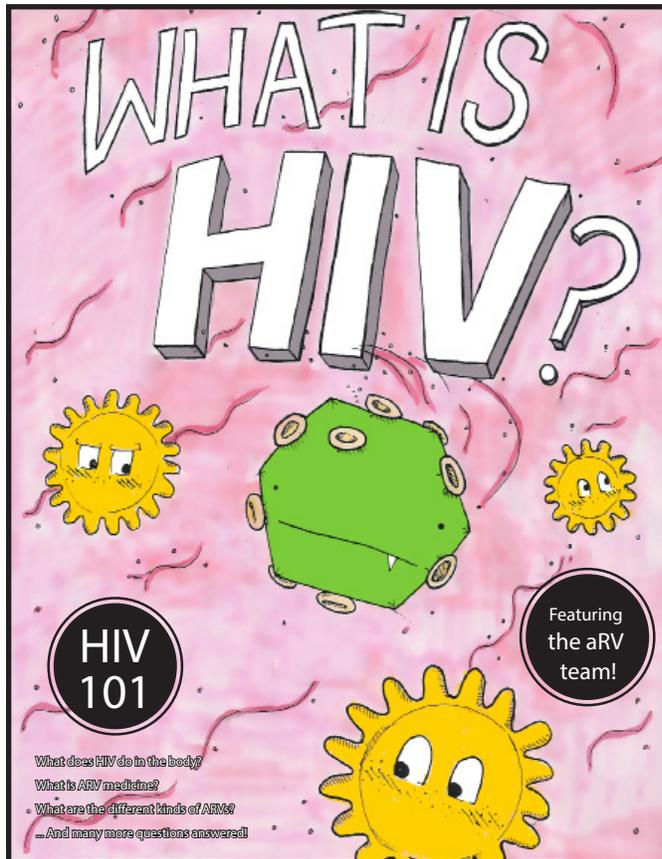
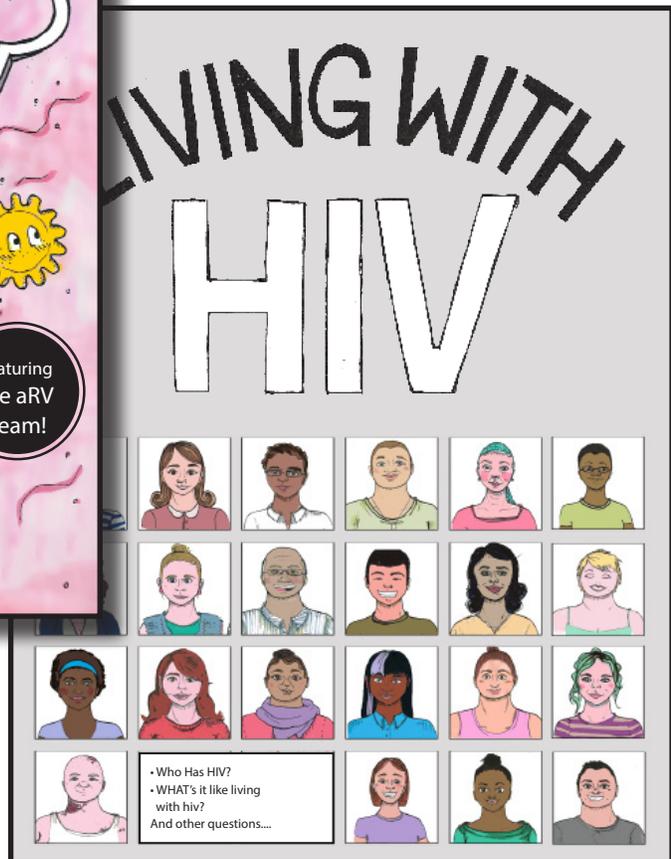


CAREGIVER GUIDE

WHAT IS HIV?



LIVING WITH HIV



DEAR CAREGIVER,

Deciding whether, when and how to disclose your HIV status to your child can be a big challenge. It is a personal decision, and we recognize that disclosure may not be the right decision for your family at a particular point in time, or maybe even ever. This short guide is for you, from other parents and caregivers who have faced the decision of whether and how to disclose their HIV status or the HIV status of a birth parent to their children. Disclosure is a process, meaning it takes time and will involve multiple conversations with different kinds of information discussed or understood by your child. We hope that this guide will help take some of the fear out of making this decision. Some parents decided to disclose their status, some decided to give partial information, and others decided not to disclose. If you decide you'd like to disclose – whether eventually or right now – the HIV Disclosure Comic Books can help you start a conversation about HIV with your child. However, both comics can also be used to teach your child about HIV and health **without** disclosing your own status.

The **first** section of this guide offers tips and wisdom for deciding whether disclosure is right for you, and preparing for it if you decide to disclose. The **second** section is a guide for the “What is HIV?” comic, and the **third** section is a guide for the “Living with HIV” comic.

We hope that these comics are useful for you and your child. Our hope is that they spark a conversation that feels healthy for you and your family, and one that continues beyond reading them together.

SECTION I: DISCLOSURE

Deciding whether to disclose.

Disclosure can take many forms.

Disclosure happens when one person finds out about another person's HIV status, regardless of who tells them. It may happen with or without the consent of the person living with HIV. Many people living with HIV tell only certain people in their lives about their status (this is called ***selective disclosure***), and they may choose to tell only certain parts of their story to those people. The parents we talked to said it was very important to share only what they felt comfortable sharing, and nothing more.

All feelings about disclosure are normal.

Caregivers told us about a range of emotions they felt about disclosing to their children. Some felt anxious, scared, upset, sad, ashamed, open, happy, unburdened, or relieved. Some felt all of these things at once, while others felt only some of these emotions. You may have multiple feelings about disclosure if and when you begin the process, and these may evolve over time. Each caregiver's personal situation is a little different, and so it makes sense that reactions and thoughts may vary a lot.

Deciding whether to disclose is a personal choice.

Some caregivers told us that disclosing their status made their relationship with their children closer, and that it relieved them of a mental burden. For some, disclosing also helped their children feel more emotionally healthy (i.e., less anxious) in the long run. Others told us that it simply wasn't the right time to disclose, for a number of reasons. Some felt their children weren't emotionally ready, or that they wanted to strengthen their relationship with their child first. Others felt that they themselves weren't ready yet. Only you can know what the right choice is for you and your family.

You don't have to disclose everything right away.

For younger children, some parents opted for a ***partial disclosure*** of their HIV status. They told their children something like, "Mommy has a virus and has to take medicine to stay well," without mentioning HIV right away. This can help with feelings of anxiety or discomfort a child might feel from seeing a parent take medicine without knowing why. It can also help caregivers feel less anxious by testing the waters and starting slowly. Other parents decided to do a ***full disclosure***. They told their children something like "Mommy has a virus called HIV." They might have told their children why they take ARV medicines or more about what HIV is. Both types of disclosure can be the right choice for different people.

Reach out to someone you trust.

Disclosing your status to your child is an important decision. Many caregivers told us that the support of someone they trusted was very helpful to them as they decided whether and when they were ready to disclose. Consider reaching out to a family member, friend, religious leader, or health care professional to help you decide what's right for you. These people can also help you feel more prepared to talk about HIV and your health.

Preparing for disclosure.

Disclosure is a process.

Remember that disclosure and education about HIV are both ongoing processes. Sharing these comic books with your child can be one part of that process, but it doesn't have to happen all in one day. These comics could be a way to start a conversation about your own HIV status. But you could also use the comics simply to teach your child about HIV without revealing your status.

The developmental stage of a child matters.

Children at different developmental stages will be able to understand HIV and your health in different ways. Remember that developmental stage may not always be the same as chronological age. This means that your child may fall into a different level in this guide than the one that matches their age. Some caregivers have told us they judged their child's "emotional maturity" instead of their age in deciding what they

could understand about their HIV status. The type of support a child needs will depend in part on which developmental stage they're in (e.g., young or older childhood, younger or older adolescent/teenager), and where they are mentally, emotionally and socially. You are the person who can best judge that. Check out the guide for each comic for details about what children at different stages may understand and wonder about specifically in terms of HIV.

Who to use the comics with.

These comics were created primarily with children ages 9 – 12 in mind, but children of different ages can also learn from them. Keep in mind that older children (especially teenagers) sometimes react differently to disclosure than younger children. Many caregivers strongly recommended talking to a health care professional you trust for support in disclosing – whether it's to a younger child or to an older teen.

Think about what you want to share with your child about your story.

Caregivers told us that it was very important to be at peace with their own life stories before disclosing. If your child asks you about your own story, it might be hard to think clearly in the moment about what you're comfortable sharing with them. Some caregivers told us that they wrote down or thought ahead of time about what they wanted to tell their child so they didn't share more than they were comfortable with. Remember, you can share as much or as little as you're comfortable with.

When and where to disclose.

Some caregivers told us they planned out a particular place and time to open up a conversation about their HIV status, while others said it happened spontaneously because the moment felt right. Others told us that they disclosed at their clinic with a trusted health care provider present. While there is no right or wrong way to do it, many caregivers recommend choosing a private place with no distractions.

Prepare for questions from your child.

Your child might ask you some questions when you disclose, or they may not – and both situations are perfectly acceptable. They may also think of other questions later on – in a week, a month, or next year. That's ok, too.

Tips for Answering Questions from your Child:

- » **Be prepared:** Is your child likely to ask how you got HIV, or to be worried about your health? Will they want to know if they have HIV, too? Will they ask what your medicines are for? It might help you feel more prepared if you make a list of questions you think your child might ask you and to think about what you might want to say in response.
- » **Follow your child's lead:** When you answer questions from your child, try not to go into too much more detail than they ask for. Think about the information your child can handle, and let him or her guide the discussion if they want to. Take your time in responding - this will also allow time for your child to listen and respond without feeling rushed.
- » **It's ok not to know the answer:** If your child asks you a technical question that you don't know the answer to, it's okay to say, "I don't know, but I can ask the doctor about it." You don't need to have all of the answers right away.
- » **It's ok to keep some things private:** Your child may ask you a direct question you feel uncomfortable answering. If this happens, one option is to say, "That's a good question, and I'd like to think about it on my own for a little bit before I respond." That can buy you a little time to process how you'd like to respond.
- » **Find resources for your child:** Be prepared to offer your child websites, pamphlets, or other books that can help explain more about the questions they might have. Connecting your child with another trusted adult can also be a great resource; often, someone totally removed from the situation (such

as a counselor) can be helpful. Try to keep the conversation open; as your child ages, they may have different questions and it may become easier for you to provide more details or more complete answers to questions. Remember, disclosure is not a one-time event – it's about opening a door to a continuing conversation about your health.

During disclosure.

Remember that your body language is communicating too.

As mentioned before, caregivers told us how important it is to be at peace with your own story before you disclose. This is because your child will read your body language or comfort level with the topic as you talk. Try to be sure that you're comfortable with your own story when you're talking to your child, as they really will pick up on your emotional cues. But if you're not yet comfortable, that's ok! Try to connect with someone you trust who can help you process your feelings if you can. Some caregivers told us that it also helped to practice first with someone they trusted or in front of a mirror.

Children react in different ways.

- » **All reactions are normal:** Children can have many different reactions when they learn that someone they love has HIV. Some children might become quiet; some might not be visibly affected right away; some might be sad or afraid and cry; some might be angry and storm off; and some might need some time alone to process. This is all normal, and there is no one "healthy" kind of reaction to have. Encourage your child to speak with you about how they feel, but also give them space to absorb the information and their feelings.
- » **Reactions can change over time:** Parents told us it was important to be prepared for children to have different reactions at different points in time. For instance, some children who reacted at first with sadness, anxiety, fear, or anger later came to accept their parent's HIV status. Likewise, some children who didn't have a strong reaction at first sometimes needed support to process their reactions later on.
- » **Monitoring your own reactions:** It might be uncomfortable, painful, or hurtful to answer some of the questions your child asks, or to hear their reactions. That's ok, and it's a normal way for you to feel. Try to let yourself feel those things without judging yourself, and to accept the feelings for just what they are – *completely normal feelings.*

Sometimes it can help to put the conversation into the perspective of the child, particularly at younger ages when the main concern that many children have is whether this changes anything for *them*. Try to be a safe space for them to share their thoughts or feelings about your HIV. If you're not sure what to say, it can be very effective simply to repeat back to them what you're hearing. For example, "I hear you saying that you're worried about me. I can understand feeling that way. Are there any questions I can answer for you right now?" or "It sounds like you're sad to hear this news. Is that how you're feeling? Are there any other feelings you'd like to tell me about?"

Although you may feel overwhelmed or angry, try not to act on your own feelings with your child in the moment. Instead, process your emotions by doing something that usually helps you – for example, this could be writing about the feelings, meditating on them quietly, or talking to someone you trust.

Keeping the conversation going.

Find supportive connections to other adults for your child.

If there are any other trusted adults in your child's life who know about your status, it can also be helpful to give your child permission to talk with them as well. Be sure to explain to them clearly if you would like them to keep your status private from others – you can say you'd like to keep it just among a certain set of people. This can create another safe space for children to discuss their feelings and thoughts about HIV in a healthy way. While this could be a family member or friend, many caregivers told us that someone totally removed from the situation – like a counselor or health care professional you are comfortable with – could be most helpful for children. You might want to tell those adults in advance if there is any information you'd be

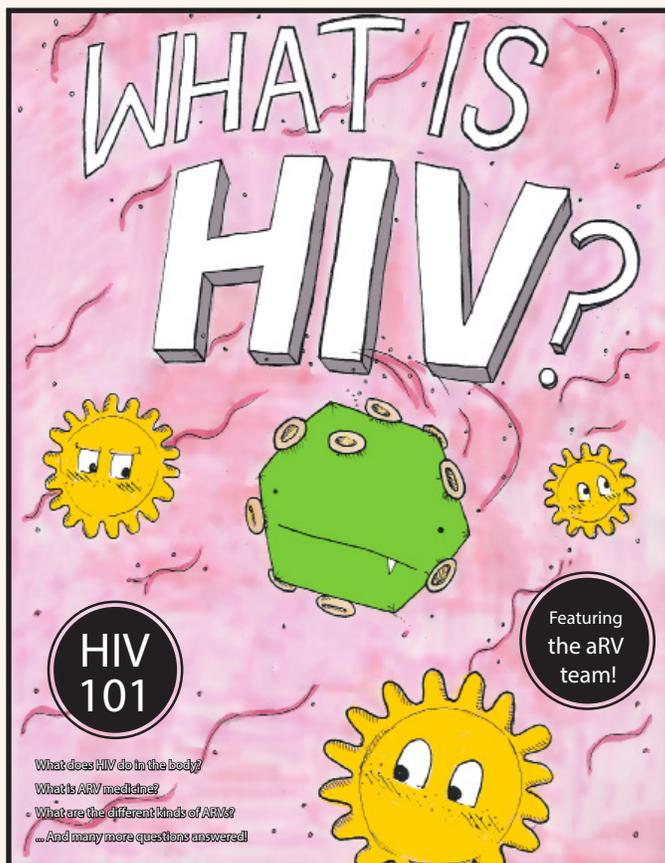
uncomfortable with them discussing with your child.

Keep checking in.

The first disclosure conversation you have with your child may last only a short time, or it may be longer. Either is completely normal, but it is only the beginning of an ongoing discussion. Some caregivers recommended checking in periodically with your child to see how they're feeling or if they have further questions. Sharing with your child more routinely about your HIV or asking them to help you with remembering to take your medicine can help to normalize it.

Make "family health" a priority.

Some parents said that they discuss their health issues in the larger context of "family health." This makes it normal to talk about things like eating right, exercise, getting enough rest, and going for regular health check-ups. When a specific health issue exists (like HIV, diabetes, asthma, etc.), families can help each other out in a number of ways. Family members can help each other remember to take medicine at the right time, monitor symptoms, remember health care appointments, and reduce stress. Some children like participating in this (in age-appropriate ways) because it makes them feel helpful and included in the larger goal of taking care of "family health."



SECTION II: USING THE WHAT IS HIV? COMIC BOOK

Deciding what to teach your child about HIV can be difficult. All of the details about antiretroviral (ARV) medication types and CD4 cells can be confusing for any adult to understand, let alone a child or adolescent. The HIV Disclosure Comic Books, "What is HIV?" can be a great first step for your child to understand what HIV does in the body and how ARVs work to keep you healthy.

Developmental Stages of Children

Children at different developmental stages will be able to understand HIV and your health in different ways. Some caregivers find it helpful to understand which stage their children might be in as a way of feeling more prepared for using the "What is HIV?" comic. Remember that your child may "fit" in a different age category- these are just general guidelines for these age levels.

For children ages 5 to 7:

- » Most children of this age group are mainly focused on whether and how things will change for them. They may also seem to be in denial about the situation – they may go on playing or seem to act like they haven't heard what was just discussed.
- » "HIV" and "ART/ARVs" may not have specific meaning to children at this age, so your conversation will need to be guided by what words they understand. Kids in this age range will likely be most familiar with the words "germ" or "bug."
- » Children of this age group may be fearful for your safety. It is best to encourage them to share their fears and provide reassurance of the success of ARV medication.
- » If you are comfortable sharing which medication you take with your child, you could tell them which members of the "ARV team" are in the medication you take. This age group has more trouble picturing abstract concepts, so this may help them visualize the medication working and put them at ease.
- » If you'd prefer that your child not tell anyone about your HIV status, keep in mind that children of this age group are usually already able to understand what it means to keep something private. They will likely be able to understand if you explain that you'd like to keep this information just in the family. You may want to be explicit about who your child can talk to about HIV, your health, and what it means to them. For example, you can say, "Grandma (or auntie, or whoever) knows about this and can talk with us about this too."

For children ages 8 to 10:

- » Kids in this age range will likely be most familiar with the word "germ," although many will also know what a virus is.
- » 95% of this age group has heard about HIV/AIDS, often from something they saw on TV, read online, or heard at school. You may want to start with a question like, "What do you know about HIV or AIDS?" to see what they have heard. They may have developed a negative impression that having HIV is a "death sentence." The disclosure conversation is a chance to reframe that for them and to let them know that people with HIV can now live a long, healthy life.

For children ages 11 to 14:

- » Kids in this age group may have heard a lot about HIV and be aware of different ways to contract HIV. They may ask you explicitly about how you got it (i.e., *Are you gay? Did you use needles? Who did you have sex with?*). Practicing in advance for how you'd answer can help you feel more prepared for these questions.
- » Kids in this age group may also display anger when they find out about their parent's HIV status.
- » This age group may be curious about which medicine you take and what it does.

General tips:

- » Ask your child what questions they have, but understand that they might not have any right then.
- » If your child asks you a technical question that you don't know the answer to, it's okay to say, "I don't know, but I can ask the doctor about it." You don't need to have all of the answers right away. Or you can acknowledge that the question is important and make a plan with your child to learn the information together.
- » Children can have many different reactions when they learn that someone they love has HIV. They are all normal; there is no one "healthy" reaction to have. Encourage your child to speak about how they feel and try to be understanding of their emotions, positive or negative.

LIVING WITH HIV



SECTION III: USING THE LIVING WITH HIV COMIC BOOK

» Deciding what to share with your child about HIV and what to tell them later can be difficult. You don't want to worry them, but you want them to have honest and accurate information. Children at different developmental stages will be able to understand HIV and your health in different ways. Some caregivers find it helpful to understand which stage their children might be in as a way of feeling more prepared for using the "Living with HIV?" comic.

For children ages 5 to 7:

- » Children of this age group may be fearful for your safety or that you are going to die. They may also want to know who will take care of them if you're not there. It is best to encourage them to share their fears and provide reassurance.
- » If you'd prefer that your child not tell anyone about your HIV status, keep in mind that children of this age group are usually already able to understand what it means to keep something private. They will likely be able to understand if you explain that you'd like to keep this information just in the family.

For children ages 8 to 10:

- » 95% of this age group has heard about HIV/AIDS, often from something they saw on TV, read online, or heard in school. You may want to start with a question like, "What do you know about HIV or AIDS?" to see what they have heard. You may need to correct some misconceptions they have about transmission, who can have HIV, etc.

For children ages 11 to 14:

- » Older children, tweens, and teens are curious and may ask specific questions about transmission. They may wish to know how you contracted the virus, or who they should "blame" for it.
- » They also may have questions about sex. Here are some good resources with more information for teaching young teens about sexual health: www.safeteens.org/stds or www.kidshealth.org/teen. You may want to review the material with your child or give them the websites to read on their own.

General tips:

Ask your child what questions they have, but understand that they might not have any right then. If your child asks you a technical question that you don't know the answer to, it's okay to say, "I don't know, but I can ask the doctor about it." You don't need to have all of the answers right away. See the first section on Disclosure for more tips on preparing for questions.

Children can have many different reactions when they learn that someone they love has HIV. They are all normal; there is no one “healthy” reaction to have. Encourage your child to speak about how they feel and try to be understanding of their emotions, positive or negative.

Talking about stigma.

This is a difficult topic for anyone to discuss, and even more so with young children. As you read the comic, you might decide to share some of your own experiences, or you might keep it more general. But don’t go into any more detail with your experiences than what you’re comfortable with. You can also take this opportunity to explain to your child that even though stigma exists, people with HIV can still lead normal lives. You can offer examples of that from your own life as well, if you choose to.

Talking about going to the doctor.

If you feel your child may worry about your health, you can explain that going to the doctor often and taking medicines is what helps keep your body healthy. You don’t need to go into any more detail than that unless your child asks and you are comfortable saying more.

Talking about methods of HIV transmission.

Page 3 of this comic discusses methods of transmission, but leaves some information out. Depending on your comfort level, you may want to go into more detail about transmission. If you do, you should know the following information:

- » Anyone can get HIV, regardless of sexual orientation or race/ethnicity, if they engage in sexual behavior with a person with HIV, or if they exchange body fluids with a person who has HIV in other ways, such as sharing needles.
- » You will not get HIV through everyday contact with people at school or work.
- » When people are taking medicine and have a very low amount of virus in their blood (called “undetectable viral load”), it is far less likely that HIV will be passed to someone else.
- » The virus is passed in semen, vaginal fluids, blood, and breast milk. It can enter the body through the vagina, penis, rectum, mouth, or any cut or open sore. It can also be passed through sharing needles while using certain drugs.
- » Babies who are born to mothers with HIV sometimes get the virus while they’re in the womb, during birth, or through breastmilk after they’re born. If the mother takes antiretroviral (ARV) medicines during pregnancy, the risk of the baby getting HIV is extremely small (less than 1%). Sometimes, the newborn baby will also take a short course of ARVs to help prevent contracting HIV.
- » HIV is not passed in other bodily fluids like saliva, sweat, urine, feces, tears, etc.

Talking to your child about sexual transmission of HIV.

If you haven’t yet talked about sex with your child but want to mention sexual transmission of HIV, you could also decide to have a basic conversation about sex first. That could lay the groundwork for later using these comics to talk about HIV. Deciding ahead of time what you will or won’t talk about can make the conversation more comfortable for you. Some caregivers told us that writing down what they wanted to say helped. Others told us that practicing with someone they trusted (family, friend, or health care professional) or in front of a mirror was helpful, too. Seeking support from other caregivers living with HIV – through an in-person support group or online, for instance – can also help with preparing to disclose.

Sexual transmission of HIV can be a difficult topic to approach with some children. Before the disclosure conversation, it could be worthwhile to establish some ground rules for yourself, such as “I will mention that it can be passed by sex, but I won’t say semen or vaginal fluid,” or “I will not go into specific details about how I received the virus.” This can help you feel more prepared.