



Hepatitis C HCCAP

What Do I Tell The Kids?

Tina M. St. John, MD

Originally published in Hepatitis Magazine, 2002. Reprinted with permission.

Learning you have chronic hepatitis is a life-changing event. Many questions flood your mind about your health and future. If you have children, you may struggle with what to tell them about your illness. Should you say anything at all? How much should you tell them? What exactly should you say?

It is quite common for parents with a chronic illness to struggle with addressing the topic with their children. This article is intended to provide you with some guidelines to help get you started.

Should I Tell My Children?

The first decision to be made is whether or not to tell your children about your hepatitis. Parents often consider not telling children in an effort to protect them from undue worry or stress. However well-intentioned this thought may be, it is ill advised. Children are very perceptive! Even if you don't tell your children *exactly* what is going on, they will invariably know that *something* is going on. Without information, children often imagine scenarios much worse than the actual situation. In this way, withholding information from your children can actually cause them more worry and stress than the truth would. Therefore, experts advise that for all but very young children (2 years or younger), it is best to discuss your situation openly with your children.

A second, equally important reason to discuss your illness openly with your children is maintaining trust. The lessons

children learn from their parents and other caretakers about honesty and trust will affect their relationships throughout their lives. Therefore, it is extremely important that you are always open and honest with your children, even about difficult topics. Trying to hide your illness or responding to your children's questions with anything less than the truth can lead to anger, resentment, distrust, and insecurity.

What Exactly Should I Tell Them?

What exactly to tell a child, and how to tell him or her depends upon the age of the child and his or her personality. However, there are a couple of general considerations to keep in mind regarding what to tell a child about your hepatitis.

- Each child is different and you know your child best. Tailor what you decide to say to suit your child's personality.
- Always tell your child the truth. Telling the truth does not mean you have to tell your child every detail of your illness. There are some things all children will be curious about, and those topics should be addressed with every child. However, beyond these common areas of concern, let your child be your guide. Your child will ask you what he or she wants to know.
- Make it clear to your child that you are willing to talk about anything he or she is concerned about regarding your hepatitis, and how it may affect things in your household.

- Be prepared! Children are generally much more open and honest about their concerns than adults are, so it's important to be prepared to talk about any topic that is of concern to your child. If your child happens upon a topic you are unprepared to discuss immediately, tell your child that you need some time to think about his or her question. Assure your child that you will get back to him or her very soon about the question – and make sure you do.

Following are some suggestions about what to tell your child based on his or her age. Remember, these are only suggestions. How and what you say to your child should take into consideration his or her unique personality and capabilities.

Ages 3 to 6. Children in this age group tend to be quite literal with their questions and concerns. A simple rule of thumb with this age group is, “stick to the facts.” You will want to tell your child in simple language what you have, and how it may affect you. It is also important to make it very clear to your child that he or she will still be taken care of despite the challenges of this illness. An example of how you might start a conversation about hepatitis with a child in this age group is shown below.

You remember when Mommy went to the doctor last week? The doctor checked me over, and found out Mommy has a sickness. The sickness I have is called hepatitis.

I wanted to tell you about Mommy having hepatitis because I'm going to need to take some medicine for a while to try to get rid of the hepatitis. The medicine could make me feel kind of tired sometimes, so your Daddy might be taking you places sometimes instead of me. Or I might need to take naps sometimes like you do. That sounds kind of

funny, doesn't it? But I need to take the medicine to try to make the hepatitis sickness go away.

One thing I want you to know is that even though I may not feel well sometimes, someone will *always* be here to take care of you. It might be me or your Daddy or Grandma or Grandpa. The important thing is that one of us will *always* be here to take care of you.

After breaking the initial news, children in this age group almost uniformly come up with several questions or concerns you will need to address. Be aware that your child may or may not directly mention these concerns. But by being aware of the concerns, you can look for opportunities to address them.

Even at this young age, your child will invariably ask or wonder if you going to die. As you consider trying to truthfully answer this question, it is important to understand what a child this age is really asking. Children in this age group think of death as “going away.” They do not understand the finality and permanence of death. Moreover, they think in rather short time spans. Therefore, when a child in this age group asks if you are going to die, he or she is actually asking if you are going to leave him or her sometime in the near future. For all but the most critical of situations, you can answer this question honestly by reassuring your child that although everyone will die someday, there is no reason to think that you are going to die anytime soon.

Logical, cause-and-effect thinking is not fully developed among children in this age group. These children think things happen “magically.” Further, children in this age group see themselves as the center of their world. The combination of magical thinking

and a self-centered view leads these children to think they are the cause of many things that happen in their world. Therefore, nearly all children in this age group will think they somehow caused a parent's illness. Your child may not tell you this, but it is almost certain that he or she will think about it. For this reason, it is a good idea to tell your child upfront that he or she had *nothing* to do with you getting hepatitis. You may need to repeat this and the other information you are trying to communicate to your child many times. One of the ways children in this age group come to terms with new concepts and information is repetition. So don't be surprised if your child asks you the same questions over and over again. It is simply his or her way of trying to understand and integrate the new information you have shared.

Another common concern for 3 to 6 year olds is, "Am I going to get sick, too?" I will discuss how to address the important topic of contagiousness later in the article under "Talking About Safety."

Ages 6 to 12. Around the age of 6, magical thinking begins to wane and children begin to understand how cause-and-effect operates in the world around them. Children in this age group are invariably fascinated with the human body and its functions. Emotionally, they are growing in sympathy and compassion.

In general, you will want to cover the same topics you would address with a younger child. However, you will need to be prepared to answer more specific questions as children this age are very curious about exactly what is happening, how and why certain things are done, et cetera. Here is an example of how a parent might begin a discussion about having hepatitis with an 8 year old child.

When I went to the doctor last week, I had a blood test and found out I have a virus in my body. The virus is in my liver and is called the hepatitis B/C virus. So I have an illness called hepatitis B/C. This virus could hurt my liver, so I'm going to need to take some medicine for a while to try to get rid of the virus.

The medicine I'm going to be taking is strong medicine, and it could make me feel tired or like I have the flu. We'll know more about exactly how I'm going to feel once I start the medicine. But I wanted you to know what's going on and what could be happening once I start taking the medicine. I may not be able to play ball with you as often, or we may need to cut back on our fishing trips for a while.

Our family is going to have to pull together. Your mom and I may need you kids to help us out with some more of the chores. But that main thing I need from you is for you to keep doing your best at school. You work on that, and I'll work on trying to get rid of this virus. I want you to know, you can always come to me if you have questions, or are worried about something. Is there anything you're wondering about right now?

It is highly likely that your child will have many questions. Always answer your child's questions openly and honestly, but stick to the question at hand and keep your answers simple enough for your child to understand. Don't be surprised if your child comes up with a question to which you may not know the answer. Simply tell your child you don't know the answer to the question, but will find out and get back to him or her.

A child this age can be a big help, and allowing him or her to help out around the house can be beneficial for both the child and

your family. However, depending on your child's personality, it is possible that he or she may try to take on too much responsibility acting more like a parent than a child. You can avoid this by keeping the lines of responsibility and your role as the parent quite clear. Be careful not to use phrases that may blur these lines such as, "You're going to be the little man of the house for while." or "I need you to be the mom for your little brother until I feel better." No matter how grown-up your child may act, he or she is still a child and needs to know that you are going to be there to take care of him or her as you have in the past.

Teenagers. As any parent of a teenager already knows, teenagers are unpredictable. However, most teens are quite knowledgeable, so you'll need to be prepared to provide them with detailed information about your illness, how it affects you, and what the treatment approach will be. Despite the adult-like level of your teen's knowledge, remember that he or she is still a child emotionally. A teen's reaction to a parent's illness is complicated by the fact that this is the age when a teen needs to begin pulling away from his or her parents. His or her concern for you and the need to pull away can lead to some strong emotional conflicts for your teen. How he or she reacts to this conflict will depend on his or her level of maturity and personality.

When you discuss your illness with your teen, it is extremely important that you be completely honest. Teens are particularly sensitive to even the slightest degree of dishonesty. Evasiveness or partial truths are likely to anger and/or alienate your teen, and should be avoided.

Be candid with your teen about how your hepatitis may affect him or her. Let him or her know that there may be some additional

chores or responsibilities involved, and that schedules may need to be adjusted. But, again, you'll want to be sure to maintain a clear distinction between your role as parent and your teen's responsibilities within the family.

Talking About Safety (Hepatitis B and C)

Your children need to learn that as long as they follow a few simple rules, they are at no risk of getting hepatitis from you. You will want to state the precautions clearly and in words that your child is able to understand, while at the same time being careful not to cause undue fear.

Rather than limiting the precautionary measures to you, it is often simpler to teach your children that these precautions apply to everyone. Establishing these habits cannot hurt your child, and may provide a good foundation for future messages you may want to communicate about communicable disease prevention.

The essential precautionary messages you need to communicate to your children are below.

- If someone is bleeding, do not touch the blood. You can help by bringing a tissue, towel, or a Band-aid[®], but then let an adult take care of the situation from there.
- [Young child]: Never to touch anyone's razor.
[Older child who shaves]: Always use your own razor; never use someone else's razor.
- Always use your own toothbrush; never use someone else's toothbrush.

It is important to reinforce the message to your children that as long as these simple rules are followed, they are at no risk of getting hepatitis from you. Assure your children that hugging, kissing, and playing pose absolutely no risk to you or them.

To ensure that your child knows and understands these safety precautions, have the child repeat them back to you periodically until you are certain he or she has a firm grasp on them.

How Is My Child Adjusting to the News?

As the old adage says, no news is good news. In other words, if your child is behaving in his or her usual way, he or she is probably adjusting normally to the new challenge your family is facing. Continued love, support, and open communication as new situations arise will keep your child feeling safe and secure.

Occasionally, children can have difficulty adjusting to news that a parent is sick. Some warning signs that your child may be having trouble include: changes in sleeping or eating patterns, new behavioral problems, academic or social problems at school, risk-taking behavior, being unusually quiet, and/or sudden backsliding on developmental milestones. If you are worried about your child, talk to his or her pediatrician. Your pediatrician can give you a referral if he or she thinks your family may benefit from some additional outside help.

Summary

Hepatitis affects the whole family, including your children. For that reason, all but the youngest children need to be told about your illness. Tell your children what you have, and how it may affect you and them. Equally important, reassure your children about those things that having hepatitis will not change such as your love for them, and taking care of them. Always remember to be open and honest; your child needs to know that even in difficult situation, he or she can always trust you.

Children are much stronger and more capable than adults often realize. After talking with your children, you may find yourself pleasantly surprised by how readily they are able to adapt to this new challenge in your family.