

WHOM TO TELL AND NOT TELL

When a Child has Viral Hepatitis

Many parents regret ever informing some family members, friends and teachers about their child's hepatitis infection. Instead of offering compassion and support, some have responded indifferently or pulled away completely.

One parent said her own mother no longer allowed the child with hepatitis to visit for fear she would infect the other grandchildren. Another parent reported one of her family members felt "morally obligated" to tell her neighbors of her child's diagnosis.

A parent in Virginia reported telling her minister about her daughter's newly-diagnosed hepatitis infection only to have the minister request that the child not attend Sunday school. "I was devastated," the mother recalled. "I felt I was shunned by the very community that I thought would offer me the most support."

Over the course of months, the minister and congregation slowly accepted her daughter, but the experience left her feeling very bitter. "I wish I could go back in time; I never would have told them," she said, echoing a sentiment shared by many parents of infected children: Once you tell someone, you can never take the information back.

When parents first hear that their child has viral hepatitis, their initial reaction is to talk about it in-depth and often in order to process, examine and explore the traumatic news. Ironically, it is when parents need to talk the most about a viral hepatitis diagnosis that they should talk the least to those outside the doctor's office and immediate family.

"When I first heard my child's diagnosis, I knew so little about hepatitis," recalled the mother of a child with hepatitis B. "My daughter's pediatrician didn't know much either. All I knew was that there was a chance my daughter could transmit the virus to others. I immediately got on the phone with the parents of a couple of her best friends to make sure they were vaccinated. Now, some of those parents have provided me with some great support, but in hindsight, I wish I had not told a soul until I knew a whole lot more."

During this period of emotional "overload," parents are often not in a good position to judge wisely and carefully whom to tell and whom not to tell.

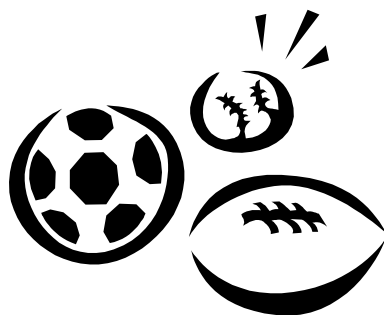
“The risk of disclosing hepatitis or HIV is that you can never fully predict another person’s reaction,” explained Chris Sinnock, a licensed clinical social worker in the AIDS Clinical Trial Unit at St. Jude Children's Research Hospital in Memphis. “Sometimes friends and family members will respond in a more positive manner than expected; sometimes they will respond negatively.”

Before sharing the news with someone, think about who has been supportive to you in the past in other ways, suggested Sinnock. “Evaluate how educated this person is about infectious diseases. What kind of comments have they made about someone with HIV, hepatitis B or hepatitis C? How empathetic is this person to others in distress?”

“Practice how you will tell this other person,” she explained. “What words will you use? Will you do it alone or with the help of someone else like a doctor, nurse, or social worker? What educational plan can you offer this person?”

“Think about how ready you are to disclose. Is the burden of keeping the secret heavier than the burden of telling? Are you comfortable with your explanation? Are you prepared to allow the other person time to adjust?” Sinnock added.

Parents need to evaluate the true health risk that their child poses to others when assessing whether to share this information and when. In schools, daycare centers and camps, most staff should have been instructed on standard precautions.



Coaches and community volunteers should also have some working knowledge of standard precautions. And parents of infected children should teach their children from a young age simple hygiene practices like handwashing, managing their own cuts so as not to expose others to their blood, and not touching the blood or body fluids of others.

There are some assumptions of “safety” that parents can make when deciding whom to tell, yet there are a variety of gray areas. Other parents, other kids and youth organization leaders, such as those involved in scouts or sports leagues, may not be well-versed in standard precautions. So whom should parents tell, if anyone?

Many, many factors enter the tough debate of whom to tell and not tell as a child leaves home for play dates, daycare, sports events, school, sleepovers and ultimately dates.

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“Parents experience guilt about not telling others,” Sinnock observed. “Most parents are quite concerned about others. They would not want another child/family to experience what they are going through. Yet, because of the social stigma, parents want to protect their child from harm. When having to choose between betraying their child or betraying someone else, what parent would not choose their child over others? A parent’s primary instinct is to protect their children from harm.”

Many parents, already dealing with the bitterness of their child’s medical condition, feel particularly angry over the suggestion that they “owe other people” information about their child’s health.

“I don’t see why I should tell anyone about my daughter’s diagnosis,” said the father of a 3 year-old who has hepatitis B. “People don’t have a right to know about my daughter’s medical condition. Frankly, it’s none of their business. If they’re that worried about catching hepatitis B, they can practice universal precautions and get vaccinated. Period. Stigmatizing my daughter is not their right. Protecting her privacy is part of protecting her health.”

Of course, privacy isn’t always easy to maintain. Many parents have found that telling *anyone* was essentially the same as telling *everyone*.

“When we moved back to my home town, I took Kyle to a family doctor,” said one angry parent. “Of course I told the doctor that Kyle had hepatitis. I’m not sure exactly what happened from there, but I do know that within hours somebody at the doctor’s office had called my son’s preschool to tell the administrator that he had hepatitis C. That day, when I went to pick Kyle up, the center’s director was waiting for me. She asked that I remove Kyle from the school that very day. So much for medical ethics. So much for respecting another person’s privacy. So much for small town friendliness. We decided to move back to the big city where being relatively anonymous would work in my child’s favor. I’ve never been so mad in my life.”

Fortunately, privacy doesn’t require a total information blackout. “What I was hearing from others in my parents’ support group had me scared half to death,” said the mother of a preschooler with hepatitis C.

“Kids with hepatitis had been turned away from schools. They’d been thrown off sports teams. They were told they couldn’t swim in community pools or go on field trips. They weren’t invited to slumber parties. They got shut out of all the fun things that go with being a kid. I didn’t want my daughter to go through that. I was fat as a kid, and I know how much it hurt to be ‘different.’ I was afraid that if I disclosed my daughter’s

condition now it would follow her for the rest of her life, like a scarlet letter. I couldn't stand the idea.

“So we took what I suppose was the coward's way out. When we signed Ashley up for preschool, we didn't tell anyone about her medical condition, but three months later we sent an anonymous note to the school telling them that one of the students had hepatitis C. We enclosed information about universal precautions. We included copies of articles and website information in case anybody wanted to learn more. I figured that was a compromise I could live with: Ashley's privacy was protected and the school had fair warning.”

Whom Should You Tell—If Anyone?

Medical Professionals

Most parents agree that because doctors, nurses, dentists and other healthcare workers are legally obligated to safeguard a patient's medical information, a child's medical condition can be safely shared with this group. Also, it may be important to the overall treatment of the child for the attending healthcare staff to know of the chronic infection when making medical decisions concerning the child.

Schools and Daycare Centers

Depending on each state and school district, a child's medical records may request information about “known chronic or infectious” illnesses. Some parents have asked doctors not to disclose their child's infectious disease and some whose children have hepatitis B have even asked the pediatrician to vaccinate their child against hepatitis B so there is no conspicuously absent immunization on their child's medical records.

According to Dr. Harold Margolis, director of the Hepatitis Division at the Centers for Disease Control and Prevention (CDC), disclosure may not be necessary if a school or institution is already practicing standard precautions.

“For hepatitis B, the child's physician might want to provide the school with a letter stating that your child is ‘immune’ or shown by testing to not be susceptible to hepatitis B virus infection,” said Dr. Margolis.

In the case of hepatitis B, the application of standard precautions for the prevention of transmission of bloodborne pathogens prevents spread of infection from these exposures, noted Dr. Margolis. “The 2000 edition of the American Academy of

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Pediatrics Red Book states: ‘routine use of these precautions avoids the necessity of identifying children known to be infected with HIV, HBV and HCV and acknowledges that unrecognized infection poses at least as much risk as the identified child.’

“Students infected with HIV, HBV or HCV do not need to be identified to school personnel, based on the assumption that school staff are using standard precautions when handling first-aid or emergency situations,” Dr. Margolis added. “Since HIV-, HBV- and HCV-infected children and adolescents will not be identified, policies and procedures to manage potential exposures to blood or blood-containing materials should be established and implemented, and parents should take an active role to ensure these are in place.”

When enrolling children in daycare centers, parents should carefully examine the center’s use of standard precautions and make sure they practice those precautions with all students to curtail the spread of all infectious diseases, including bloodborne viruses.

Parents can also take action by learning about policies and efforts to teach standard precautions in schools, daycare centers and camps. Find out what agencies or organizations in the community have educational programs that teach standard precautions. You do not have to disclose your child’s diagnosis to ensure this preventive education is taking place in your child’s daycare or school.

Studies in daycare centers around the world have rarely found HBV transmission between children. No such studies are available on HCV transmission in daycare settings. Unless a child with chronic viral hepatitis exhibits highly aggressive behavior, such as biting, they do not need to be excluded or treated differently during play times.

“Disclosure of a child's infectious status is not needed to prevent secondary transmission in [daycare] settings,” said Dr. Margolis. “However, procedures should be in place for any special health problems or medical conditions that a child might have and that might need specific action. Examples of conditions needing procedures/actions might include allergies, asthma, diabetes, epilepsy and sickle cell anemia. These conditions can cause life-threatening attacks that may require immediate action. You should know 1) what happens to the child during a crisis related to the condition, 2) how to prevent a crisis, 3) how to deal with a crisis, and 4) whether you need training in a particular emergency procedure. Again, all aid should be rendered using standard precautions.”

There are a number of laws that protect the confidentiality of school health records. The Family Educational Rights and Privacy Act of 1974 (the Buckley Amendment) mandates that any institution that receives federal funds is prohibited from releasing a

student's records to anyone other than school officials who have been determined to have a legitimate interest in the child. There are also protections for privacy of a student's medical records under the Americans with Disabilities Act.

Babysitters and Camps

Camps, like schools and daycare centers, should follow standard precautions and their staff should be appropriately trained. Parents need to be advocates in ensuring all children who attend the camp are protected by proper precautions.

Babysitters, who come into the home, may not be so well-versed in standard precautions.

“We have one child with hepatitis C and three uninfected children,” said a mother. “Occasionally, a teen babysits the child with hepatitis C. How dangerous is it for an uninfected child to clean and apply a bandage to a scraped knee on the infected child without latex gloves? I don't want my child to feel they are somehow dirty or untouchable. Do I need to tell every babysitter I have in my home to use latex gloves? I really don't want to disclose my child's hepatitis C status to the community.”

According to Dr. Margolis, “It is good practice generally for all of us to use precautions when dealing with blood and body fluids containing blood. You could make it a practice that all of your babysitters use latex gloves when handling any body fluid, followed by good hand washing. You could present this practice as a preventative measure to protect the health of both your children and the babysitter. The babysitter's course developed by the American Red Cross has specific training on this issue. They recommend that latex gloves be made available within the household and that sitters use the gloves when handling blood or body fluids.”

Youth and Sports Events

Sports events or accident-prone outdoor activities, like hiking, present a little more difficult scenario when deciding how much caution to exercise. Often, the events and games are organized by parent volunteers who are not professionally trained in standard precautions.

Many parents admit that to share information about their children's disease with the soccer coaches or Girl Scout leaders is tantamount to sharing it with the entire community.

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Some parents say to be on the safe side, they attend every game or event to ensure they are present to apply bandages if their child is injured or bleeds. But that requires a wariness and ever-watchfulness that is stressful.

If the child is participating in a sport like football or soccer, it is important to make sure the coaches, volunteers and participants all practice standard precautions.

No parent wants another child to become infected with hepatitis viruses, and no one wants to be sued by a coach, teacher or parent who claims they would have taken extra care to practice standard precautions if only they had known a child was infected with hepatitis B or C. Nor do parents want to expose their own children to the discriminatory acts that informing invariably invites.

The social and legal ramifications facing families and children chronically infected with hepatitis have not been thoroughly tested or explored in courtrooms across the country. These guidelines will be written in the years ahead as parents and others push for clarification from courts and government agencies.

Play Dates and Sleepovers

The age of the child and the type of relationship the infected child's parents have with other parents play a role in deciding how to handle play dates and sleepovers.

Obviously, if parents are good friends and have disclosed the child's hepatitis status and the other parents will follow standard precautions, this is the best route.

Because play dates and sleepovers are not usually organized, "official" events, it is unreasonable to expect that the chaperones will know about standard precautions and will not only use them but will ensure that the children use them.

Each family has to make a personal decision in these circumstances and it is extremely difficult to do. Some parents never inform, some always do, some don't inform but don't let their children attend such functions without them and some try to guess if the children will be "active" and more likely to have accidents resulting in blood spills, letting this potential scenario guide them in their decision-making process.

"The first time my daughter slept over at someone's house was in first grade," said a mother of a girl with hepatitis B, "I was a nervous wreck the entire night. In my state, hepatitis B vaccines are not required, and obviously I was not going to say anything to the parents, whom I barely knew. My daughter is pretty laid back and not a physical risk

taker, so I hoped nothing would happen. But of course you never know. Now that she's in third grade, sleepovers don't bother me as much because she's older and knows to take care of her own blood spills."

Extended Family Members and Friends

Parents report reactions from extended family members they've told range from "shunning" to warm support. As mentioned earlier, parents need to think carefully about who needs to be told and why.

Are there health risks that must be considered? Does a family member provide childcare and require training in standard precautions?

Conclusion

Those parents who share their young child's diagnosis with others often find how the information is shared is almost as important as with whom one shares it. Experts suggest a five-point plan:

- Determine who needs to be told.
- Identify their level of understanding about the hepatitis.
- Try to predict their likely response to the information and prepare yourself mentally for it.
- Tell them about the diagnosis (which includes asking them not to say anything about the hepatitis to the child or to anyone else).
- Prepare an education packet so that they can prepare themselves to deal with the reality of a child who has hepatitis.

A balance must be found, when determining whom to tell and not tell, that protects the rights of the individual and the health of us all. Every parent struggles with this issue every day.