

# DISCLOSING TO OUR CHILDREN

## What the HIV Experience Has Taught Us

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If hearing your child is infected with HIV or hepatitis B or C is the worst that can happen to a parent, telling your child about the infection runs a close second.

When should parents disclose? How should they tell a child? What will a child ask? Will they ever forgive the parents who infected them? Are silence and secrecy justified to protect a child from a painful diagnosis?

Two pioneers who have peered into the disclosure cauldron are Lori W. Wiener, coordinator of the Pediatric HIV Psycho-Social Support and Research Program at the National Institutes of Health, and Heidi Haiken, coordinator of Social Work at the Francois Xavier Bagnoud Center in Newark, N.J., an innovative program that works with parents and children with HIV.

For more than 10 years, Haiken and Wiener have worked with hundreds of families infected with and affected by HIV on the emotional and social issues related to the disease. Wiener, who has a PhD, has researched and written about the impact of disclosure on family members.

Their combined experiences have produced two cardinal rules for parents of children infected with chronic, viral infectious diseases:

- Never lie. You don't have to name the disease if children are very young, but never, never lie. The damage to the parent-child relationship will surpass any short-lived benefits gained by deceit.
- Disclose as early as you can, especially once kids start asking questions. The longer you wait, the harder it gets and the greater your chance of undermining your child's trust in you.

"We even tell parents who come to the center that if they don't tell the kids by the time they reach sexual maturity, we will," Haiken said. "But of course it's much, much healthier to have this information come from the parents."

Both women acknowledge that disclosing is very traumatic for parents. "For some

parents, it's just devastating," said Haiken. "They feel guilt because they infected the child because of their past sexual behavior or drug use. They feel guilt that the child has to suffer. Even for parents of children who contracted it from transfusions or are adopted, disclosure is extremely difficult."

Wiener, who has written several research papers on this topic, found the longer parents withheld the diagnosis, the more embedded the lies became and the harder it became to disclose the truth. "Parents often fear that once they disclose new and different information, that their child will no longer trust them," she said. "Following disclosure, many of these children feel embarrassed that other people in their family have been aware of the diagnosis before they had been informed. Once disclosure takes place, these issues and feelings can be successfully dealt with in individual and group counseling sessions with parents and children."

Haiken and other social workers at the center work hard to help parents work through their guilt, or at least face it without flinching, before they disclose.

"I tell them you didn't mean for this to happen, it's clear you never wanted to hurt your child, look at all the wonderful things you've done for your child," said Haiken. "After a while they get there, they see it, but it's still very difficult. No parent ever wants to infect her child. It's something they felt they had no control over."

In terms of disclosure, parents who are themselves living with HIV or viral hepatitis have additional challenges to face. They fear disclosing their own life-threatening disease to their children. But generally, says Wiener, by the time children reach ages 6 to 10, they realize the consequence and finality of death. It is useless to shield children this age from the knowledge that their parents have a serious or terminal illness.

The disclosure process, timetable and style are often dictated by the parents' health. Can they focus on their kids and execute disclosure, or are their own health problems overwhelming? Are they getting the support and time they need or are their own medications, insurance forms and other factors too overwhelming?

"Foster or adoptive parents have the luxury of not having to worry about their own illnesses, so the emotional and financial stress on the entire family may not be as intense," noted Haiken.

The journey to disclosure begins early, says Wiener. "The child and parent should first have a sense of trust – that is the highest priority." Disclosure occurs little by little in age-appropriate ways as soon as a child can communicate. Just like talking about

adoption, it's always on the table, though not all the details or medical terms may be exposed just yet.

Ideally, when the parent discloses the conversation should go something like this, suggests Wiener.

“Do you remember when I told you that you had a germ in your blood? That’s why we have blood work done every year. (And) Do you remember I told you that you got the germ from blood? Well, that germ is a virus that is called HIV or hepatitis....”

“You see, the disclosure dialogue is a constant building process,” she said. “If the child asks why the parent didn’t tell them earlier, the parent needs to be able to say, ‘I never lied to you; I told you what was wrong — I just hadn’t told you the name of the virus.’”

It may take a child weeks, months or years to absorb the diagnosis. “Try to be where the child is at when they ask questions,” wrote Wiener. “Let the child know that no matter how difficult the subject matter, he or she can always ask questions or share feelings. Be careful, however, not to provide more information than the child wants or is prepared for. They may not be ready for a virology discussion.

“You never want to be in the position of telling a 12 year-old about his or her disease that you have never even referred to before,” she added. “That is my main concern in the disclosure process. We’ve interviewed a lot of children who have been disclosed to. Most felt they had been told at the right age and by the right person except those whose parents had a doctor tell them. Those were the only kids who remained upset about the disclosure process.”

At NIH, counselors work intensely with parents of HIV-infected children to prepare them for the disclosure discussion. Social workers even have parents write out what they will tell their children and then play the part of the child in role-play situations. Generally, parents should be prepared to answer the following questions, depending on the child’s age and development. (Some questions apply if the parent is infected also.)

- Why did this happen to you?
- Where did you get it from?
- Are you going to die?
- Am I the reason you got sick?
- Who else in the family has it?
- Why do I have it?
- Why don’t (siblings) have it?

- Am I going to die?
- Will this hurt?
- Who else knows I have this?
- Who can I tell?
- What will happen to me and (siblings)?
- Can I get married? Can I have children?

Here are some general guidelines Wiener has identified for parents to consider as they prepare for the disclosure discussion.

1. Where do you want to make the disclosure, and who should be part of the discussion? “You don’t want to have a ton of people there, just those whom the child trusts and feels most comfortable with,” cautioned Wiener. “Try to anticipate the child’s response based on his or her emotional age and maturity. Be careful never to disclose when you’re angry, or during an argument. Have the discussion in a safe, comfortable environment.”
2. What is the most important message you want your child to walk away with from this discussion? Possibilities include: Nothing is going to change... I am just now giving you the name of the virus... We will always be there for you... I will never lie to you... Nothing you did caused this disease.
3. How exactly will you disclose the actual diagnosis? “We have parents write out how they’d like it to happen, and they always start out with, ‘Do you remember?’ Weave in pertinent aspects of the child’s life and pick up the threads of your past discussions about infections,” suggested Wiener. “Rehearse the questions and answers, including ‘How did I get it? Can I get married? Can I have kids? Who else knows about it?’”
4. If the diagnosis is to be kept secret, who else can the child talk to? “If parents tell a child not to tell anyone, the first thing a child will do is go tell someone,” said Wiener. “They’ll feel resentful if they have no one to talk to. Parents need to find others in the community for the child to talk to. If there isn’t anyone nearby and the child wants to tell his or her best friend, I would tell them to talk with me, the parent, first. I would explain that not everyone is as educated as we are, and it’s important that we make a plan and educate the friend about this infection first. After all, we don’t want anyone to treat us badly.”
5. Give the child a journal or diary or a way to express his/her feelings about the infection. Encourage the child to use art or writing to express feelings. “If HIV had a

face, what would it look like? Or start a discussion with, ‘If I had a million dollars, I would get rid of this virus. What would you do with a million dollars?’ Keep those discussions going,” Wiener suggested.

“It is usually not until days or weeks after disclosure that the child has the courage to ask more questions,” she added. However, after finally making the disclosure, some parents feel so relieved and so exhausted from the ordeal that they may not have the emotional energy to talk about it again. This blocks open communication at a time when sharing concerns about the disease and its impact on the family is most important.

6. Red flags to look for in a child following disclosure: These include difficulty sleeping, changes in appetite, withdrawal, ticks, new fears, mood changes, difficulty concentrating or hoarding things. If you see any such problems, talk to your child and if necessary, seek help from a social worker or psychotherapist. Remember, disclosure is not a one-time event and a child needs constant reassurance that they did not cause the disease.
7. Don’t forget siblings in the disclosure process. Whether or not a sibling is told depends on age, said Wiener. “If the sibling is close in age, I don’t make it a choice; the sibling must be told. But, I do give them a choice of whether the infected child tells the sibling or if the parents tell the sibling. You need to give the child a sense of control. Living with secrets in the home does not promote a healthy emotional climate. I try to minimize the amount of secrets or lying that’s going on. However, if there’s a medical procedure or if they’re on interferon which makes them grouchy, it’s important that siblings know why.”

Even after disclosure is made, the full reality of the diagnosis may not come about for years. “It may not be until someone dies, or they get sick for the first time or they can’t go to a party and drink like everyone else that the reality really sinks in,” said Wiener. “At that point, it becomes an emotional reality, not just an intellectual reality.”

Wiener finds most parents do feel relief after making disclosure. The burden of secrecy is lifted, and children who already intuitively know something is wrong often feel better after they are told of their diagnosis. Siblings, especially if they are older, are also relieved when the veil of secrecy is lifted.

“The demands of keeping the family secret is a heavy burden for a young sibling and may threaten healthy development,” Wiener wrote in a study of siblings of HIV-infected children. “As inquisitive peers begin asking siblings why their brother or sister is sick, it

becomes increasingly difficult not to tell the secret. One 9-year-old girl describes: ‘I want to tell people. Right when I almost say it, I remember in my head I’m not allowed to.’”

Resentment of the special treatment given to the sick sibling may cause the healthy sibling to feel less loved, Wiener explained, particularly if no explanation for the preferential treatment is provided.

Heidi Haiken, who has worked with more than 400 HIV-infected kids, has found disclosure to be beneficial to parents and kids alike. “By and large, the kids do well and are glad they’ve been told,” she said.

But disclosure is just a step in the journey. Parents must be prepared to ask, probe and continue the dialogue about health safety, standard precautions, medical treatments, good nutrition and the fundamentals of safer sex with their infected children.

“In our program, we start teaching safer sex at age 10 to 13,” said Haiken. “We give out condoms, talk about masturbation and how to keep yourself and your partner safe. We don’t deny they’re sexual beings; we focus on how to be safe with it, how drugs and alcohol can make you do things that aren’t safe.”

That safer sex discussion is just one more elaboration on the discussion that began when parents tell their infected toddlers never to touch anyone’s “boo-boos.”

Most parents of infected children and teens don’t have a Heidi Haiken or Lori Wiener in their hometowns. And, they can’t count on local schools to teach standard precautions or to delve into the nitty gritty of safer sex procedures. Parents must be open and honest as they continue these discussions, no matter how painful or awkward, throughout their children’s lives.