on their mind and sometimes a child may hear about their parent's infection accidentally, for instance, from someone else or when the parent takes medication.

It is good to tell your child about the infection little by little and give the disease a name when you feel like you are ready for it and the child is old enough to understand. A safe and supportive atmosphere is important when telling to the child about the infection. It is good for the child to hear that there is medication for the disease with which the parent can live a full life.



WHEN A CHILD IS HIV POSITIVE

When a child is HIV positive, the age and level of development of the child as well as their ability to process matters and words must be taken into consideration when telling about the infection. It is good for a child to

know as early as possible about matters concerning their own health so that the child can take care of him or herself and understand why, for instance, they must have regular health inspections and blood tests. It is easier to arrange the medication if the child knows why they must take it and why it is important to take the medication at the exact time and the in the exact manner. When the child is aware of the infection the child knows how to behave in blood infection risk situations (e.g. nose bleed or open wound). These can be discussed beforehand with the child and the child can be taught how to behave in these kinds of situations without panicking.

It is also good to discuss with the child the persons that know about the infection and with which the child can talk about it.



WHEN A TEENAGER IS HIV POSITIVE

Teenagers spend a lot of time thinking about themselves, their self-image and their future. Insecurity and the development of self-esteem are a part of adolescence. One of the biggest questions an HIV positive teenager has is: Am I normal and is this what is happening to me normal? Long-term illness is always a challenge in adolescence. Living with HIV comes with a lot of insecurity: about the future, about what happens in the body, about how others react, about who you are and what you are going to be.

In adolescence, the teenager becomes detached from the parents and the relationship with the parents can become loose. Adolescence might include a lot of questioning and rebellion against parents and authorities. In adolescence, the teenager may also rebel against regular medication and refuse to take HIV medication. When this happens, the treatment chain of the teenager should tighten their cooperation. It is recommended to share your thoughts with your own nurse, doctor or HIV support centre professional. The teenager's opinions must be taken into consideration but it is the adult's task to explain why it is important to take the medication regularly.

It is important for the teenager to be accepted among friends. The teenager might want to hide the HIV infection from friends or consider who to tell about it. The fear of not receiving understanding or approval after the

infection has been revealed is big. This can limit the circle of friends and affect social relationships.

Children and teenagers from multicultural families are in a different position compared to Finnish children. They have to balance between two different cultures, their own family and the social environment and circle of friends in the new home country.

Different cultural and religious views or the relationship between the parent and the child can have an impact on how the teenager adapts to the new culture and develops identity.

It is important for an HIV positive teenager to understand the effects of HIV infection on sexuality and sexual behaviour. The first experiences related to sexuality and sex are groundbreaking for every adolescent both physically and mentally. When a sexually transmitted disease is added to the mix, the situation becomes all the more complex. It is important that the young person receives adequate information regarding safe sexual behaviour well before they start their sex life in order to be able to protect themselves and potential partners.

It might be difficult for the teenager to openly talk about sensitive and confusing matters with their parents. A more suitable party in this case would be, for instance, school nurse or other healthcare professional. For instance, when talking about menstruation, the topics can also include potential pregnancy or, when talking about the puberty of a boy, the possibility of becoming a father. It is important to tell the adolescent that it is possible to have children in the future in spite of the HIV infection.



HOW TO TELL

Not everything can be told at once. Telling is a path that proceeds little by little. It is good to prepare the child or adolescent and tell about the disease first on a general level before naming it. First, it is recommended to discuss what the child or adolescent knows about diseases on a general level. Have they heard or read somewhere about HIV or AIDS? It is good to tell about the infection when there are no other major changes in the child's or adolescent's life, such as moving, change of friends or the turmoil of puberty.



It is recommended to use words and mental images that are familiar to the child or adolescent. You should use correct terms, such as blood infection, virus, bacterium, immune system, etc. It is good to check what the child or adolescent thinks is meant by, for instance, blood infection, and clarify difficult terms.

It is also recommended to go talk with the child or adolescent about the fact that HIV as a disease can trigger various fears in other people and cause discrimination. You can remind the child or adolescent that there is no need to tell everyone about the infection. You can contemplate with the child or adolescent, who to tell about the infection. For instance, in day-care, school and hobbies, it is recommended to have a couple of adults who know about the infection with which the child or adolescent can have safe and confidential discussions about the matter. It is also good to think what kinds of reactions might take place if the child or adolescent cannot keep the information about the infection to themselves.

Children and adolescents react to the information in various ways depending on their personality. The child or adolescent might have several questions or may become completely silent and not want to discuss the matter at all. The reaction can also be complete silence, tears or shock. Another potential reaction is to focus on other matters. Some can be relieved and others may want to discuss the matter again with an adult.

It is essential to accept the reactions and respond appropriately. Even if the child or adolescent does not talk about the infection, it is good to discuss it again after some time. You can, for instance, ask whether the child or adolescent has understood what the discussion was about and if they have questions. A matter that has not been talked about for a long time may first feel strange and you must give the child or adolescent time to accept it. You must offer the child or adolescent opportunities to talk about HIV and not just wait for them to starting talking.





LIVING WITH HIV

It is possible to live full life with HIV infection. An HIV positive person does not cause a risk of infection to their surroundings because HIV is not transmitted in regular interaction in, for instance, hugging, kissing, public toilets or shared dishes. An HIV positive person can share the same household with other people, cook food and have hobbies without worries. HIV positive children can attend day-care, clubs and school and go swimming, do exercise and participate in day-care or school trips just like any other child.

There have been no identified incidents in Finland where HIV has been transmitted from child to child by accident. Day-care centres and schools should have guidelines for various risk situations, such as biting, fights and wounds. In practice, the school nurse is responsible for the healthcare of their school and will provide guidance in risk situations and with potential blood infections. When necessary, the hospital taking care of the treatment of the HIV positive adolescent can also be contacted for further instructions.



WHO SHOULD KNOW ABOUT THE CHILD'S OR ADOLESCENT'S INFECTION OUTSIDE HOME?

There is no obligation to tell about HIV infection in Finland but confidential relations in day-care and school help a child or an adolescent and people around them to better understand HIV infection. School and day-care staff and other operators who are in contact with HIV positive persons are covered by confidentiality obligation. A child's or adolescent's medical records cannot be disclosed without written consent from the parents.

Professionals are recommended to cooperate when dealing with an HIV positive child or adolescent and gather all the supporting parties together. The aim of the cooperation is to diminish the fears related to HIV. It is imperative that the professionals treating the child or adolescent get appropriate information and that they have been given the contact details of the healthcare unit responsible for the medical care of the child or adolescent. An employee at the Finnish AIDS Council can be asked to come to the school to discuss HIV on a more general level.



MEDICAL TREATMENT OF A CHILD OR ADOLESCENT

Medication that has been started at an early stage can limit the harm caused by the virus to the child's or adolescent's body. The starting date of medication depends on the deterioration of immune system, i.e. rapid diminishing of helper cells (CD-4). Starting medication is always considered individually. The child or adolescent and the guardians must be prepared for lifelong medication and understand the significance of regular medication on their life and future. Irregular medication may lead to weaker effectivity of the medication and deteriorated health.

It is recommended to discuss with the child or adolescent step by step how they, for instance, keep the medication with them, how they remember to take the medication regularly and where and when they should take them. Spending time with friends may make taking care of the medication more difficult. It may become irregular or stop altogether. Problems may be caused, for instance, if friends are not aware of the child's or adolescent's condition and they try to take the medication in secret. It is recommended to discuss these matters as well with the care professionals and, for instance, school nurse.

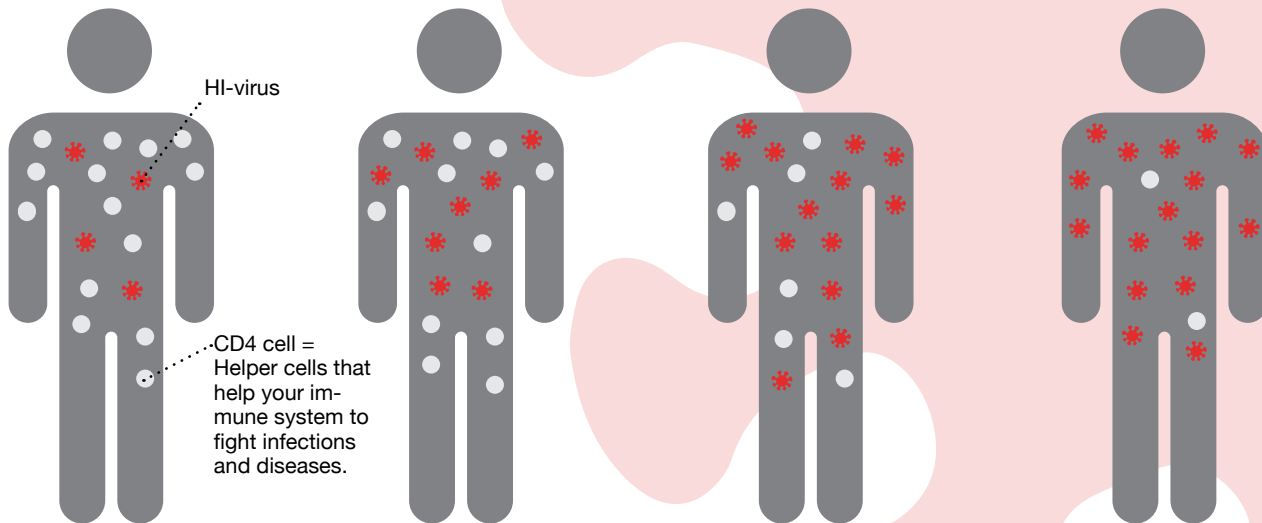


PROFESSIONAL HELP

HIV positive people will get treatment and their situation will be monitored at the outpatient clinic by a doctor of infectious diseases. The condition of the infection and the immune system will be monitored at appointments. After medication has been started, its actualisation and effect on the virus will be monitored. When dealing with children or adolescents, growth and development will also be monitored. The aim of the treatment is to support the customer in knowing the disease and how they can affect and maintain their health. Hospitals engage in interdisciplinary cooperation in order to promote the health of the customer. The care team can include, based on what is required, for instance, a social worker, psychologist, physiotherapist and



PROGRESSION OF HIV IF UNTREATED



STAGE 1

You feel healthy. A healthy lifestyle will help you stay healthier. Maintain a healthy diet and take regular exercise. When you start taking medication, the aim is to halt the progression of HIV beyond stage 1.

STAGE 2

You may develop some symptoms, such as a rash, cough and stomach problems. You should consider starting medical treatment.

STAGE 3

You may feel sick and require hospital care. You may lose weight and feel tired.

STAGE 4

Without medication, you feel extremely ill. Your HIV infection has progressed to AIDS. Your immune system is too damaged to protect you from diseases that arise because of the virus.

nutrition therapist. From the hospital, the HIV positive child or adolescent can also be directed to the AIDS Council or other service providers.

In addition to hospital monitoring, children attend regular child health centre and school nurse appointments. Upon the consent of the parents, the hospital can be in contact with the child health centre, day-care centre and school healthcare.

Transferring the treatment of an adolescent from the children's hospital to the adult department will be considered case by case. Transferring the treatment to the adult department will lead to greater responsibility of the adolescent: they have to be able to take care of the regular clinic appointments and medication. Well planned and organised transfer of treatment will promote the commitment of the adolescent to the treatment at the adult department.

THE FINNISH AIDS COUNCIL

The AIDS Council is a professional organization that works to prevent HIV infections. The council offers services to people who have been infected with HIV, people close to those infected, and those who worry about being infected. Low threshold services offered by the AIDS Council include rapid HIV testing and advice by phone or online. You can take an HIV test at any Council location by reserving an appointment by phone. AIDS Council offices are located in Helsinki, Tampere and Oulu.

The phone service operates Mon-Thu from 10.00 a.m. to 3.30 p.m., tel. +358 20 7465 705 and Internet counseling at **www.hivtukikeskus.fi/www.aidsCouncil.fi** **www.hivtukikeskus.fi/www.aidsCouncil.fi**. Further information on HIV, testing and offered services can be found on the Finnish AIDS Council's website in Finnish, Swedish, English and Russian.

The AIDS Council also offers crisis and support discussions and peer support. All AIDS Council services are free of charge, anonymous and confidential. The services are available in Finnish, Russian, Somali and English. Interpreters can be used at the customer's request.

More information about multicultural HIV work:

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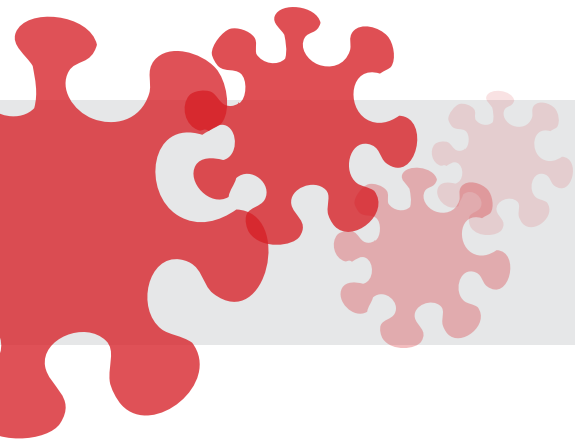
SOCIAL GUIDANCE

The Finnish AIDS Council also offers social guidance for HIV positive persons. The topics discussed in social guidance may include living, residence permits, subsistence, working life, studying and various benefits and rights. Social guidance also helps with potential discrimination situations.

PEER SUPPORT GROUP AND ADAPTATION TRAINING COURSES AT THE AIDS COUNCIL

The peer support group and adaptation training courses offer an opportunity of meeting other HIV-infected people and people close to them. For more information on the group and the courses, please contact the AIDS Council.

The AIDS Council also has a group for children and adolescents meeting 4–6 times a year. The group welcomes all HIV positive children and adolescents living in Finland. The activities of the group are planned according to the age, development level and needs of the participating children and adolescents. The aim of the group is to offer empowering support for the development of HIV positive children and adolescents. Before participating in the group, the child or adolescent will meet the group instructor with their family, if possible.



HIV FOUNDATION

Unioninkatu 45 K, 00170 Helsinki

**HIV Foundation counselling and
appointments for HIV tests** +358 207 465 705

(Mon-Thu, 10.00 a.m. to 3.30 p.m.)

www.hivtukikeskus.fi www.aidsCouncil.fi

