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hepatitis C BASICS

.....Disclosure.....

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Hepatitis C is a disease that is not fully understood.

Because of this, it is scary to think about telling people you have hepatitis C. Telling others about your diagnosis of HCV can be difficult to do. Sharing this information can affect many areas of your life. These include your healthcare, marriage, family, insurance and other areas. Common feelings that people have when thinking of sharing this information include:

- Fear of being treated differently or being left by others
- Fear of seeking medical treatment and having HCV included in their medical records
- Fear of not getting health and life insurance
- Fear of making loved ones sick
- Fear of dying
- Fear of being seen as a “disease” rather than as a person
- Fear of losing control over bodily functions and life

- Fear of losing a job
- Fear of being attacked when telling someone that they may have been put at risk for HCV

This process of telling your family, friends and co-workers can be made easier by getting advice from either a professional or from another patient with HCV. It is important to think about all the issues before sharing your HCV status because of the possible personal and work situations that may result.

Family and Friends

Telling family and friends about having HCV is important, but can be difficult. You should wait to tell others until you feel ready. You should also have enough facts before sharing this information. The need for support and the possible risk of infection is usually why most people tell their spouses and significant others first. However, it is important to be careful and think things through before sharing your HCV status. Telling loved ones can be upsetting for everyone involved. A family member or loved one may have a hard time accepting this news. They may need emotional support that the person with HCV is unable to give at the time (especially if that person has just learned that they have the disease).

Here are some questions to think about before talking about having HCV:

- Do you have enough facts to answer simple questions that can help other people feel less scared?
- 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 handle the emotional issues that can come up after telling people you have hepatitis C?
- How has this person handled bad news in the past?
- Do you trust the person you are telling?
- Is there someone you trust who can be with you when you tell someone who may not handle the news well?
- Will sharing the news help you or will this bring you more problems?
- Will keeping this information a secret cause more problems than sharing it?

Sharing fears and feeling supported can be very important. Planning ahead by learning the facts about HCV and sharing information with friends and loved ones may help.

Disclosure in a Business Environment or Sharing the News at Work

Telling people at work that you have HCV should be a carefully thought out decision. The Americans with Disabilities Act (ADA) can help protect you, but less obvious discrimination can occur.

The ADA protects you from being treated unfairly because of your disease in the work place. The ADA defines disability as “a physical or mental impairment that greatly limits one or more of the major life activities of an individual.” A recent court ruling stated that a disability has to be two things: it has to change your ability to do certain tasks at work, and it has to be permanent or long lasting. It is not clear exactly how this ruling will affect the ADA’s impact in the long run. You should check with the ADA or a benefits counselor before sharing your medical status to an employer.

According to the law, any person who is disabled is protected. At work, his or her pay, benefits, application procedures, job duties, promotions, etc. are all protected. However, having HCV does not mean a person will definitely receive this protection. For example, if a person has HCV disease, but does not have any symptoms, protection is not guaranteed. They may be able to get protection if they have side effects to HCV treatments. Also, a person cannot be fired just because he or she has HCV. Employers with 15 or more employees must make “reasonable accommodations.” But the definition of “reasonable” is not always clear. Plus, the “accommodations” must not be too difficult for the employer to make. These “accommodations” could include time off for doctors’ appointments, allowing more unpaid time off from work, changing the job duties, and allowing a flexible work schedule.

Although the ADA provides legal protection from discrimination, an employer can still make it hard to get these benefits. The decision to share the news of your diagnosis with your employer must be made carefully. Sometimes discrimination that can occur at work is not obvious. For example, someone with HCV may not get a promotion. This may be because the employer thinks that

people with HCV are always tired and would not have enough energy to do the job well. Another possible problem is discrimination from co-workers because they fear exposure to HCV.

Some questions to ask yourself when thinking of telling people at work that you have HCV 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 tell the employer at this time?

If you have symptoms that make it difficult to work normally, it can help to tell your employer. Then your employer can make adjustments for you. Telling your employer may become more important when you are being treated for HCV. This is because of the possibility of moderate to severe side effects. These side effects may mean you have to change your work schedule, job duties, etc.

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

Denial

Denial is a way of handling both good and bad results. It can be a good in that it allows 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 telling family, friends and co-workers. However, denial can also stop someone from getting the medical care they need. It can also stop someone from changing their habits to make their life healthier.

Conclusion

Deciding to tell others about your HCV status is a hard decision that should be made carefully. You should think about your own situation and relationships with others. Care and support from friends and loved ones can be very helpful in learning to live a good life with HCV. At the same time, telling others without fully thinking through the decision can cause problems. Make sure you have the facts about hepatitis C before making this decision. Talking over the possible pros and cons 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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The information in this fact sheet is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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