



HIV in the family

To the reader

This brochure is intended for families in which a parent, young person or child has HIV. The brochure was prepared in cooperation with the HUS Children's Hospital and Hivpoint.

LIVING WITH HIV

You can live a full life with HIV. HIV cannot be transmitted through hugging, kissing, sharing a toilet, or using the same dishes. A person living with HIV can work, participate in social activities, and start a family. HIV positive children can go to a daycare centre, clubs and school. They can also go swimming, play sports and participate in trips organised by their school and day-care centre, just like other children their age. HIV has never been accidentally transmitted from one child to another in Finland.



How can HIV be transmitted?

HIV does not transmit easily. HIV is not transmitted by air or by touch, or in everyday activities.

HIV transmit in the following ways:

- through unprotected vaginal or anal intercourse with a person with HIV who is not on effective medication
- receiving the semen, pre-seminal fluid or vaginal fluid of an HIV positive person in your mouth
- by receiving a blood transfusion or organ transplant contaminated by the HI virus (blood and organs donated in Finland are tested)
- by using a needle, syringe or other injection equipment infected with the HI virus
- from a mother who is living with HIV to her child during pregnancy, birth or breastfeeding (if the mother is not on effective medication)

With HIV medication, you can live an ordinary life without symptoms

At the moment, there is no cure for HIV, but regular HIV medication stops the progress of the infection.

Support from family and friends helps those living with a chronic illness. That is why it is important that families can talk openly about issues related to HIV, and that the necessary and correct information is available to everyone.



TALKING ABOUT HIV

When a parent has HIV

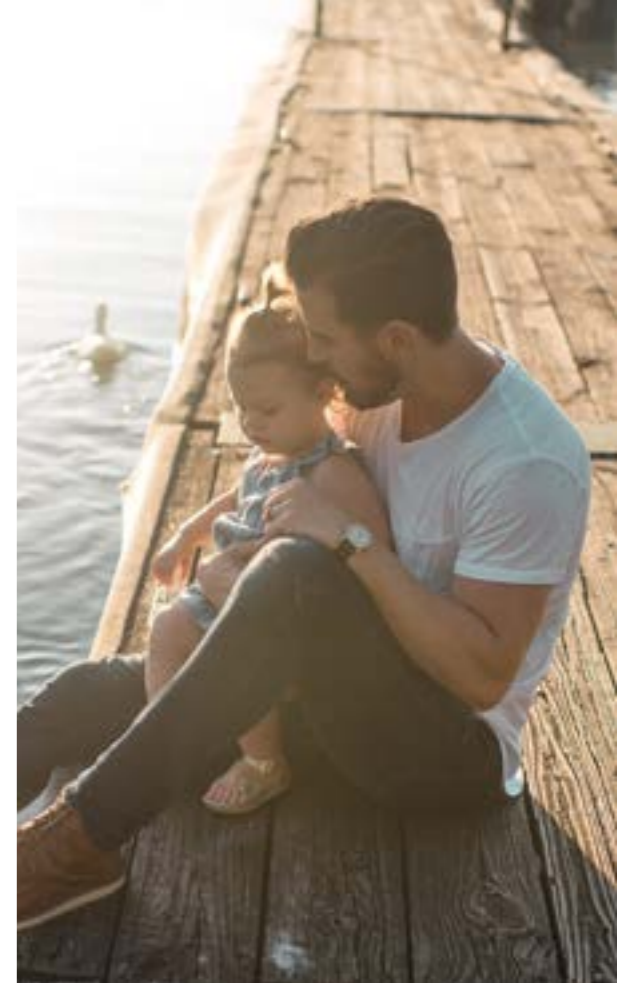
Parents with HIV often wonder whether they should tell their children about it, and when would be the right time to do so. Most parents want to provide their children with a carefree and safe childhood and teenage years. The parents may feel that their medical condition has nothing to do with their children, and would rather not burden them with sad and difficult issues. They may feel shy about answering the questions their children ask: How did you get infected? Are you dying? Have I been infected? Children may notice that something is bothering their parents, or a child or young person may find out about their parent's HIV by accident; for example, after being told by someone else or noticing a parent taking HIV medicine.

A child should be informed about the illness in stages. Give the illness a name when you feel ready and the child is old enough to understand it. It is important to inform the child in a safe setting and to provide support. The child should be told that medication is available for the illness, which helps the parent to live a full life.

When a child has HIV

When a child has HIV, how they should be told about the illness depends on their age and stage of development, and their ability to process issues and words. The child should be told about factors affecting their health at the earliest possible stage, so that they can look after themselves and understand why they need regular medical check-ups and blood tests, for example. It is also easier to administer medication when the child knows why they are taking it.

You should also let the child know which people already know about the illness, and with whom they can discuss it.





TALKING TO YOUR CHILD ABOUT HIV

You cannot tell the whole story at once.

Sharing is a path to be followed in stages, while slowly moving forward.

You should prepare the child or young person by discussing the illness in general before naming it as HIV. You can start by discussing what they know about falling ill and illnesses in general. Have they heard or read about HIV or AIDS? Open the discussion during a quiet period, free of other major events in the child's or young person's life, such as moving house, changing friends, or the emotional tumult of adolescence.

Use words and images that are familiar to the child or young person. Give issues the correct names and make sure that the child understands them. Explain the more complicated words, if necessary.

You can tell the child or young person that they do not have to tell everyone about the HIV infection.

Together you can discuss who the child can talk with about HIV.

You should also make it clear that HIV can raise various fears in people, which are mainly due to prejudice and lack of information.

The way the child or young person reacts to this news will vary according to his or her personality. They may have a number of questions, or fall silent and be unwilling to discuss the issue. Other possible reactions include utter silence, crying, or shock. They may also choose to avoid the issue. Some may be relieved, while others may want to think about the issue and discuss it further with an adult.

The key is to accept the child's reactions and respond accordingly. You should return to the issue after some time has passed, even if the child or young person does not bring it up. For example, you can ask if they have understood the discussion, or if they have any questions. An issue on which a long silence has been maintained may feel strange at first. Accepting it will take time.

You should provide the child or young person with opportunities to discuss HIV rather than waiting for them to raise the issue.

Who, outside the home, should know about a child's or young person's HIV infection?

In Finland, there is no obligation to inform people, but confidential relationships at a day-care centre or school can help a child and those around him or her to gain a better understanding of HIV.

All staff in schools and day-care centres who interact with a person living with HIV are bound by professional secrecy.



HIV AND YOUTH

One of the most common questions among young people is: Am I normal? Young people may worry about their self-image, are often insecure and in the process of developing their self-esteem. Young people, in particular, may find it difficult to accept that a chronic illness is part of who they are.

Rebellion against parents and authority are common during adolescence. Young people may also question the need for regular medication and refuse to take their HIV medicines. In challenging situations of this kind, everyone involved in the care of the young person need to work in close cooperation. It is important to listen to the young person's views and opinions, but it is the adult's responsibility to thoroughly explain why it is important to take the medication regularly.

In a young person's life friends often become more important, and a young person living with HIV may wonder who he or she should tell about the illness. Young people may fear not being understood or accepted, which may affect their social relationships. In these circumstances, the young person should be provided with the opportunity to talk about the issues with a trustworthy adult.

A young person's first experiences related to sexuality and sex may be both physically and mentally tumultuous.

It is important to inform the young person that, despite their HIV status, they have the right to a good and satisfying sex life and the possibility to have children in the future, if they so wish.

MEDICATION

HIV cannot be cured at the moment, but regular HIV medication stops the infection from progressing. With HIV medication, you can live a normal life without symptoms.

A person living with HIV who is on effective HIV medication will not transmit HIV to others.

Before medication is begun, a doctor will assess the case. When medication is started at an early stage, there will be less damage caused by the HIV to the child's or young person's organs. The decision to start medication is always individual. The child or young person and their guardians must be committed to life-long medication, and must understand its importance to their lives and future. If taken irregularly, the medication may not work properly, leading to a deterioration in health.

Thorough discussions should be held on issues such as how to carry the medication around, how to remember to take it regularly, and where and when to take it. The child may find it difficult to take the medication when spending time with friends. He or she may start taking it irregularly, or stop taking it altogether. Problems may arise if the child or young person tries to keep the medication secret, as part of trying to prevent friends from finding out about the HIV. Such issues should be discussed with medical staff.

The transfer of a young person's care from a children's hospital to the adult side should be planned individually. This will mean giving the young person more responsibility: he or she must be able to manage the medication and regular visits to the clinic. A well-planned transfer will promote the young person's commitment to treatment via adult healthcare.



HIVPOINT

Hivpoint is a non-profit organisation engaged in HIV prevention and providing services for people living with HIV, people who are close to them and those worried about HIV infection. Hivpoint's low-threshold services include HIV rapid testing; phone, chat and online counselling; and sexual counselling. You can be tested for HIV at all Hivpoint offices by making an appointment by phone.

- Phone counselling is available Mon-Thurs at 10.00-15.30 on 0207 465 705
- Online counselling and chat services can be accessed from www.hivpoint.fi

At Hivpoint, we offer crisis counselling, support counselling, and peer support. All Hivpoint services are free of charge, anonymous and confidential. We offer our services in Finnish and English. If you wish, an interpreter can be used.

Hivpoint has offices in Helsinki, Tampere and Oulu.

Peer support group and adaptation training courses at Hivpoint

Our peer support group and adaptation training courses will provide you with the opportunity to meet other people living with HIV and people close to them. Hivpoint organises groups for adults, children and young people. Contact Hivpoint for more information on groups and courses.



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