



## How to Tell Children They Have Hepatitis C

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### Forward

Experts who have studied children with cancer and HIV/AIDS recommend parents tell their child about a hepatitis C infection as soon as she or he can understand the information, starting at age 8 or earlier if the child is asking detailed medical questions.

Early disclosure is critical to how the child and family cope and live with hepatitis C. How that disclosure occurs, and the building process that leads to that moment, hinges on the child's age, maturity, family situation and medical condition.

### Two important rules for parents and caregivers to consider are:

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

When the time to disclose arrives, it is never easy. Parents fear children will question them about past drug use or other behaviors if that played a role in the infection. Parents who are themselves infected with hepatitis C fear disclosing their own disease to their children. But by the time children reach ages 6 to 10, it is useless to shield children from the knowledge that their parents are struggling with a serious illness.

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### HCSP FACT SHEET

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## How to Tell Children They Have Hepatitis C —CONTINUED FROM PAGE 1

Adoptive and foster parents must be prepared to answer tough questions about the role birthparents, orphanages and re-used medical equipment may have played in their infection.

If an uninformed older child or teen is not asking about his or her visits to the doctor, don't assume the child is not interested. It is important to impart this information even if the child appears uninterested. Children will soon realize their medical histories differ from those of their friends. A child may begin to study diseases in school and realize that the precautions parents take to prevent infection are not practiced by others.

Timing is also important. Parents need to find a time and place to tell a child about the diagnosis that is comfortable for them. If parents are nervous or tense the child will pick up on the body language and start to panic. And, telling children about their hepatitis infection when there is a medical crisis is tricky because the child may be upset that the parent withheld information.

Lori W. Wiener, coordinator of the Pediatric HIV Psycho-Social Support and Research Program at the National Institutes of Health (NIH), says trust between parent and child is paramount during disclosure. Disclosure should occur little by little, beginning when the child can communicate.

Ideally, Wiener explained, when a parent discloses the conversation should begin, "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. Do you remember I told you that you got the germ from blood? Well, that germ is a virus that is called hepatitis C."

"The disclosure dialogue is a constant building process," Wiener 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 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 he or she asks questions. 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.

"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," Wiener added. "Most children I've worked with felt they had been told at the right age and by the right person except those whose parents had a doctor tell them."

At the National Institutes of Health (NIH), counselors work intensely with parents of HIV-infected children to prepare them for the disclosure discussion. Generally, parents should be prepared to answer the following questions, depending on the child's age and development. (Some questions apply only if the parent is infected also.)

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## How to Tell Children They Have Hepatitis C —CONTINUED FROM PAGE 2

- 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?
- Can I get married?
- Can I have children or will they be infected?

Here are some general guidelines parents can consider as they prepare for the disclosure discussion.

- Where do you want to make the disclosure and who should be part of the discussion? There should only be the child and parent(s) present. “Be careful never to disclose when you’re angry, or during an argument. Have the discussion in a safe, comfortable environment,” says Wiener.
- 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.
- 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?’”

- 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, such as the child’s doctor. 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.”

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 hepatitis C 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

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**How to Tell Children They Have Hepatitis C** —CONTINUED FROM PAGE 3

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.

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, he or she should be told, but it should be the infected child’s decision to tell a sibling, or let the parent tell. Living with secrets in the home does not promote a healthy emotional climate. 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 hepatitis C treatment, which may make them ill, it’s important that siblings know why.

**Suggested reading:**

My Mom Has Hepatitis C, by Hedy Weinberg and Shira Shump, M. Ed., with Gregory T. Everson, M.D., available at [www.amazon.com](http://www.amazon.com)

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