



HOW DO I TELL MY KIDS?



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HOW DO I TELL MY KIDS?

A Booklet about HIV
Disclosure in the Family

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It was during the holidays and my son and I were talking about life and our family and he asked me why I have to take medication. I told him and he was okay. He was quiet but okay.



INTRODUCTION

This booklet is for adults who are thinking about telling their children that someone in the family is living with HIV.

Talking to children about this can feel scary as it may bring out many different feelings and concerns about how children will react.

Part of feeling comfortable about talking to children is being ready and prepared. The decision about when and what to tell depends on a lot of different factors, including the child's age and stage of development. Telling children about HIV is never a one-time conversation but a back and forth process over a period of time.

This booklet is designed to guide and support parents and caregivers through the process of telling children, often called "disclosure". They will learn about why, when and how to tell, and much more.

WHY SHOULD I TELL MY CHILDREN?

Telling children about HIV in the family is a difficult decision. Parents worry about how children will react. It is important to think about how and when to tell children and to plan carefully for disclosure. There are many benefits to sharing this information with children.

Disclosure often brings family members closer together allowing them to talk freely and put an end to the secrets. Once children learn about HIV, it gives them a chance to ask questions and get answers. Children who know may be able to join support groups and find friends who are in similar situations.

Research has shown us that children who know about HIV in the family can cope better, understand what their parents are going through, feel better prepared for the future, more involved in family decision-making and closer to their parents.



When my Mom first told me she was HIV+, I understood why she had to take pills and see the doctor for check-ups

Sometimes when children do not have enough information, their imaginations can run wild. Telling them may reduce any anxiety they may feel. While they might be worried, sad or shocked at first, these feelings tend to lessen over time. The disclosure process can build trust between you and your child and strengthen the family unit.

It can be difficult to make the decision to tell children about HIV. There are many reasons why parents want to keep it to themselves but keeping secrets in the family can be hard. Having to watch what you say and do can create feelings of guilt and anxiety.

Kids are smart. They know when there is a secret in the family.

It is important for children to hear about HIV from parents, not someone else. The goal is to be honest and open with them in an age appropriate manner.

Even though some parents may struggle with the idea of talking about HIV to children, telling them can have benefits. Many parents talk about feeling better that the "secret" is out in the open.



I wasn't sure how to bring it up with him. Then the conversation seemed to happen so naturally. He didn't have any questions at first, but I told him that he could always talk to me about things. I am glad that I told him.

Other positive feelings that parents have expressed about telling children are:

- Issues can be dealt with as a family
- There is more trust and honesty between family members
- Clears up myths and misinformation about HIV
- Children may meet other kids who are affected by HIV and learn that they are not alone



Even though it was hard and I was shocked, it is better to know



Our communication has improved because of all the discussion we have had

WHAT DO PARENTS WORRY ABOUT?

Parents sometimes fear what a child's response to the news will be. Many parents talk about wanting to protect their children and not wanting to upset them or disrupt their life.

Due to the unfair stigma and discrimination associated with HIV, parents are often concerned that children will be negatively affected if they know. They fear that children will tell others and that this will result in negative attitudes from friends, neighbours, teachers or others in the community.

I was really worried about what my child would think of me...



**You don't have
the fear of secrets. It
gives more confidence as
we are all in this together.**



Here are some of the things parents worry about:

- Children will be burdened with worry
- It will disrupt their schoolwork
- Others will judge them
- Children will not keep it to themselves and will tell others
- They will ask too many difficult and personal questions

Although you may be reluctant to tell your child, remember that children have access to information about HIV in school, on the internet and through social media.

Disclosing can be an opportunity to correct any misinformation they have and give you a chance to educate them about the facts of HIV.

**People run away from
people with HIV. I always
worry about who knows
about us.**



WHAT DO I NEED TO THINK ABOUT BEFORE TELLING MY CHILDREN?

Remember that talking about HIV with your children is a process that unfolds over a long time.

- Start by laying a foundation – having open discussion about general issues that affect your family before you start talking about HIV.
- Learn about healthy communication with children. By having open conversations about different topics and listening closely and respectfully to your children’s opinions, you help prepare them for difficult conversations in the future.
- Developing a strong relationship will help your children trust what you say and encourage them to come to you with questions and problems.
- Laying this strong foundation will help make sure that disclosure about HIV is part of how you talk to your children about issues affecting the family.

There are a number of stages in the disclosure process*

1. Acceptance: Coming to terms with your HIV diagnosis and coming to terms with your identity as a person living with HIV.
2. Education: Knowing the facts about HIV and the services available to people living with HIV so you can answer questions correctly and with confidence.
3. Establish your motivation for disclosure: Is it your choice or do you feel you have to tell because of other circumstances?
4. Evaluate the environment: Do you have a safe place to talk about this with others? Do you have good support from others? What are the costs and benefits of disclosing?
5. Assess potential outcomes: Spend time thinking about how your children may react. Develop a plan for telling your child – use the support of a counsellor or social worker or another person living with HIV who has been through it. Be prepared to have not just one conversation but many, ongoing conversations with your child that may change as they grow older.



After you find out, you find that there are others around you that have it as well and you aren't alone

Make sure you have someone to “de-brief” with after the first time you tell your children. You will need the support and encouragement if it was difficult and you can celebrate if it went really well!

* <http://hivdisclosure.ca/support-model/>

WHAT'S THE BEST AGE TO TELL MY CHILDREN?

Parents usually struggle with when and how to tell children about HIV.

It is helpful to normalize general conversations about HIV in your home if and when it comes up so that your children feel they can ask questions; build a relationship with your children. It is always a good idea to tell them in person but know that due to circumstances beyond your control, this may not always be possible.



The more comfortable you are talking about HIV, the more comfortable your children will be hearing about it

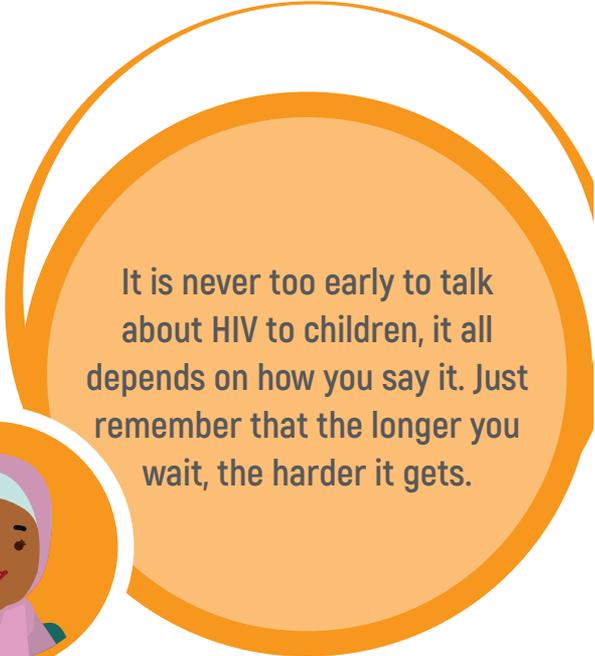
Children mature differently. There is no “ideal age” for disclosure. Assess how your child reacts to other difficult or serious topics or situations before making the decision to tell them. Once the decision is made, a disclosure plan can be put in place, ideally with the help of a counsellor, peer support worker or social worker. Remember that older children may already have some information about HIV.

Parents often think and plan what to say ahead of time. This will help you feel less anxious for when the time is right to tell. But sometimes the child just blurts out a question and you feel prepared enough to take the opportunity to tell.

Before telling a child it is important to make sure that:

- There are no other major additional changes happening, for example moving, family separation or changing schools.
- Lots of time is set aside to spend with the child before and after.
- Not to be too anxious about the disclosure as your child will sense this and become worried too.

This is usually an emotional time for families. It is important for parents to try not to get impatient or upset with questions children ask. Sometimes children need a bit more time to understand the information. This is often the time when parents seek advice from supportive family members or HIV organizations who offer support services.



It is never too early to talk about HIV to children, it all depends on how you say it. Just remember that the longer you wait, the harder it gets.



HOW DO I TELL THEM? WHAT SHOULD I SAY?

When it comes to disclosing about HIV in the family to children, a few things should be taken into account. Some examples include what children are worried and thinking about, how to tell children and possible ways children may react to the news.

These concerns can lead a parent to remain silent, hoping that they will protect the child. However, children who have not been told often do worry and also may have a sense that things are different in the family. For example, children may see parents taking medications or may accompany them to doctor's appointments.

Sometimes I stay
home from school
because I worry
about my mom



Children's concerns can be expressed in words and in their behavior. Children worry about different things at different ages. Some of the things they may worry about are:

- If their parent has an illness such as cancer and whether they are going to die
- If they have done something to make their parent sick
- If their parent is okay while they are at school
- Fear for what the future holds for them
- Trying hard to please their parent and do things for them
- Take on parental roles such as caring for siblings

**When my Mom has
a headache I rub her
hands and bring her tea**

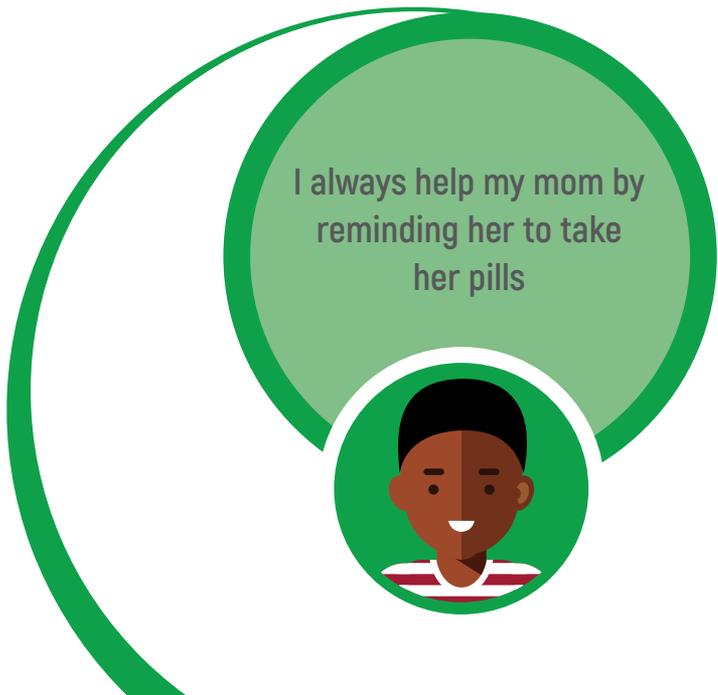


Children react to things very differently. Some parents anticipate a child's reactions to be much worse than the actual response. It is important to spend time together after the initial disclosure and let them know that they can share any questions, thoughts or feelings they have.

Children and youth at any age may exhibit some behaviour in reaction to disclosure such as nightmares and temper tantrums, or may even become a little more quiet than usual. This may be the time to reach out for support for your family to help you through this challenging time.

It is important to remember that you cannot foresee how a child will respond to being told you are living with HIV. Every child is different and they may have unique reactions. It may also depend on what other issues are happening in their lives at the time, some of which you may not know about.

There is no single way to talk about HIV to children. Families have different ways of dealing with things. What works for one may not work for another.



AGES AND STAGES

The following are some general guidelines to follow when talking to children according to their age and stage of development.

0-3 YEAR OLDS

Children between the ages of 1-3 tend not to be developmentally ready to hear about HIV.

It is not generally advised that children are told at this time, as there are no specific benefits. It is important for parents to remember that young children are very smart and observant; therefore, watching the language used in the home around HIV and other health concerns will set the tone for later conversations.

4-7 YEAR OLDS

It is common for children of this age to notice that their parent takes medications every day and they may surprise their parent when they ask why.

What do children 4 - 7 worry about?

- What are those pills and why do they take them every day?
- Do I need to take those pills?
- Are they sick because I was bad?

How will my child respond?

At this age children are easy to distract and won't be able to understand complex information or understand the need for confidentiality. They may be interested in where babies come from, especially if Mom is pregnant. This is a great time to get age-appropriate books and start to have conversations about sexual facts and reproductive health issues.

8-12 YEAR OLDS

Children this age may be ready to hear some information but not all of it.

This is called "partial disclosure" where you start to tell but don't actually name HIV itself. You can then gradually work up to actually naming HIV as the issue. It is up to the parents to decide when a child may be ready to begin to hear information.

Some parents choose to disclose all the information at one time and then deal with questions and concerns as they come up. Regardless of the approach, once HIV has been named, children will need accurate and up to date information about how HIV is transmitted as well as some information about the emotional impact this illness can have on families. Issues of stigma and the need for confidentiality can be hard to talk about but are also necessary at this stage. This is where careful planning with the support of a counsellor, social worker or peer support person can be very helpful.

These pills make my body strong. But they are made especially for adults so you can't take them. You can take the yummy vitamins instead!



What do children 8 - 12 worry about?

- What is wrong with them? It must be bad if they have to take pills every day.
- Are they going to die? What will happen to me if they die?
- Will anyone else in the family get sick?
- Why is my family different?

How do I tell my child?

Start by using simple words and easy examples to help them understand.

- Talk openly about HIV. Have some books and pamphlets on hand to help answer any questions or concerns the child may have.
- Take it slowly – disclosure is a process that will happen over time.
- Tell children who they can and cannot tell and why some personal information should not be shared. Be prepared to talk about the difference between confidentiality and secrecy.
- Always give hope. Reassure them about the range of treatments available and how they can help people with HIV live as long as anyone else.
- Remind the child that it is not their fault.

I go to the doctor because I sometimes I need a check-up. I take medicines every day to make sure my body stays strong and healthy.





I have a certain kind of virus/bug in my body. I'm lucky that I have very good doctors and medications and that keep me strong and healthy.

How will my child respond?

Children between these ages may have a lot of questions or concerns. They may:

- Be afraid of getting HIV themselves
- Need more discussion around transmission and how you can get HIV
- Have questions about sex
- Worry about their future and your health
- Show little interest, seem to be fine with the information, shrug and move on – this can be a bit of a letdown if you've spent a lot of time preparing!
- Come back to you time and again to ask more questions

13-18 YEAR OLDS

Youth at this age are generally ready to receive clear information about HIV.

They may also ask more questions about what will happen in the future. At this age it is very likely that youth have heard about HIV through the school curriculum, the media or from their friends. They may also have heard a lot of discriminatory and stigmatizing attitudes as well as incorrect and outdated information. In this digital age we have so much information at our fingertips that they may know or suspect you have HIV before you tell them.

Even though I have HIV,
I can take good care of our
family and myself.
Try not to worry.



What do teenagers worry about?

- What will my friends think? Will they still want to hang out with me? Will they still want to come to my house?
- I'm worried about my parent(s) health. Who can I talk to?
- They need me to help at home but can I still do what I want to do?
- I can tell they have a secret. Why? Don't they trust me enough to tell me?

How do I tell my teenager?

- Say you have a health issue and name that as HIV
- Explain what HIV means and check that they have accurate information about transmission and prevention as well as treatment and staying healthy
- As always, be prepared to have more than one discussion as questions arise
- Let them know who else they can speak to
- Tell them about places where they can get support in the community
- Be optimistic and remind them that it is not their fault

Did you get HIV because you slept with a lot of people?
Why didn't you tell me before?
Don't you trust me?



How will my teenager respond?

The older they are, the more likely they are to express some anger about not having been told sooner. Depending on their level of accurate information about HIV, they could have the same concerns as younger children but may also:

- Ask more difficult questions about how you got HIV
- Act out by arguing with others and engaging in high risk behaviours
- Find that school work and grades are negatively affected
- Need to be provided with information about drugs, safe sex and making healthy choices

How to respond to some common questions

Children are curious at each age and stage of their development. They may ask questions that might be difficult to answer. Try to let the child lead the conversation. This is a great way to gauge how much information to give them. Here are some possible responses:

Child's Question	Possible Response
Are you going to die?	"As long as I take my medications as I should, I can live as long as anyone else. I take my medication and it keeps me healthy."
Can I get it too?	Explain the ways HIV is and is not transmitted. "You don't have it and you cannot get it from hugging me or kissing me."
Who else has it?	Before you disclose someone else's status you should speak to them directly to see how they feel about having their status disclosed and ask their permission to share.
Who else knows?	Say who else knows. "It is okay for you to talk to these people. This information is private so if you want to talk about it, you can ask these people."
Is there a cure?	"The medications are very good and keep people with HIV healthy for a long time. Doctors are working hard to find a cure."

Some responses can make children feel uncomfortable and shut down discussion. Try to avoid the following responses:

- You don't need to know that
- You're too young for that. We'll talk about that when you're older.
- Why would you ask me that?
- Now that's a silly question!

You can respond to children in positive ways that encourage them to open up. Try asking:

- What do you think about that?
- How are you feeling about what I've just told you?
- That's a good question!
- Does that answer your question? I can find out more information for you if you like.
- Thank you for sharing that with me.



She said 'OK. I'm glad you told me' and went back to reading her book. There I was prepared for a big conversation and she just accepted it and moved on! A few weeks later she came back with some more questions.

PRIVACY AND CONFIDENTIALITY IN A DIGITAL AGE

In today's world, information can be shared quickly, easily and often anonymously. Children and youth master new technologies and social media platforms quickly and effortlessly and are often far ahead of their parents in this way. If your child uses social media or surfs the internet, it is a good idea to include this in your conversation with them.

- Make sure they know where to find accurate and helpful information about HIV so that they can do some reading in their own time.
- Talk to them about stigma and ignorant attitudes. Remind them that they can't believe everything they find online, hear from their friends or see on social media. Even celebrities they follow may express discriminatory, uninformed and hurtful attitudes.
- If you are concerned about confidentiality, ask them not to post anything about HIV in your family on Facebook, Twitter, Snapchat or any other social media platforms.
- Be aware of who else is in your photos/selfies, even in the background. You may be compromising their privacy.
- If you share a computer and don't want to your children to see what sites you've visited, make sure you know how to erase your browsing history.
- Encourage your child to tell you if they experience cyber-bullying or any posts/comments that make them feel uncomfortable, even if these are about you.
- Help them learn how to react to cyber-bullying and hurtful posts or comments online.

IN CONCLUSION

Here are some things to consider before disclosing to children:

- Talk to someone who can help. It might be another parent living with HIV, a counsellor, healthcare professional or support person who works at an HIV organization.
- Think carefully about when and how you want to tell your children. Do you want to tell only the oldest for now or all of them together? Consider their ages and maturity levels. Together with your support person, take time to plan the conversation carefully—who and how to tell, when to tell and what to say.
- Practice what you will say. Rehearse it with your support person. Practice it out loud on your own. Try to anticipate the questions your kids might have and how you will answer them.
- Be prepared for your kids to hear you, shrug it off and move on. Sometimes kids do that. It could be anticlimactic! Or they might listen and need time to digest the news.
- Who will support you afterwards? Make sure there is someone supportive you can talk to and debrief with after you tell your kids for the first time.

If and when you decide to tell:

- Try to be as relaxed and present as possible when you talk to your child. Staying calm and connected will help set the tone of the conversation. Kids can be quick to pick up on facial expressions and body language and may take their cues from you.
- Choose a time and place when you won't be interrupted. You might want to turn off your phone and make sure there is ample time for questions and conversation.
- Keep an open mind. Listen to their questions and insights. Try to understand how they might be feeling. Ask your children to repeat back to you what you've just said. This will allow you to see how they have understood it.
- If confidentiality is an issue, talk about why you want to keep this private and not tell everyone.
- Tell your kids how you'd like them to handle the potential telling of others. Explain who knows, who doesn't and who you're OK with knowing.



- Remember that your child will need someone to talk to about this other than you. Maybe it's an older sibling, a peer who is also affected by HIV, a counsellor, teacher, healthcare professional—someone the child trusts who can support them.
- Check in regularly with your kids. Ask them how they're feeling and if they have any questions. But also remember that it is OK to just get on with life and not talk about HIV all the time, if that's where they're at.
- Keep them informed about your health and your doctors' visits to allay any worries or fears they may have.
- Keep in mind that disclosure is an ongoing process, not a single event. Commit to an ongoing open and honest conversation with them.

RESOURCES

Each province and territory has an HIV information hotline that may also help you and answer your questions. They can give you the names of HIV organisations near you.

PROVINCE	
Alberta	800-772-2437
British Columbia	800-661-4337
Eastern Arctic	800-661-0795
Manitoba	800-782-2437
Newfoundland & Labrador	800-563-1575
New Brunswick	800-561-4009
Northwest Territories	800-661-0844
Nova Scotia	800-566-2437
Nunavut	800-661-0795
Ontario	(English) 800-668-2437 (French) 800-267-7432
Prince Edward Island	800-314-2437
Quebec	800-521-7432
Saskatchewan	800-667-6876
Yukon Territory	800-661-0408 ext.8323

www.catie.ca Canada's source for HIV and Hepatitis C information

www.teresagroup.ca The Teresa Group advances the dignity and wellbeing of children and families affected by HIV and AIDS

NOTES

