Disclosing Your Hepatitis C Status

A hepatitis C diagnosis involves more than living with a virus; it also includes decisions about whom to tell, when to tell and what to tell others. Disclosure involves complex moral and legal issues.

There are certain circumstances in which you must disclose. For instance, if you are aware of having hep C and want long-term disability or life insurance, you must tell the truth when asked about your status. If you do not disclose to a sexual partner and you transmit HCV to them, then you may be held liable for this. People have been sued and criminally prosecuted for failure to disclose their HIV status. These cases may set a precedent for HCV.

Although the decision to self-disclose is largely a personal choice, there are moral concerns surrounding this subject, particularly if you have been in a relationship with someone, potentially exposed them to your blood, and didn’t reveal your HCV status. Also, disclosure involves a certain amount of risk. If you tell someone you have hep C, you may encounter ignorance, fear, discrimination or harsh judgment. Hep C carries a stigma, in part because the disease is associated with injection drug use, but also because the virus can be transmitted to others.

If you do decide to disclose your hepatitis C status, here are some suggestions to help you through the process:

- Know the risks to disclosure. People may be upset about this news. You may face discrimination. Relationships may change or end. Loved ones may worry about you. On the other hand, people may be supportive and offer to help. Hep C is so common that you may find out that the person you are disclosing to knows of others who are living with it.

- Before you tell others, be sure you know how hepatitis C is transmitted. People may want to know if they are at risk of contracting the virus from you. Hep C may be passed when the blood of an uninfected person comes into contact with HCV-positive blood. Hepatitis C is most commonly spread when sharing injection drugs and their equipment, but there are other modes of transmission. Sexual transmission of hep C is a low risk, especially in heterosexual relationships. Hepatitis C is not spread by kissing, hugging, sharing food or drinking from the
same glass.

- Be prepared to answer questions. You may be asked how you got hep C. If you are uncomfortable with disclosing how you acquired it, then don’t. It is enough to say that you aren’t sure; few people are ever 100 percent sure.
- Share information. Arm yourself with knowledge from websites, literature, or other resources to help answer further questions the person you are disclosing to may have.
- Ask them to keep the information confidential. However, if you tell one person, be prepared for others to know. Some people aren’t very good at keeping secrets.

After revealing your hep C status, do not expect family and friends to digest all of this news instantly. Give them time to react and respond. Everyone does this at their own rate. If this process becomes prolonged or negatively affects your relationship, you may want to talk to a counselor, member of the clergy or other trusted advisor.

Specific Disclosure Circumstances

Internet Disclosure Disclosing on the Internet is especially risky because the Internet is forever. If privacy is important to you, do not post information about yourself on Internet chat rooms and social media. If you want to join a web-based group and still maintain a certain amount of anonymity, use an alias, though even this can be traced back to you. If you don’t want others to know your status, don’t share anything on the Internet about having hep C.

Health Care Settings Your health care provider may not disclose your HCV status without your prior consent. The information in your medical record is protected by the Health Insurance Portability and Accountability Act (HIPAA). Your information may be shared with your insurance company if they are paying for your care. Because health care professionals take precautions when handling blood and other body secretions, they are not at risk of acquiring HCV from you.

Sex Partners Although the risk of transmitting HCV sexually is low, it can happen. The risk is higher in men who have sex with men (MSM) and in people who are HIV-positive. The risk is almost nonexistent in long-term monogamous heterosexual relationships. However, regardless of the level of risk, there are issues surrounding disclosure of one’s hep C status to those you are having sex with or hoping to in the future.

To sort this out, you may want to ask yourself, “How would I feel if someone I had sex with didn’t tell me that they had hep C?” Most of us would want to know prior to the first sexual encounter. It is reasonable to get to know someone better before telling them you have HCV. When the relationship looks like it is headed in a sexual or serious direction, this is likely the time to open up about your status.
Unfortunately, when conflict arises in a relationship, an angry or hurt partner may make public any information that you may have said in confidence. Although there is not much you can do about this, there are some precautions you can take early in the relationship. First, give yourself a clear conscience from the beginning by practicing safer sex. Second, never put your HCV status in writing. Don’t disclose your HCV status on a dating service questionnaire or in emails to prospective dates.

Telling Children Sometimes it may feel necessary to tell a child that you have hep C. For instance, your condition may be severe, and you want children you live with to know why. What to tell them largely depends on their age and your assessment of their ability to handle this information. Children can sense when something is wrong, and acknowledgment gives them the space to ask questions. Try to find something genuinely reassuring to tell them. Be brief but truthful. Ask them if they have any questions. Tell them that they do not need to worry about your health.

Even if you don’t disclose your HCV status, tell children who live with you how to stay safe. Make sure they know never to use your toothbrush, razor or cuticle clippers. Tell them they should not share anyone’s personal items.

Last Reviewed: March 4, 2019