

NORMAL LIFE AND HEPATITIS C

Can You be “Normal” if a Child has Hepatitis C?

A Parent's Perspective

Letter from a Hepatitis C Mom

By Janis M.

Can anyone maintain a normal life with a child with hepatitis C? Is this possible?

I don't believe it is totally possible; there's just a feeling in your heart that is different.

We as parents have to try to maintain a day-to-day routine that is as normal as possible for the child's mental well-being.

Along with the disease, depression will try to dominate. The child does actually go through a grieving process. It can be very tough for them to work through feelings of anger, disappointment and depression.

We need to build them up mentally by being positive and being open to talk about any subject. They need a lot of love and hugs and laughs. A positive outlook will help give them the strength they need to fight this invader now and in the future.

When your child makes new friends and gets invited anyplace new, it's difficult. With each new friendship comes the ordeal of having to tell the friend's parents about your child's health status and you don't know if they will understand. Sharing the information exposes your child to possible rejection and ridicule.

If your child's school has an outing, you go because something could happen to them and you need to be there.

When and if your child is on interferon treatment, it gets tougher. The shots and medicine hurt and your child just feels bad. After awhile, the side effects appear to lessen but the shots three times a week make your child's arms or legs very tender and very sore.

Starting my child on this treatment was the hardest thing I have done so far in my life because there is no way of knowing if it will work. Every time you take them for their shot and you see the pain they feel and the tears in their eyes, your heart literally feels like it's being ripped out. You pray to God that this will help, given the pain it is causing.

You don't have any choice when the doctor says the choices are either treatment to slow down the liver damage or a liver transplant. It's tough not to spoil your child because you don't know how many tomorrows there are.

Nothing about this disease is normal and trying to live as if life is normal may be totally impossible. As parents, we have to strive to build our children up and support each other.

I have been on the liver transplant list for two and a half years and have chronic, active hepatitis C and cirrhosis, as does my son. Although this all seems overwhelming, we live day to day and have hope for the future and whatever comes our way.

(Janis passed away in the summer of 2001 due to complications from a liver transplant. There is a scholarship fund set up in her name through PKIDs.)