Questions Kids Ask About HIV

Questions about HIV and what it is

What does HIV mean?

H stands for Human.

I stands for Immunodeficiency.

Immunodeficiency means the immune system doesn’t work right. The immune system is a team of cells in your body that work to keep germs from making you sick.

V stands for Virus.

A virus is a tiny germ that is so small you cannot see it. A virus can make people sick. It turns healthy cells into sick cells and then your body feels sick. Put together, HIV is a virus that makes people’s immune system not work well.
Do I have something bad inside me?
HIV lives in cells inside of people. Sometimes we think of germs as bad because they can make people feel sick. HIV is just one kind of germ. Many people get sick with different kinds of germs. This doesn’t mean that they are bad. Having HIV does not mean you are bad.

Can I see HIV with a microscope?
HIV is so tiny that you cannot see it with a regular microscope. There are special microscopes called electron microscopes that can be used to see the HIV.

How do you know it’s in my blood?
There are special tests that we use to measure the HIV in your blood. These tests are done in laboratories in the hospital. If people are not taking medicines that fight the HIV, the tests measure a lot of HIV in their blood. When people are taking medicines that fight HIV there is not much HIV in the blood.

Why do you have to test my blood so much?
We test your blood so we can keep track of how much HIV you have. This helps us to make sure all your medicines are working to fight the virus. The tests also help us to make sure the rest of your body stays healthy.

Why does the virus make me sick?
HIV is a strong virus when it is inside the body. It infects a type of immune cell called a CD4 T-cell or helper T-cell. Helper T-cells are very important to keep your immune system working. Your immune system is what keeps you healthy from germs, such as those that cause colds, the flu or strep throat. When the HIV makes the helper T-cells sick, they cannot help your body fight other infections. HIV can also make other parts of your body such as your liver, kidneys or bone marrow not work as well. Once it is inside your body, HIV does not go away like most other viruses.
How did I get HIV?
Most children with HIV got the virus from their mothers at the time they were born. If a woman has HIV when she is pregnant, the HIV can pass on to her baby unless she takes medicine to protect the baby.

Can people tell I have HIV when they look at me?
No one can tell on the outside if someone has HIV. People with HIV don’t look any different than anyone else.

Questions about HIV and medicine

Why do I have to take medicine every day?
The medicines you take stop the HIV from getting into new helper T-cells and making them sick. They also keep helper T-cells that already have the virus from making more HIV. When you take medicine, it goes into your stomach and from there it gets into your blood and travels all over your body. It is important for the medicine to be in your body everyday so that it can always be there to stop any cells from making HIV and to keep the HIV out of new cells. If the level of medicine in your blood gets too low, the HIV can escape and infect new cells.

Why do I have to take the medicine if I feel good?
Medicine is for sick people.
You don’t feel sick because you take your medicines. If you didn’t take your medicines, the HIV would make your helper T-cells stop working and your immune system would have trouble fighting other infections. If the HIV gets very strong and makes all your T-cells sick, you can get more infections, lose weight and feel sick and more tired.
**Will my medicines ever change?**
Sometimes when your body can no longer use your medicines to fight the virus, the doctors may change them. They may also be changed as you get older.

**What happens if I forget to take my medicine or don’t take them?**
Over time, if you continue to forget or you stop taking your medicines, they may stop working to control the HIV. The HIV may change so that even if you restart your medicines they won’t work as well. This is called viral resistance. There are only a certain number of medicines that fight HIV, if your virus gets resistant to the medicines; it is harder to find medicines to fight the HIV.

**Why doesn’t my brother or sister have to take medicine?**
People who don’t have HIV do not have to take medicines to fight HIV. Almost everyone has to take medicine at some time in their lives as most people get sick with something. Your brother or sister may need medicines for something else. If this happens it will be important for them to take their medicines, too.

**My medicine makes my tummy hurt, why do I have to take it?**
Sometimes even things that are good for you (like medicines) can cause some problems. Some of the HIV medicines can make your tummy hurt. This usually gets better over time. If it doesn’t get better or if your tummy hurts really bad, you should let your parents and doctor know. You may need to change to a different medicine.
Will it be hard to swallow pills when I’m ready to stop taking liquid medicine?  
Many of the liquid medicines don’t taste very good, so most kids are happy when they get big enough to swallow pills. Just like you learn to do other things, like how to ride a bicycle, you can learn to swallow pills. You should let your parents or your doctor know when you want to learn to swallow pills. They can help you learn.

Why do I take so many medicines?  
Since HIV is a strong virus, it takes a lot of medicine to keep it under control. It takes at least three different kinds of medicines taken all the time to keep the virus from hurting your immune system. Sometimes the medicines can be put all together into one or two pills, but sometimes they come in a lot of different pills.

What else can I do to stay healthy?  
In addition to taking your medicines, there are other things you can do to help you stay healthy. Getting enough sleep, getting regular exercise and eating healthy foods are all good for you. It is also important to get all of your immunizations as these can keep you from getting other infections. Another way to keep away germs is to wash your hands regularly.

Should I take vitamins?  
If you eat a lot of different foods every day, you can usually get all the vitamins you need. Sometimes your doctor will say you should take extra vitamins, such as vitamin D or a multi-vitamin (a pill with a lot of different vitamins in it). They would know this based on your blood tests.

Talking about your HIV with others

Do I have to tell anyone about my HIV?  
You do not have to tell anyone about the HIV. Sometimes it is important for other people to know about the HIV. One example
would be the nurse at school. They can help take care of you better if they know about the HIV. It is important that any doctor taking care of you knows about the HIV. When you get older and have a serious girlfriend or boyfriend, it will be important for them to know about the HIV.

Even if you don’t have to tell anyone about the HIV, it is OK if you want to tell a friend or other person about the HIV. It can help to talk to friends or relatives about the HIV. It is important to know that they still like you and still want to be your friend.

How can I explain to a friend that I trust what it means to have HIV?

It is important that you can trust your friend, especially if you don’t want anyone else to know. Let your friend know there is nothing unsafe about being friends. Let them know that they will not get the virus by being your friend. Be ready to answer the questions they may have. Explain that the virus is not passed by eating together, swimming, sharing a toilet or playing together. Let them know they don’t have to do anything special to be a friend.

Why is HIV something private but it’s ok to tell people when I have the flu or a cold?

Some people don’t know much about HIV. They think HIV is something really scary. They may be afraid of people with HIV. Sometimes your parents tell you not to tell other people about the HIV. They say this because they don’t want you to be teased or have other kids be afraid of you. It isn’t because there is anything wrong with you. Having HIV is nothing to be ashamed of. Your parents love you and want to protect you.

Will kids make fun of me if they know I have HIV?

Some kids may make fun of you. They may make fun of other kids for other reasons, such as because they wear glasses or have braces. Some kids don’t understand that when they make fun of people it
hurts their feelings. Some kids may not care about other kid’s feelings. Most kids would not make fun of you.

**HIV and transmission**

**Is my blood dangerous?**

Since HIV lives in blood cells, if the blood of someone with HIV gets inside another person, that person could also get HIV (this is called “transmission”). However, if someone just got some blood on their skin and washed it off, they would not get HIV. HIV is not the only virus that can be in blood. That is why people should not touch other people’s blood. You should tell an adult if you get a cut and are bleeding. Don’t let other kids try to help, wait until the adult comes to help. Cuts and scrapes should be covered with band-aids. Once the cut or scrape is cleaned and covered, you can return to play with your friends.

**Can I accidently give HIV to friends or family?**

It is very hard to give HIV to someone else accidentally. The HIV doesn’t live for a long time outside of the body. It isn’t passed to other people by spit or skin. So you can’t give HIV to someone else just by being around them. A person can’t give HIV to another person by playing or eating together, hugging, kissing, having sleepovers, swimming or sharing things like toys or clothes. It is important not to let other people touch your blood if you have a cut. It is also a good idea not to share your toothbrush or razor with anyone. This will help protect everyone.

**What does HIV have to do with sex?**

One way that HIV can be spread is through unprotected sexual intercourse. For more information about HIV and sex, talk with your parents and health care providers. You can also read our handout called “HIV: Teens and Sex.” It is available on our website. You can ask your health care provider for a copy when you come to clinic.
More questions about HIV

Are there other kids who were born with HIV?
There are many children all over the world who are born with HIV. Like you, people can’t tell by looking at them that they have HIV either.

Are there kids born with HIV who now are adults and who have families of their own?
Yes. HIV has been around for many years. Children who were infected years ago when they were babies and have stayed healthy because they took their medicines are now growing up to be adults. Some of these children are married and have families of their own.

Why do people in other countries die from HIV but people in the United States don’t?
In many countries it is hard to get the medicines that fight HIV. Also, people in many countries do not get tested for HIV before they get sick. If someone is very sick with HIV even if they get the medicines, they may die before the medicines start working. In the United States it is easier for people to get HIV medicines. Even in the United States, people also die from HIV if they don’t get tested for HIV before they get sick.

What research is being done on HIV?
There are many scientists researching HIV. It is because of this research that we now have many medicines to treat HIV. The research has also helped doctors learn how to treat women with HIV who are pregnant so they don’t pass the virus to their babies. Scientists are working very hard to find a cure for HIV. At this time they don’t know how to cure HIV, but as they learn even more about how HIV works, they hope to find a cure. Many children throughout the world have helped the doctors and scientists with their research by taking part in research studies. This is how we have learned what medicines are best for children and how much medicine each child should take. You can ask your
doctor if there are any research studies at your clinic you could take part in.

**HIV and my future**

**Will I be able to have kids?**

Women with HIV can have babies without passing them the virus. If a woman with HIV is pregnant, she can take medicines to fight the HIV. These medicines will keep the baby from getting HIV. It is possible to get pregnant without passing the HIV. Doctors can help couples do this safely.

**Will I die?**

Everybody dies eventually. However, even though you have HIV no one expects you to die when you are young. Taking your medicines everyday will keep the HIV under control and not able to hurt your body. One of the reasons that you go to the doctor and get your blood taken is to make sure the medicines are working and that they are not causing your body any problems. The doctors may need to make changes to your medicines to keep you healthy. We expect all of the children we see in clinic to grow up to be adults.

**Where can I get more information or support?**

- Videos by kids for kids on living with HIV from Baylor College of Medicine: bipai.org/dvds-videos
- Staying Healthy with HIV AIDS: www.aids.gov/hiv-aids-basics/
- Kids Health HIV and AIDS: kidshealth.org/kid/health_problems/infection/hiv.html
- Reach Ministries – www.reachministries.org

Seattle Children’s offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children’s will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children’s. However, your child’s needs are unique. Before you act or rely upon this information, please talk with your child’s healthcare provider.

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