Being a Positive Mother

Forward
A diagnosis of hepatitis C (HCV) can be distressing; add pregnancy to the equation and the distress multiplies. This fact sheet addresses three situations that HCV-positive women may confront: 1) considering pregnancy, 2) currently pregnant, or 3) have already had children.

The technical term for an infection passing from mother to unborn offspring is vertical transmission. Horizontal transmission refers to household members passing an infection to each other during their daily routines. Theoretically, HCV can be passed horizontally, say if an uninfected person cuts himself or herself with a razor that has HCV-positive blood on it. However, the circumstances for HCV to be transmitted between household members have not been proven and are so unusual that we say that HCV is not passed horizontally.

Vertical transmission is also uncommon, but it does occur. The prevalence of HCV is low among women of childbearing age (1.2%). The Centers for Disease Control and Prevention (CDC) does not recommend routine HCV testing for pregnant mothers. Among HCV-positive women, the CDC estimates that the rate of vertical transmission is 4% to 6%. Pregnancy for HCV-positive mothers is NOT discouraged.

Note: HCV vertical transmission risk appears to be higher for those with high viral loads. The risk significantly increases for women who are HIV/HCV co-infected, with estimates of approximately 10 to 20%.

There are no universal guidelines for labor and delivery regarding HCV-positive women. Some obstetricians avoid performing amniocentesis during pregnancy. This procedure tests for fetal abnormalities by inserting a long slender needle.

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into the pregnant woman's abdomen and withdrawing amniotic fluid. This fluid surrounds the fetus. Some experts discourage the use of fetal scalp monitoring. This procedure records the fetal heartbeat by threading a thin wire into the soon-to-be-born infant's scalp. Alternative monitoring techniques are available. Prolonged rupture of membranes (more than 6 hours) may increase HCV vertical transmission risk. In simpler terms, this refers to the length of time the bag containing the amniotic fluid is broken before delivery occurs. There are no recommendations advising the use of Caesarean section rather than vaginal delivery.

**Note:** *Ribavirin is only used on a case-by-case basis. Women taking ribavirin should never become pregnant during and for six months after the completion of HCV treatment. HCV treatment using ribavirin may cause birth defects and fetal death. If you are concerned about becoming pregnant during HCV treatment, talk to your healthcare provider about newer, ribavirin-free medications.*

All major medical guidelines recommend routine testing of children born to HCV-positive mothers. Infants can begin life with their mother's HCV antibodies but this does not mean they are HCV positive. Since infants’ immune systems take time to develop, the American Association for the Study of Liver Diseases (AASLD) recommends holding off on HCV testing until children are at least 18 months old.

HCV-positive children usually have little or no symptoms. According to the AASLD, disease progression is minimal for the first 20 years of a child's life. There are direct-acting antiviral medications approved to treat children infected with hepatitis C. The cure rates are up to 100% for all HCV genotypes. Please refer to our Hep C Medications blog: hepatitiscmedications.hcvadvocate.org

Approximately ninety-four out of a hundred times, an HCV monoinfected woman will give birth to an HCV-negative baby. Statistics may be reassuring, but the reality is that motherhood is a complicated role. Worry is a frequent companion for mothers, and a woman who is considering pregnancy is probably going to have some fears about this. If you go ahead with a pregnancy, it will be a long time before you will know if your baby is one of the 94% or the 6%. You may fret about this. Since worrying does more harm than good, it is wise to keep anxiety to a minimum. Try to think positively. Learn how to relax and manage stress. Take good care of yourself. As an HCV-positive mother, your child will need you to be well. Motherhood lasts a long time and learning how to maintain your health and sanity will benefit you and your family.

After your child is 18 months old, you can request HCV testing. This is a blood test and children do not like to have their blood drawn. If your child needs to have blood drawn for another reason, ask the medical provider to include an HCV antibody test on the lab order.

If your child is HCV-positive, then you will probably experience strong emotions. This is normal. Worry, grief, fear and guilt are common reactions. Start by getting good information and support. Other women have children with HCV or other chronic diseases, so learn from their experiences. Lean on others until you are strong enough to cope. Learn how to manage worry and guilt. These two emotions can do more harm than good.

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Request a referral to a pediatric hepatologist or gastroenterologist. If your child’s primary care provider does not know much about HCV, you may want to see if he/she attempts to learn about it. If you are not satisfied, find another provider.

You may find out you have HCV long after your children are grown. You may be a grandmother.

Experts recommend testing for your children. It may not be easy to discuss this with them, even if they are adults. Reassure them that their chances of having HCV are very low. If you acquired HCV via injection drug use, you do not have to disclose this or other details to your children.

Above all, take care of yourself. If you feel guilty, forgive yourself. You did not intend for this to happen. Learn how to live with a chronic disease. Join a support group. Seek professional counseling if you have trouble coping or experience depression. Be a role model. Show your child how to live well.

Related publications:

- **Women and Hepatitis C: An HCV Guide**

- **Women and HCV**
  www.hcvadvocate.org/hepatitis/factsheets_pdf/Women_and_HCV.pdf

- **A Guide to Understanding Hepatitis C:**

For more information

- **Americans with Disabilities Act**
  www.ada.gov

- **Centers for Disease Control and Prevention**
  www.cdc.gov

- **National Cancer Institute:**
  https://www.cancer.gov/about-cancer

- **Waldenstrom Macroglobulinemia at the Mayo Clinic**
  www.mayoclinic.com

This fact sheet was originally written by Lucinda Porter, RN. It has been reviewed and updated by Alan Franciscus.