

TALKING TO CHILDREN

How to Talk to a Child About Viral Hepatitis

How children view their liver disease and learn to live with viral hepatitis depends greatly on how honestly and effectively parents and caregivers communicate about the disease.

Parents can't make the disease go away, but they can educate their child, safeguard their privacy and give them the information and role models they need to live their lives fully.

But it's no easy task. Disclosing a child's hepatitis diagnosis opens a Pandora's box of issues, ranging from parental sexual behavior, parental drug use and discrimination to tough questions about illness and death.

If a child is adopted or in foster care, the disclosure will also inevitably highlight the role birthparents and interim institutional care may have played in the transmission of the disease. The diagnosis can add to feelings of being "different" that may be already present by virtue of adoption and of being a different race than the adoptive parents or the local community.

But saying nothing can be equally destructive to a child and family. "Secrecy creates a lot of lies and mistrust within a household," wrote Mary Tasker, author of *How Can I Tell You*, which explores HIV and disclosure. "That kind of mistrust leaves it up to the child's imagination, which can be much more fearful."

The American Academy of Pediatrics Committee on Pediatric AIDS came to a similar conclusion when it researched how disclosure of a cancer diagnosis impacted children. It found that children who were informed about their diagnosis had better coping skills and higher self-esteem than those who were not told. Similarly, parents who disclosed HIV status to their children early on experienced less depression than parents who did not disclose.

When and how parents tell their child about a viral hepatitis infection depends on the child's age, maturity, family dynamics and clinical issues. The information shared with a child will change as a child's understanding and maturity increases, but the guiding principle, experts say, is to impart information as honestly and age-appropriately as possible.

Parents need a communication plan that commences before a child is out of diapers, addresses disclosure at an appropriate age and keeps on going until the teen walks out the door for college or their first apartment.

“The most important thing is to have a plan,” said a mother of two young girls, ages 12 and 9, who have hepatitis B. “The worst part of dealing with the disease was telling the kids that they had it. I didn’t know how they were going to react, and I didn’t know how I was going to hold up.

“Fortunately,” she said, “I talked to a counselor who explained that I needed a plan to help me stay on track. He was right. I wasn’t able to follow my plan completely but it gave me a feeling of confidence and control. That’s something you don’t get very often with hepatitis.”

There is no “best” communication plan. The plan will be revised and changed over time. If parents ask the right questions, seek expert advice when needed and return to the drawing board whenever necessary, they will create a plan that will work for the child and the entire family.

Every communication plan should answer some basic what, when, why and how questions. For example:

- Who should tell the child that he or she has hepatitis? The news should come from parents, but should anyone else be involved, such as a mental health professional or pediatrician who is known to the family?
- Who else in the immediate family needs to know and when should they be told?
- Is there anyone in the extended family who should be told?
- Should the information be shared with anyone outside the family, such as a teacher, daycare staff, playground attendants, sports coach or a religious leader?

Parents should consider these questions carefully. And also consider a child’s personality. A plan should accommodate a child’s strengths, fears and openness. And it should address whether a child will share that information with others.

Obviously, part of this communication plan includes figuring out whom to tell and whom not to tell. Should friends, babysitters, daycare providers or Girl Scout leaders be told?

Once a plan has been devised, parents may want to review it with a pediatrician, a mental health professional, or members of a hepatitis support group. Approach only those people whose professional integrity or personal experience can be trusted. It is essential that they respect a parent and a child's privacy and treat the family with sensitivity, dignity and respect.

Sometimes it takes tremendous emotional strength to deal with unhappy issues in an honest way. When a child looks a parent in the eye and asks if he or she is going to die because of hepatitis, it's tempting to simply say "no." It's better to tell the truth — "I don't know, but we're doing the best we can," or "I wish I had a good answer for your questions but unfortunately I don't."

The bottom line: Honesty always. Correct information is better than disinformation. Honesty is key to any communication plan because children won't share their fears and imaginings with adults they don't trust.

Forthrightness is also essential. A child's hepatitis must be addressed clearly and directly. Children sense and distrust evasiveness. An 8 year-old who doesn't get his or her questions answered may think he or she is being treated like a baby and may begin to resent, if not ignore, the rest of what a parent says.

A teen who doesn't get questions answered may think a parent has something to hide, or he or she may stop communicating and look elsewhere for answers.

Evasiveness may also be misinterpreted as guilt. It is critical that children not associate guilt with hepatitis. Hepatitis is a disease, not a punishment.

Communication is a precious thing—and it must be protected at all costs. Reassurance, honesty and forthrightness will encourage a child to keep the lines of communication open.

A communication plan, which should be revisited at least once a year, should include the following:

- What do you think your child wants to know at this time?
- What do you think your child needs to know now?
- What do you think your child can and can't handle?

- Are you going to give your child specific medical information or generalities?
- What is the most age-appropriate information to give?
- Are you going to discuss the prognosis?
- What peripheral issues (such as the use of standard precautions or safer sex) need to be addressed?

Talking to Children Ages 2 to 7

Experts offer a relatively simple game plan for young children through age 7 who are too young to be told of their hepatitis diagnosis:

- Create a communication plan that deals with doctor visits, injections and blood draws, treatments and travel related to the illness.
- Decide whom to tell about a child's diagnosis and determine what parents can do to ensure their continued support.
- Be prepared to be a behind-the-scenes advocate on behalf of a child at his or her daycare center and school.

There is a fairly strong agreement among experts and parents that there is no reason to discuss a hepatitis diagnosis with young children. They can't understand hepatitis or its ramifications. Parents can contribute to a child's confusion, fear and anxiety by talking to them about a subject they can't handle.

“Communication in general is a difficult subject for most children,” says Charlean Clemmons, a counselor who specializes in children's health issues. “When you mix low communication skills with a complex subject you can create real problems.”

The younger the child the easier it is to avoid discussing the viral hepatitis diagnosis itself. Because of their limited attention span, life experience and knowledge, preschool children will focus on the obvious and timely disease issues rather than on the bigger hepatitis picture.

Until they are 7 or 8 years old, if they are given the names of diseases or told they have an illness, in all likelihood they won't understand it, and they will probably repeat the information to others. Young children also have a hard time distinguishing between real

and imaginary until they are 5 or older. They learn best by experience.

During these early years, it is important to teach standard precautions and to begin to explain that blood can carry germs or viruses; therefore, it is important that only a parent, nurse or daycare teacher touch their blood. Similarly, it's important to teach a child never to touch another person's blood or body fluids in order for them to stay healthy.

"The communication plan needs to change as your child ages and his condition changes," said the mother of an 11 year-old boy with hepatitis C. "I didn't talk to David about safe sex when he was very young but I did harp on the importance of universal [standard] precautions. I didn't tie the precautions to hepatitis either. We started talking about blood being one of his private body parts and nobody else's business when he was very small, almost 4 years old.



artwork by Lisa

"As he got older, about kindergarten age, we started talking about viruses and bacteria and germs, what they were and how they are everywhere. When he was about age 7, we told him about his hepatitis. We didn't dump everything on him all at once, we just sort of eased into it," she added.

A child who is receiving regular injections or goes to the doctors frequently should be given very simple explanations for the medical treatment. Essentially, all they want to know is why they must endure the medical procedures. For example, a child who has blood drawn annually for liver tests to ensure the hepatitis virus is not harming his or her liver could be told the following:

"Every year, the doctor takes a sample of your blood and tests it to make sure you are healthy. We want to make sure that you are always healthy." Or, "There may be a problem with your body, so we need to test your blood to make sure you are healthy."

If a child asks why a sibling doesn't undergo the same blood test, a parent could say, "There is a chance that an organ in your body may have gotten hurt. We need to check every year to make sure it's healthy."

If a child is receiving regular interferon injections and blood tests, a parent could explain that there is a germ that could harm his or her body and this medicine will help.

Questions are usually simple and can be answered with concrete explanations. Most of the focus will be on dealing with a child's anxiety over needle sticks and pain.

Until they are age 8 or 9, parents and caregivers should consider:

- What do you think the child wants to know at this time?
- What do you think the child needs to know at this time?

Importance of Behavior Modeling

Parents must be aware that they send important signals about their child's hepatitis and how they view the disease long before they ever say the "H" word out loud.

"With my 4 year-old child, the biggest communication problem was my own body language," said the mother of a girl with hepatitis C. "It was very difficult for me to take my daughter to the doctor without giving off what my husband called 'fear rays.' As a result, my daughter, who wasn't particularly frightened of the doctor's office or what went on there, started to take after me.

"Things didn't settle back down until I began acting like medical visits and treatments were everyday routine matters, although I confess we did make a trip for ice cream after every appointment," the mother added. "In my case, the problem wasn't when or how I talked to my young daughter or even what I said. My communication problem was me. I was creating a sense of fear and I simply had to stop."

Small children with viral hepatitis will probably be most fearful of doctor visits, treatments or even hospital visits. Author and social psychologist Dr. Avis Brenner noted that these young children will probably feel stress because they lack information about their condition, fear the unknown, remember prior negative medical experiences and are afraid of pain.

According to Dr. Brenner, children who don't know much about their medical situations need to be assured that the encounter is not some sort of punishment. They should be told generally why they are going to the doctor or hospital and what they can expect. Dr. Brenner also suggests making a list of a child's questions and making sure that they are all answered in a way the child can understand.

Helping children develop an appropriate frame of reference for their experiences can fill some of the information void. "We didn't want to talk about the disease itself but we felt

that we had to talk to John about things like his frequent visits to the doctor,” said the mother of an 8 year-old. “Our counselor helped us identify a frame of reference and communication strategy that worked for him.

“When John pointed out that his friends at school didn’t have to go to the doctor all the time, we pointed out that everybody in his class was unique. One of the kids had red hair. One was unusually short and another wore thick glasses,” she said. “There were kids in his class who were hyperactive and couldn’t sit still for long, a boy who lived in foster care and a little girl who had to wear a hearing aid. We told John that he had interesting stuff in his blood and that was why the doctor liked to see him so often. When we explained it that way, John quit thinking of his doctor visits as something that made him weird and started thinking about the appointments as something that made him uniquely John.”

Remember, a child isn't the only one who will lack information about his or her condition. Other people are likely to ask him or her why they are going to the doctor, why they are missing so much school or preschool and why they are afraid of shots.

Dr. Arden Dingle, who treats young children with serious illnesses, suggested, “It is helpful to teach children to answer pointed medical questions politely with general information. Such as, ‘I’ve missed school because I was sick but I am better now,’ or ‘My doctor told me it is important to wash my hands before meals’ or ‘My mother told me it’s better not to share cups.’”

Have children practice so they know how to answer when these questions come up. These role-playing scripts are also used by multiracial adoptive families who want to give their children the verbal skills to effectively deflect rude or intrusive questions.

Defusing Fearful Medical Visits

Fear of the unknown often centers around trips to a hospital or treatment center or doctor’s office. Children in this situation should learn about when and where they are going several days before the trip. Dr. Brenner encourages parents to help their children pack the travel bags, and don't forget a reassuring toy or photo. Preparing the child's room for his or her return also communicates to the child that the trip will be over soon and everything will return to normal.

Providing guidelines for a child’s behavior also helps reduce their fear of the unknown. “We wanted to give Rachel a set of guidelines that she could apply in any situation,” says the mother of a 7 year-old with hepatitis C. “Some of these guidelines had to do

with hepatitis C, others did not. For example, ‘What do you do when a stranger asks you to get into his car? You scream and run away.’ Or ‘What do you do when a nice person holds the door open for you? You say thanks.’ Or ‘What do you say when somebody wants to know about your private body parts (we include blood in this)?’ You say, ‘Mom says it isn’t good manners to talk about private body stuff.’ Or ‘What do you do when a person starts to bleed? You get rubber gloves to clean up the mess, etc.’

“Of course, throughout the whole process we’re mostly aiming toward the hepatitis and standard precautions issues, but when we include it with other important information that kids hear about in school it doesn’t sound so ominous or out of the blue. It just sounds like a generic response to a generic question. And who’s to say that it isn’t? Good advice is good advice,” she added.

Dealing with memories or unpleasant past medical experiences can be particularly difficult. Parents need to discuss the unpleasant memories and explain again why the experience needs to be repeated. Parents can explain, “Sometimes people have to have medical tests done more than once because things change and the doctors want to know when changes happen.”

In particular, warned Dr. Brenner, don’t promise the child that this medical experience will be different than those in the past. Trust is crucial in dealing with a child who has hepatitis. You can’t support your child emotionally unless your child trusts you. Lie to your child and the fragile bonds of trust will be broken.

But you can do whatever you can to make these unpleasant experiences tolerable. “My son hated to go to the doctor,” said the father of a 5 year-old boy with hepatitis B. “It was always a negative experience. He’d whine, cry and complain for hours beforehand. It was a miserable experience for everybody. We decided that we had to put a positive spin on things, so we put a calendar on his wall and put a sticker on every date that he went to the doctor without complaining. He felt so proud every time he put up that sticker! Later we learned that by chance we were copying a program at his nursery school where the kids each got a sticker if they behaved during the day.

“One day he told us that he must be an extra good kid because he had two sticker pages—one at home and one at school,” the father explained. “That was when we learned how important it was to create a positive environment around even the most unpleasant experience.”

Fear of pain, according to Dr. Brenner, is best dealt with by finding out what the child imagines will happen and then providing them with age-appropriate information. Accept

that at some level your child is going to fear the pain and will respond with tears, anger and confusion. Make sure your child understands that the pain will be kept to a minimum. Even when parents can't make the pain go away, they can be there with support, love, understanding and comfort.

Talking to Children Ages 8 to 12

Experts recommend that during this age period parents and caregivers explain in age-appropriate terms their children's viral hepatitis diagnosis.

Between ages 8 and 10, children's fears change. They used to be afraid of monsters and other imaginary characters, now they are more likely to be afraid that a real person might hurt them. They are beginning to understand cause and effect. They understand that climbing a tree could result in injury. They understand that death comes from an injury, illness or accident.

While their comprehension of disease may increase, their fears do not necessarily decrease. But they may talk about their fears less openly now, so it's important that the adults in their lives look for opportunities to broach and revisit the topics that may be bothering them.

Disclosure will probably add to those fears. Parents must follow their child to see how well they're coping with the information of their illness. The child's age, maturity and emotional vs. analytical outlook all contribute to his or her well-being after disclosure.

The whys and hows of telling a child about a viral hepatitis diagnosis are critical to building and maintaining a healthy relationship. "I told my child right away about his hepatitis because I wanted him to know that I tell him important things and that I respect his intelligence," said the mother of a 9 year-old child who had just been diagnosed with hepatitis C.

"He needs to be able to depend on me and he won't if he thinks I am not open and honest. I may not tell him the whole truth—I think there are still some things that he's too young to handle—but I tell him as much of the truth as is appropriate and I don't lie. That reassures the both of us," she added.

When the child has a concern, does he or she articulate it to a parent to try to deal with it privately? Is the relationship between parent and child changing? Does the child's vivid imagination, communication skills or behavior ever pose a problem?

It is critical that parents take time out from their busy schedules to talk to children during this age. This is also the age when personal values are learned, so it is important to model a confident and honest outlook on the disease.

Continued confidentiality is critical at this age. If parents fear a child will talk publicly about his diagnosis, then they must take time to talk about the possible negative ramifications of public disclosure. Every child needs to talk. If needed, parents can find a support partner, a formal support group or a professional counselor for their child.

As the child adjusts to the knowledge, it is important to look at how the family as a unit is faring now that the hepatitis diagnosis is out in the open. How are siblings doing? Is there jealousy that the child with hepatitis gets a lot of attention? Are standard precautions being promoted enough within the family?

How are parents faring with the stress of the illness and medical and travel expenses?

If a child is not the only family member with hepatitis, how is the health of parents and caregivers? Is additional support or counseling needed?

Families that have more than one member who is infected with viral hepatitis may recognize early on that the disease is only one part of each individual's human package. They won't associate the disease with behaviors or guilt and the child with hepatitis may not feel different from everyone around him.

During this time, when children are in school, parents may have to continue to be advocates for their children. How much information is in the school records? Should any of it be removed, considering the school is required to practice standard precautions with everyone regardless of their known infectious disease? Should a child's teacher be told if medical issues require the child to miss more and more school?

When revisiting the communications plan, is it time to tell anyone else about a child's viral hepatitis? Is there enough trust now between a parent and a child's best friend's parent to risk disclosure?

Is it time to tell members of the extended family, especially if they are close to the child, or is it better to remain quiet about a child's infection?

During the ages of 11 and 12, kids vary quite a bit in their maturity level. Parents and caregivers must judge how much information to share about sexuality and the role it plays in transmission of viral hepatitis.

Don't avoid this topic even if you feel uncomfortable discussing it, or because you talked about it "once" or gave the child a book. Pre-teens need to hear parental messages about sexuality often. They are poised to enter the "I am invincible" stage of life and the more information they have about health risks, such as alcohol, drug use and sexual activity, the better.

Talking to Teens About Hepatitis

"Teenagers are in a far different situation than younger children when it comes to their hepatitis diagnosis," said Charlean Clemmons. "On the plus side, they want to know what is happening with their bodies. They have the communication skills necessary to understand what you need to tell them about the virus. They have more real world experience that helps them understand the ramifications of the hepatitis and accept their medical treatments.

There are complications when it comes to communicating and dealing with teenagers. They are more likely to be involved in behaviors, including unprotected sex and injecting drug use, that could spread the hepatitis virus. Though unconfirmed, some suspect body piercing and deep kissing may also transmit hepatitis viruses.

Teens often feel different from others and are prone to feelings of alienation, depression, societal retaliation and self esteem problems. Teenagers also have the ability to gather information (sometimes inaccurate information) from people other than their parents and their doctors.

"While they are going to have emotional issues with the diagnosis, including anger, frustration and fear, they already know that life is unfair and that bad things can happen to good people," Clemmons added. "This gives them a leg up when it comes to acknowledging the inevitable. That said, they also know, given our environment of scientific change and research, that the prognosis for their disease is likely to improve with time and research."

It is important when parents develop their communication plans for their teens that they realize they have very little control over what their teenagers think, learn or feel. They need to remember that there are other entities, including doctors, peers and support groups, who can also help their child. They are not in this alone.

Ideally, parents of teens should be in one of two situations: Either they have an ongoing dialogue about hepatitis with the adolescent that started years ago with the initial diagnosis, or the family has just found out that the teen is infected.

If a parent has just found out, then these guidelines for disclosure should be followed:

- The teen must be informed as soon as possible.
- The ramifications of the disease must be discussed and a medical or mental health professional should be enlisted if needed.
- Necessary behaviors or changes in behavior must be addressed to prevent transmission, including standard precautions and safer sex practices.
- Ongoing discussions must occur to help the teen accept the realities of viral hepatitis.

Telling a teenager that he or she has viral hepatitis is far more complicated than breaking the news to an 8 year-old. But similarly, follow-up, support and reassurance is needed.

- The teen will need continued intellectual, emotional, spiritual and physical support.
- The parent needs to monitor a teen's use of standard precautions.
- Teens should be encouraged to find support systems, either from local groups or from safe Internet sources, for the kind of support that parents can't readily give.
- There will be times when this almost-adult person wants to be treated like an adult and times when your almost-adult child wants the same support you would typically give a much younger child.

One way to support teenagers is to keep them informed about their disease and related issues. This gives them a sense of control that they don't have if parents keep them out of the loop. It also helps them take ownership of their disease.

“Parents should tell their kids everything they can about their health condition,” said Daniel, who contracted hepatitis C from an infected parent. “And if they don't know stuff they should go to their doctor for help. They really got to be honest. My mom is like from some other planet. She doesn't want to tell me anything other than I have hepatitis C and I shouldn't drink alcohol and have sex. Yeah, big help. Most of what I learned about the hepatitis I got from brochures at the county health department. But that doesn't tell me anything about me. How sick am I? How sick is my mom? How will we be doing in a couple of years? I mean, what are my chances? I really need to know what's going on.

“It took me a long time, but I finally got my mom to let me talk to the doctor,” said Daniel. “I talked to him alone. I couldn’t talk to her about serious stuff like sex or drugs or dying. I mean, she couldn’t even talk straight about the bug to begin with. I don’t trust her on the other stuff either. If she had started when I was younger, then maybe, but not now. This is my life we’re talking about. Maybe the problem is that she has hepatitis C too. Maybe she doesn’t want to think about her own stuff but we got to be honest with each other. She can’t help me if I can’t trust her. And she’s got to trust me, too. I can handle it. We could help each other deal with whatever. That’s family.

“Well, it could have been worse,” Daniel added. “When my girlfriend’s parents found out she had hepatitis C, they threw her out of the house. Called her a druggie and just threw her out. It makes no sense. Judging people is just the worst. Nobody should judge their kids for getting sick. They should do whatever they can to make things good.”

David, who has hepatitis B, found it helpful to talk to his doctor. “It helped me to be given a few absolutes,” he explained. “I wanted that sense of control. For example, the doctor told me about the importance of not drinking. Choosing not to drink alcohol as a way to protect my liver makes me feel like I am taking charge, like I am winning. Using universal [standard] precautions gives me control over the spread of my disease. I may, well I do, have hepatitis B, but I’m not going to give it to anyone else. It may not sound like a lot of control, but when you don’t know what’s going to happen to you in the future, anything you have control over just gives you that much more hope.”

“I sure wish my parents had told me about my hepatitis B when I was younger,” said 16-year-old Cheryl. “They didn’t tell me about it until the doctor pushed them to tell me. They’ve always treated me like a kid. They were like, well she’s only 16, we won’t tell her until she’s older and has serious boyfriends. But I was already doing it. Everybody was doing it. I mean, my boyfriend was using a condom and everything most of the time because I didn’t want to get pregnant, but we didn’t worry about it when I was having a period because it can’t happen then. Getting pregnant, I mean. I wasn’t worried about anything else. Then I found out I had hepatitis, and I had to tell my boyfriend that he might have hepatitis B, too. It was like ‘Thanks a lot, Mom and Dad. You might have warned me.’”

Teenagers should be encouraged to get additional support from a variety of sources, including credible on-line support groups, therapists, telephone hotlines, teachers, doctors and school counselors they trust. Teenagers are old enough to reach out to other people for help. These are the same people teens reach out to for help with other adolescent crises.

“The teenager with a handicapping condition is confronted with the normal crises of adolescence,” said Ruth Arent, author of *Stress and Your Child*. Hepatitis and adolescence certainly present a formidable challenge.

“Combined with the ongoing difficulties of the past [medical history], these ‘normal crises’ may upset some of the established ways he or she has learned to cope. This may be very upsetting to the child and the parents. Remain optimistic. All young people need support to handle the regressions, demands and problems that lie ahead,” she added.

Finally, remember that teenagers, while they want and need your support, should also to be treated with the same level of respect *you* wanted when you were a teen.

“I wish my parents would remember that while I am partly a kid, I am mostly an adult,” Karen, a 17 year-old who was recently diagnosed with hepatitis C, explained. “They don’t need to protect me from reality. I’ve already read about hepatitis on-line and talked to other hepatitis C kids in chat rooms. We’ve studied infectious diseases in school. I know other kids at school who have things like cancer and diabetes. I realize that people die. I know they want to support me but pretending I’m not sick isn’t helping. I can’t help but think that they are hiding things from me because things are getting worse.

“Another thing I hate is when my parents talk to the doctor for me as though I couldn’t speak English,” she added. “And then when they want to make all of my health decisions for me. You know, it’s my life. Of course I want their help. Of course I want their support. Of course I want their advice. But it’s still my life, and I need to figure out how to deal with the hepatitis myself.

“I need to decide who to tell and who not to tell,” Karen explained. “I need to learn to protect myself and others. My parents don’t have to panic when I get angry or depressed about the disease. I have a right to feel that way. But I’ll get over it if they will just let me work things through on my own. I want to say to them ‘Offer me your support; there are times when I’ll want it. There are times when I’ll need it. But there will also be times when I’ll want to talk to a doctor or to someone my own age or to just handle things on my own. You have to accept that. It’s my disease and my life and my decisions. I have to be comfortable with where I am.’”