

a series of fact sheets written
by experts in the field of liver
disease

HCV Education & Support:

Disclosure

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Hepatitis C is a highly stigmatized disease. Revealing a diagnosis of HCV can cause anxiety on a number of levels. The ramifications of this disclosure can impact medical, marital, family, insurance and other areas of one's life. Common feelings that people experience when considering disclosing their HCV status include:

- Fear of others treating me differently or leaving
- Fear of seeking medical treatment and having HCV documented in their medical records
- Fear of denial of health and life insurance
- Fear of infecting loved ones
- Fear of dying
- Fear of being viewed as a disease rather than as an individual
- Fear of losing control over bodily functions and life
- Fear of losing employment
- Fear of violence when telling someone that they may have been put at risk for HCV

Most of these issues can be helped by seeking either professional or peer support when telling family, friends or business acquaintances. It is important to consider all the angles before disclosing one's HCV status because of the potential personal and business consequences.

Family and Friends

Telling family and friends about HCV status is important but can be difficult if not properly considered. People should be advised to wait until they feel emotionally ready and have enough facts before divulging their status. The need for emotional support and the potential risk of exposure makes it likely that people will choose to confide in spouses and significant others first. However, it is important to be cautious and think carefully before deciding to disclose HCV status. Telling loved ones can be an upsetting experience for everyone involved. A family member or loved one may have a difficult time and need emotional and informational support that the newly diagnosed person is unable to provide at the time especially if one was just recently diagnosed.

Here are some questions to consider before discussing HCV status:

- Do you have enough facts to answer basic questions that can alleviate others' fears?
- Why are you telling them?
- What is the worst thing that could happen? The best thing?
- What is your biggest fear about telling this person? The best thing?
- Are you ready to take on the emotional issues that can be the consequence of telling people you have HCV?
- How has this person reacted in the past to intense disclosures?

- Do you trust the person you are confiding in to not tell others without your permission?
- Is there someone you trust who can be with you for a tough disclosure?
- Will this help you or will this bring you more problems?
- Will keeping this information a secret create more difficulty than disclosing it?

Sharing fears and feeling supported can be extremely important. Preparation with facts about HCV and sharing educational material with friends and loved ones may be helpful in this process. Planning the disclosure – when, where and how to disclose – will help the experience be more positive for all involved.

Disclosure in a Business Environment

Disclosing HCV status in a business environment should be a carefully thought out process. The Americans with Disabilities Act (ADA) offers legal protection in certain areas, but other, less obvious discrimination can occur.

ADA allows for certain protections from discrimination in the work place. The ADA describes disability as a physical or mental impairment that substantially limits one or more of the major life activities of an individual. A recent court ruling limited the reach of the ADA by ruling that a disability cannot be measured solely on the ability to do certain tasks at work, but must also be permanent or long lasting. It is unclear exactly how this will impact ADA in the long term, but before disclosing medical status to an employer an individual would be well advised to consult with the ADA or a benefits counselor.

A person that is designated as disabled is entitled to protections from any practices in the workplace that could affect wages, benefits, application procedures, job assignments, promotions, etc. However, having HCV does not automatically entitle one to these benefits. For example, if a person has asymptomatic HCV disease they are not automatically entitled to protections. However, they may be entitled to benefits and protection if they are experiencing HCV treatment side effects. In addition, one cannot be terminated from employment solely because of HCV status. Furthermore, employers with 15 or more employees must provide reasonable accommodations – the key is ‘reasonable’ and the accommodations must not cause undue hardship on the employer. These accommodations could include time off for doctors’ appointments, providing additional unpaid leave or job restructuring, and granting a flexible working schedule.

While the ADA provides legal protection from discrimination, an employer can still make it difficult to pursue these benefits. The entire issue of disclosure in the work place must take into consideration discrimination that may not be readily apparent. For instance, someone with HCV may be passed over for promotions because of a perception that they are chronically fatigued. Another potential problem is discrimination from co-workers because they fear exposure to HCV. Employers cannot require disclosure, and, with the use of universal precautions, there isn’t any justification to prohibit people living with HCV from performing job duties due to concerns about HCV exposure.

Some questions to ask when considering disclosing HCV status at work are:

- How will it affect the day-to-day working environment?
- How will it affect future promotions?
- How will it affect relationships with co-workers?
- Is it really necessary to disclose at this time?

If someone is experiencing symptomatic disease, disclosing HCV status may be helpful so that the employer can make certain accommodations. Disclosure may become more important when considering treatment for HCV because of the possibility of moderate to severe side effects. These side effects may require a work schedule change, change of job responsibilities or other accommodations.

Employees that feel reasonable accommodations are not being made, or that discrimination is occurring, may begin a grievance process. For more information about the Americans with Disabilities Act, call 1-800-949-4232. Some states offer broader protections than the ADA. For more information, contact your local disability office.

Denial

Denial is a very important psychological mechanism which has good and bad consequences. It can be a good way to allow people to slowly accept a diagnosis of HCV. When the time is right and someone accepts the fact that they have HCV, they will be more prepared to deal with the realities of disclosing their health status to family, friends and business relationships. At the same time, denial can prevent someone from seeking the necessary medical care and making lifestyle adjustments to stay healthy.

Conclusion

Disclosing HCV status is a decision that each person should weigh carefully based on his or her own individual circumstances. Care and support from friends and loved ones can be very beneficial in learning to live well with HCV. At the same time, unnecessary, premature, or poorly thought out disclosure may be problematic. Accurate, reliable information about hepatitis C in an important tool to have at hand when considering this issue. Talking over the possible benefits and difficulties with a counselor and/or others who are living with HCV may be helpful before making any decisions.

Probably the best advice one can give a newly diagnosed person is "You don't have to tell anyone until you are ready."


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