

TO TELL OR NOT TO TELL

One Mother's Guidelines

A Parent's Perspective

Should I Tell?

By Karen W.

When I learned my son had hepatitis B, children in my state weren't required to be immunized against this disease. I wandered through uncharted social territory, lost in a maze of decisions that all appeared initially to lead to the same conclusion—children could be hurt by my son's virus.

My son should have been my top priority as I wrestled with options during midnight debates with memories of Ryan White's struggle for acceptance tugging at my conscience. But what about the other kids who risked being infected by mine?

Should I tell?

I stumbled through the first year burdened by the feelings of helplessness and desperation that accompany the process of dealing with a child's infectious disease. My son looked and acted so normal, yet hepatitis had the potential to destroy our lives.

Could I hide behind a smile through the years, hoping for a miracle to come along and save us? I tried, but found that there were people outside our family whom I wanted to tell. Was I looking for sympathy? Understanding? Compassion? Probably.

The emotions we parents try to force back behind the facade of daily life relentlessly fight to be recognized, often when we are least prepared to control them. I still fight back tears when I talk with other moms about college and career plans that seem so far in the future. Depending on my son's hepatitis, our future years could be filled with sickness and suffering.

As the years have passed, I have told fewer people and set these guidelines for myself:

- Accept that I am not responsible for the health and safety of everyone else's children.
- If I tell, I will find out who my true friends are by the way they treat my son.
- Remember the message of safe sex advocates? When you have sex with one person you are having indirect contact with everyone they've had sex with. In my case, telling one person carries the risk of them telling everyone they know. It's a small world.
- This information belongs to my son. It is his body and his life, and he deserves the chance to handle it in his own way. I should not and will not ruin it for him.

I still struggle to turn the tables on this disease by living life as if there is no tomorrow, spending every possible second enjoying my children. I humbly acknowledge that they are a gift to be cherished, whether that gift lasts a day or decades. This virus has offered me the power and insight to focus on what really matters, and in this respect I am luckier than many parents with healthy children.

I hope this is something I am able to teach my son when he is wondering one day “whom to tell.”