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Care and Treatment for Children Living with HIV

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Table of Contents

- [The Good News](#)
- [HIV in Children](#)
- [Preventing Illnesses](#)
- [HIV Care and Treatment for Children](#)
- [The Challenge of Adherence for Children Living with HIV](#)
- [Children Living with HIV and Disclosure Issues](#)
- [Taking Care of Yourself](#)

The Good News

Every parent wants their child to be healthy and safe. When your child is living with HIV, there are some extra steps to take to make sure that they get the right care. The good news is that children living with HIV, just like adults living with HIV, are living longer, healthier lives with improved treatments.

Note: For many children living with HIV, the parent is also living with the virus. It is important that you take care of your own health, even as you handle your child's needs. If that seems difficult, ask your local AIDS Service Organization about any help available.

HIV in Children

HIV is somewhat different in children than in adults. Children living with HIV normally have much higher [CD4 cell](#) counts than adults living with HIV, but may also have higher [viral loads](#) (the amount of HIV in the blood).

In adults, HIV weakens a fully mature [immune system](#). In children, HIV attacks a developing immune system. As a result, children living with HIV - even those on HIV drugs - are more likely than both HIV-negative children and adults living with HIV to get bacterial infections, including ear infections and [pneumonia](#).

In addition, children living with HIV who are not taking HIV drugs are more likely to become sick with shingles (herpes zoster), [Mycobacterium avium complex \(MAC\)](#), and a lung problem called lymphoid interstitial pneumonitis (LIP). LIP symptoms include fever, coughing, and shortness of breath. A child living with HIV who cannot catch their breath is a medical emergency. Thrush (white patches in the mouth due to [yeast](#)) is common in children living with HIV who are not on HIV drugs and can make it difficult to eat. Since infections can start in the mouth, it is important that children living with HIV see a dentist regularly.

Children living with HIV who are not taking HIV drugs may be small for their age and may not grow at the same rate as HIV-negative children. A child living with HIV may be undersized or underweight because of a loss of appetite (not wanting to eat) related to HIV or because of some of the drug treatments. Children living with HIV may have [diarrhea](#), which can also make it difficult to gain weight. It is important that children living with HIV have proper [nutrition](#). But getting kids to eat right can be hard, even when children are not living with HIV! If you have questions or need help, it is important to ask your child's health care provider or an AIDS service organization for a referral to a dietician who knows about the nutritional needs of children living with HIV.

Lastly, children living with HIV who are not taking HIV drugs may also have more learning and thinking problems. Some of these thinking and behavioral difficulties, as well as many of the illnesses listed above, can be prevented by taking HIV drugs. Children living with HIV who take HIV drugs can now grow into healthy adults, get jobs, have HIV-negative children – and make many of their dreams come

true.

Preventing Illnesses

Vaccinating your child is one of the most important things you can do to keep him or her from getting sick.

The US Department of Health and Human Services (DHHS) has made recommendations to prevent children living with HIV from getting [opportunistic infections](#) (OIs), or diseases that attack the body when the immune system is weak. All infants living with HIV up to the age of one year are given medicine to prevent pneumocystis pneumonia (PCP, also called *Pneumocystis jirovecii*), a type of pneumonia that is more likely to affect people with weakened immune systems. After the first year, some children should still receive preventive medicine depending on the health of their immune systems.

If a child living with HIV tests positive for exposure to [tuberculosis](#) (TB), it is important that the child take medicine to keep TB from developing. Depending on the child's age and [immune system](#), medication may also be given to prevent MAC, which is caused by a germ that can affect the lungs or the gut. In some cases, as the child's immune system becomes stronger, their health care provider may suggest that these kinds of preventive medicines can be stopped.

Vaccinating your child is one of the most important things you can do to keep him or her from getting sick. Children living with HIV are immunized for most diseases in the same way as HIV-negative children.

Check with your child's health care provider about any special requirements for vaccinating children living with HIV. For example, it is important that children living with HIV get the measles, mumps, and rubella (MMR) vaccine and the chicken pox (varicella) vaccine if their CD4 cell counts are high enough. However, they should not receive these vaccines if their CD4 counts are very low.

No parent can protect a child from every germ. While you may want to keep your child living with HIV away from people who have colds and the flu, it is important to understand that your child will eventually be around someone who is sick. Teach your child to wash their hands often and thoroughly – which you are probably already doing because of the COVID-19 pandemic. Because children often rub their eyes or put their fingers in their mouths or noses, keeping hands reasonably free from germs and using tissues to wipe your child's eyes or nose can help keep your child healthy.

HIV Care and Treatment for Children

Finding a pediatrician (children's doctor) with whom you feel comfortable and who has experience treating children living with HIV can be very important for your child's health. It is helpful to have a local pediatrician who is close by and can help with all of the regular childhood issues, and to also consult a health care provider who is an HIV expert (especially if your local pediatricians do not have a lot of experience treating children living with HIV). Expert HIV pediatricians (Pediatric Infectious Disease Specialists) will often work at a children's hospital or medical center with an HIV program. If you find it difficult to get to such a specialist (for example, because the medical center is far away), talk to your local AIDS service organization. They may be able to tell you how to get help with transportation or other issues.

HIV drug treatment works very well for most children and starting it early will keep HIV from causing more damage to your child's body. The World Health Organization (WHO) recommends that all children living with HIV receive HIV drugs, regardless of their CD4 count. The WHO also suggests that starting HIV drugs be a priority in all children younger than five years of age. The WHO treatment guidelines can be found [here](#).

The DHHS has also put together a set of [pediatric treatment guidelines](#) that recommend when children should start medications and which ones they should take. The DHHS recommends that children of all ages take HIV drugs, regardless of CD4 count, viral load, or clinical symptoms.

Your child's HIV specialist is the person to talk to about when to start HIV drugs, which ones to start, and what the possible [drug interactions](#) and [side effects](#) might be. There is not as much information available about the use of HIV drugs in children as in adults, and not all HIV drugs are available for children. Still, the US Food and Drug Administration (FDA) has approved many HIV drugs also for children. The pediatric treatment guidelines mentioned above also include an overview of approved HIV drugs for children. Finding the right dose is important. Children's doses are based on their weight, so dosing will have to be adjusted as your child grows.

Once treatment is started, it is important that your child be checked regularly to make sure that the HIV drugs are working well and not causing any serious side effects. Work with your pediatrician to keep a close eye on your child's growth, development, and lab tests (such as viral load and CD4 counts). If you see problems, you may need to talk with your child's HIV provider about changing to different HIV drugs. It is also important to ask your child if they are experiencing any pain. Staying aware of how your child is feeling will help you to know if they have become ill or are experiencing side effects.

The Challenge of Adherence for Children Living with HIV

Medicines cannot work if they are not taken correctly. If children do not take their HIV drugs exactly as directed, HIV can mutate, or change. Some of these changes enable HIV to survive and reproduce (make copies of itself) despite having the HIV drugs in the bloodstream. When this happens, we say that HIV has developed resistance to one or more of the HIV drugs your child is taking and he or she will likely have to change to another treatment (for more information, see our fact sheet about [resistance](#)).

The best way to avoid resistance is to take medicine just as it is prescribed. This is called [adherence](#) and means taking the right amount of medicine at the right time and in the right way (with food, or on an empty stomach), without missing or stopping. Children, just like adults, need to be adherent to their HIV drugs' dosing schedules for the treatment to work well.

Ask your pediatrician or other parents for suggestions about how to help your child take medication.

When talking with your child's health care provider about which HIV drugs your child will take, think about your day and how you will fit taking HIV drugs into your child's schedule. If you are also living with HIV, you may want to think about how your child's dosing can fit with your own. It may be helpful for both of you to take your HIV drugs together, as a type of family activity; however, your child may take different HIV drugs that need to be taken on a different schedule.

Getting children to take medicine can be a real challenge. Children may not like how medications taste, or they may have trouble swallowing pills. Many children do not understand why they should put up with the drugs' side effects. Older children may hide pills or pretend to take them.

It may be especially difficult for kids to take their medicines in front of others. Taking pills in public or in a social situation may cause embarrassment or emotional distress. Going on vacation, trips, or to camp may make it more difficult for children to stick to their medicine schedule. It is important to talk about these situations with your child and plan ahead for problem times.

Both you and your child may need extra help with your child's adherence. Ask your pediatrician or other parents for suggestions about how to help your child take medication (you don't need to tell the parents which medications your child is taking, or why he/she is taking them). Try using reminders, rewards, timers, mobile phone apps, color-coded messages, and weekly dosing packets to check

adherence. If your child is having trouble taking a particular HIV drug, talk to your health care provider. It is possible that the HIV drug can be switched to a different one or that your child can be put on a different schedule.

Children Living with HIV and Disclosure Issues

You can teach your child what to do if they cut themselves and how to get rid of their used bandages and other items.

Many parents are concerned about whom they should tell about their child's HIV status. It is your right to decide this for yourself. Your child living with HIV is not a danger to others. HIV **cannot** be [spread](#) through casual contact or saliva, tears, or sweat. Your child **cannot** transmit HIV to someone by hugging, going to school, or sharing toys, utensils, food, and drinks. It can be very helpful for children living with HIV to understand this so they can interact at school and with other children without concern.

It is important for parents to help their children take responsibility for protecting themselves and protecting each other. HIV can be transmitted through blood and certain bodily fluids (semen, vaginal fluids, and breast milk). While the chance is extremely small that infected blood on a toothbrush or razor could transmit HIV to someone else, it is best not to share these items. You can teach your child what to do if they cut themselves and how to get rid of their used bandages and other items.

Those who need to know about your child's status are the people involved in their care, such as nurses, pediatricians, dentists, and social workers. It may be helpful to get support from your health care providers or local AIDS service organization as you decide whom to tell. While it is for you to decide when is the best time to tell your child about their HIV status (see our fact sheet on [Talking with Your Children about Your HIV Status or Your Children's Status](#)), it is very important to tell your child before they become sexually active.

Taking Care of Yourself

Any childhood illness can be hard for parents as well as for their kids. As a parent, you might find yourself wishing that you could take the sickness away from your child. You may feel upset because the medication that you need to give your child causes them distress. You may feel helpless when there is not a good way to explain the situation to your child. Remember that these are normal experiences and feelings for any parent.

It is as important to take care of yourself as it is to take care of your child living with HIV. Here are some tips:

- Find information and resources at a local AIDS service organization (click [here](#) to search the POZ directory in the US)
- If you feel alone, find other parents who can understand and provide support. If there are no other parents nearby who have children living with HIV, find a group for parents of children with other on-going health care needs or look for an internet group.
- If you are living with HIV, take care of your own emotional and physical health. Many parents put their children's health first. You need to stay healthy to help your child.
- If you have other children, find special time for them too.
- While you want your child to be healthy and safe, it is important to allow him or her to enjoy normal childhood experiences.
- Remember that it is okay to ask for help from family and friends. While being a parent is a full-time job, sometimes being a good parent means taking a break!

Additional Resources

Select the links below for additional material related to care and treatment in children living with HIV.

- [HIV Treatment for Children \(Be in the Know\)](#)
- [HIV and Children \(POZ\)](#)
- [Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection \(HIV...\)](#)
- [Elizabeth Glaser Pediatric AIDS Foundation](#)
- [HIV and Children \(HIVinfo\)](#)
- [Growing Up With HIV \(Terrence Higgins Trust, United Kingdom\)](#)
- [HIV Home Care for a Child \(University of Rochester Medical Center\)](#)



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