

A Guide to:

HCV Disclosure



HEPATITIS C
SUPPORT PROJECT

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The information in this guide 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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Foreword

Millions of Americans live with chronic hepatitis C virus infection (HCV). This disease is more than a medical diagnosis; it is a social and emotional issue. HCV touches the homes, workplaces and communities of all those within its reach. Each person living with HCV is faced with many decisions, including whom to tell, when to tell and what to tell others.

If you disclose your HCV status, be prepared, and do it with your eyes wide open. Disclosure may have a dark side to it. HCV carries a stigma. People may be upset about this news. Discrimination may occur. Relationships may change or end.

Disclosure also has a bright side to it. People may discover an abundance of love and support. You may forge strong friendships. It may make you a stronger person. You may find that HCV brings more gifts than burdens into your life.

This guide explores the subject of disclosure. It looks at both the emotional and practical sides of telling others that you have HCV. This guide may ask more questions than provide answers. Disclosure is not a “one size fits all” issue, so there is no single approach for managing it. We hope that these questions will help you to find your own answers. Perhaps in doing so, you will find what many of us have found – that HCV is easier to live with when everyone knows the facts. The decision of whom to tell is a personal choice. Remember you don’t have to tell anyone until you are ready.

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1. Disclosure: A Complex Issue

Some people are comfortable when disclosing their HCV status. However, for most, there are times when disclosure is difficult or complicated. Some of this may be due to the stigma associated with HCV. There are many sides to this. The hardest stigma to confront is from HCV's association with injection drug use. Misinformed people sometimes assume that all hepatitis C patients have a history of injection drug use in spite of the many ways hepatitis C can be acquired. Our society lacks compassion and understanding about injection drug use. Those who never used injection drugs do not want to carry this label. Former injection drug users may feel haunted by their past and want to be rid of this reminder. Active injection drug users carry the burden of having two stigmatized diseases – addiction and hepatitis C.

Other factors that prevent disclosure are:

- Concern over discrimination or other job-related consequences
- Fear of abandonment or mistreatment by others
- Fear of being judged by past behavior
- Concern that medical record documentation will result in denial of medical, disability or life insurance
- Concern that medical record documentation will effect relationships with their medical provider and the standard of medical care received
- Unwillingness to worry loved ones and/or the desire to “protect” them from the truth
- Fear of violence or other harsh consequences occurring as a result of telling another person that they may have been put at risk for HCV
- Fear of making the diagnosis ‘real’

2. Before You Disclose

It is important to have accurate information before you disclose your HCV status. The people you

tell may be frightened or upset by this information. They will likely ask questions. If you can answer their questions or provide resources, this may help reduce the intensity of their feelings. If you are scared or poorly informed, they may also be scared. Facts can help to restore perspective. Facts can be used to create a plan. If you believe the situation may be difficult, try practicing what and how you will tell them. Think about questions that might arise and practice answers beforehand. See www.hcvadvocate.org for HCV information and answers to common questions.

Here are some questions to consider before disclosing HCV status:

- Do you have enough facts to answer basic questions?
- Are you able to provide written information about HCV?
 - What is your purpose for disclosing?
 - What is the worst thing that could happen? What is the best?
- Where is the best place to disclose?
- When is the best time to disclose?
- Will keeping this information secret create more difficulty than discussing it?
- Are you ready to handle the emotional issues that may be a consequence of telling others you have HCV?
 - Do you trust the person in whom you are confiding?
 - How has this person reacted to intense disclosures in the past?
 - Is there someone you can talk to and get feedback from before you make the disclosure?
 - Whom can you talk to if the disclosure goes poorly?
 - Is there someone you trust who can be with you during a tough disclosure?

3. Legal and Moral Issues

Hepatitis C is a blood-borne virus. It is not passed casually or easily. You can help stop the spread of HCV. Learn how to act sensibly and responsibly. For information about HCV transmission, see the *Resources* section at the end of this guide, visit www.hcvadvocate.org or write to HCV Advocate, P.O. Box 427037, San Francisco, CA 94142-7037 to request information.

In general, you are not legally required to tell anyone that you have HCV. However, it is important that you are aware of legal and moral issues surrounding this subject. Although you are not required to disclose, there are certain circumstances in which you must be honest. For instance, if you are aware of having HCV and want life or medical insurance, you must disclose this when asked. If you do not disclose to a sexual partner and they become infected by you, then you may be held liable for this. People have been sued and/or criminally prosecuted for failure to disclose their HIV status. These cases may set a precedent for HCV.

Your medical 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).

4. Deciding Whom to Tell

Your personal and professional network probably includes many people. You may have living parents, siblings, children, a spouse or a partner. There are people you work with, your friends, your doctor, nurse, and dentist. Take your time deciding to whom and when to disclose. You do not need to tell everyone all at once. You probably have had HCV for a while. Start by coming to terms with it for yourself. You may also want to tell the person or people who are closest to you – those whom you usually tell everything.

As soon as possible, talk to anyone who has a transmission risk factor in common with you. It is not necessary to disclose that you have HCV, but it is important to give enough information so they can protect themselves. For instance, you may not be ready to tell your children that you have HCV, but it is important that they know never to use your toothbrush or razor. You may not want to tell your sex partner. If you postpone this, make sure you practice safer sex or abstain from it altogether until you are ready to disclose. HCV transmission will be covered later in this guide.

5. Telling Family and Friends

Telling family and friends about your HCV status is important, but can be difficult if not properly considered. It is usually wise to wait until you feel emotionally ready and have enough facts before divulging your status. People usually choose to confide in spouses and significant others first. This is particularly true because of the need for emotional support. However, telling loved ones can be a traumatic experience for everyone involved. A family member or loved one may have a difficult time accepting the news and may need emotional support. The newly diagnosed person may be unable to provide this support, especially if he or she was recently diagnosed.

When disclosing HCV to others, it is common for sexual partners, family and friends to ask if they are at risk of acquiring HCV from the person disclosing this information. The best way to answer this question is by providing facts and resources. Do not forget to emphasize that HCV is not spread casually. You cannot spread it by kissing, hugging, sharing glasses or eating utensils. See *Appendix I* for answers to some common questions that you may be asked.

Do not expect family and friends to digest all of this news instantly. Give them time to react and respond. Everyone does this at his or her own rate. If this process becomes prolonged or negatively affects your relationship, you may want to talk to a counselor, clergy person or other expert.

Some people may want to know how you became infected. This is partly out of curiosity, and partly human nature. Remember, the decision to tell anyone how you may have contracted hepatitis C is yours alone. You do not have to tell anyone how you got it.

6. *Telling Children*

This may be the hardest disclosure to make. As parents, we want to protect our children from pain. No parent wants to give bad news to his or her children.

Should you tell children at all? This depends on their age and your assessment of your child's ability to handle this information. Since children can sense when we have something on our minds, it is a good idea to talk to them so their imaginations do not make things worse than they might already be. Try to find something genuinely reassuring to tell them. Be brief but truthful. Ask them if they have any questions.

The CDC recommends that family members be tested. Talk to your children's doctor about this. If your children are adults or old enough to give their assent, talk to them about testing. The most important issue to discuss is prevention. Make sure they know never to use your toothbrush, razor or cuticle clippers. Explain to them that they should not share anyone's personal items. If your children are too young to protect themselves, put these items out of reach.

Note: A good book to use when telling younger children is *My Mom Has Hepatitis C*, by Hedy Weinberg, Shira Shump, Gregory T. Everson and Joy Chen.

7. *Disclosing to Sexual Partner(s)*

The Centers for Disease Control does not categorize HCV as a sexually-transmitted disease. Infection rates are very low in long-term monogamous

relationships. However, although the risk is low, HCV can be transmitted sexually. Be responsible: find out how to protect others from being infected by you.

Telling your HCV status to a sexual partner is probably the trickiest disclosure situation. If the person is a potential partner and you have not had sex, this is the least complicated scenario. It is still problematic because it forces you to engage in a conversation that may end the relationship. Some people are philosophical about this, saying that they do not want to be with anyone who will reject them over this issue.

The question of when to tell is tricky. Do you wait until you are sure that a sexual encounter is about to happen or do you tell at the earliest opportunity? You probably do not need to disclose on the first date as long as there is no sex. Ask yourself how you would want to be told by someone else. How would you feel if your partner knew all along but did not tell you until after you had sex?

You may want to wait until the time is right to disclose your HCV status. Undoubtedly, the best time is before a relationship becomes sexual. However, it may not be wise to disclose your status when you first meet unless you are immediately planning to engage in sex. It is reasonable to get to know each other better before you tell anyone you have HCV. When the relationship becomes serious or sexual, this is likely the time to be upfront. This gives your prospective sexual partner a chance to know you as a human being rather than as a disease.

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, especially on the Internet. Never dis-

close your HCV status on a dating service questionnaire or in emails to prospective dates.

Sex is a basic part of life. None of us would be here without it. However, many of us are uncomfortable talking about it. Honesty and openness are important. Be honest with yourself and your partner(s). If a partner is uncomfortable with the current sexual practices in your relationship, it is his or her right to express and change this. If you want to practice safer sex, you also have the right to express and change this.

8. Workplace Disclosure

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 may occur. Some states offer broader protection than the national ADA laws. Check with your local health department or disability office about any laws that may provide more protection.

The ADA provides certain protections from discrimination in the workplace. 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 not clear exactly how this will influence the ADA in the future, 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 with a disability designation is entitled to protection from any practices in the workplace that could affect wages, benefits, application procedures, job assignments, promotions, etc. Having HCV does not automatically entitle someone to these benefits. For example, people living without any symptoms of HCV are not automatically entitled to protection. However, they may

be entitled to benefits and protection if they are experiencing HCV treatment side effects. In addition, you cannot be terminated from employment solely because of HCV status.

Employers with 15 or more employees must provide reasonable accommodations for employees who meet ADA criteria. The key is “reasonable.” Accommodations must not cause undue hardship to the employer. Examples of reasonable accommodations are time off for doctors’ appointments, providing additional unpaid leave or job restructuring, and granting a flexible work 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 workplace must take into consideration discrimination, which may not be readily apparent. For instance, someone with HCV may be passed over for promotions because it is perceived that they are chronically fatigued and not up to additional responsibilities. Another potential problem is discrimination from co-workers because they fear HCV exposure.

Some questions to ask when considering disclosure of HCV status at work:

- How will HCV disclosure affect the day-to-day working environment?
- How will this information affect future promotions?
- Will this disclosure affect relationships with co-workers, and if so, how?
- Is it necessary to disclose this information at this time?
- Would you prefer to disclose in a general way rather than specifically stating you have HCV?
- Are there ways you can prepare for this disclosure, such as by anticipating questions and providing information to those to whom you are disclosing?
- Is there someone in your life who can support you before and after you disclose your HCV status?

For those experiencing symptomatic disease, disclosing HCV status may be helpful, allowing the employer to make certain accommodations. Disclosure may become more important when considering treatment for HCV because of the possibility of side effects. These side effects may require time off for illness or appointments, a change in work schedule, job responsibilities or other accommodations.

Employees who experience discrimination or who feel that reasonable accommodations are not being made, may initiate a grievance process. If possible, try to settle any disputes before taking legal action. When disclosing in the workplace, talk with the Human Resources Department first so that it can be documented in case there are future problems. Information given to the Human Resources Department is confidential. Make sure you tell them that you do not want this information disclosed to anyone else without your permission. Both parties should insist that whatever is agreed upon be put in writing.

For more information about the Americans with Disabilities Act, call 1 (800) 949 - 4232.

9. Disclosing to Medical Providers

Although you do not have to tell anyone your HCV status, it is a good idea to tell your medical providers and dentist. Disclosure gives important information about your medical condition. It may explain certain signs or symptoms that you have. It gives your medical team the whole picture.

When you disclose, you add to the collective body of information about HCV. This can benefit everyone. Clinical observation is an important aspect of medical practice and research. For instance, many HCV patients report pain in the liver area. For years, patients were told that this was impossible because the liver has no sensory nerve cells. Now we know that although the liver does not have these cells, the capsule around it does.

Disclosure alerts healthcare professionals to practice what they should already be doing – protecting themselves and others from transmitting diseases. In medicine and dentistry, everyone is required to follow safety guidelines known as universal precautions. When properly followed, the risk of transmitting and acquiring HCV is very low. In fact, the risk of infection for those in healthcare is the same as the general population.

If you feel uncomfortable when disclosing your HCV status, you do not have to. It is not your responsibility to enforce universal precautions. Healthcare professionals are supposed to treat all bodily fluids as potentially infectious. This way they rely on good habits to protect themselves and others.

Most medical providers appreciate knowing this information. However, they are human and they may ask you this common question: “How did you get HCV?” You do not have to answer this unless you want to. Some vague but truthful replies are, “From infected blood” or “I am not sure.”

Tragically, some medical providers react negatively. Unkind words can come out of anyone’s mouth, even from those we expect to be compassionate. Some patients have even been denied medical care because of hepatitis C. You have the right to be treated with respect.

If you feel you are treated in a disrespectful way, there are a number of actions you can take. You can stop working with that professional. This is probably the most sensible response. This frees you up to work with someone who is compassionate and respectful.

You may also respond to disrespect by saying something like, “That remark sounded unkind to me. Did I misunderstand you or did you mean to say that?” Sometimes off-handed remarks are made when doctors and nurses are busy or preoccupied. They may still be compassionate and wonderful at what they do. If they are, they will probably appreciate your directness. Some of the

strongest patient-provider relationships start out poorly but gain strength built on mutual respect and trust.

If you have a complaint about your medical provider, try to address it directly. If the complaint is not resolved, the next step is to complain to the provider's superior. Clinics and hospitals usually have a patient advocate. This is the best place to seek resolution. If you need to take further action, send a written complaint to your state's medical board.

A compelling reason to attend an HCV support group is that it provides a format for patients to network with each other. Patients talk to each other about medical providers, giving warnings or recommendations. Since patients are experts of their own experiences, this can be an excellent resource. It is also a good place to vent feelings and get feedback about problems with medical providers.

You should not donate blood, tissue or organs without full disclosure. Blood banks do not want HCV-positive blood, but occasionally it is required for research. Tissue and organs may be donated to HCV-positive recipients.

10. Other Disclosure Situations

You may engage in other activities with potential risk factors. Anytime there is a potential for blood exposure there is a potential HCV risk. Tattoos, piercing, manicures, shaving are all sources of potential infection risk. The risk in these situations is very low. Professionals should follow procedures to protect themselves and others.

If you engage in injection or inhaled drug use, anyone you share paraphernalia with is at a high risk of acquiring HCV from you. Everything used for these purposes is a potential source of infection. This includes the drug, the needle, the syringe, the straw, the cooker, the water, the cotton, the tourniquet, and preparation surfaces. Responsible drug use includes full disclosure and taking precautions.

If you believe you acquired HCV from past drug use, you may want to contact people with whom you used. They may also have HCV and may need to be tested.

11. Guilt

People feel guilty for all sorts of reasons. HCV patients may blame themselves for not taking better care of themselves. Those that may have transmitted HCV to another person are especially prone to guilt. If you do feel guilty, try to move out of that feeling. Guilt is destructive to us and to those around us. Do not hold yourself hostage for past behaviors that you can do nothing about. No one sets out with a goal of acquiring hepatitis C! If there is something you can do to resolve a past problem, then try to do so.

Important Note: *If you have thoughts of suicide or hurting yourself or others, seek immediate professional help. Also, seek professional help if you experience depression that is incapacitating or lasts longer than 2 weeks.*

12. Denial

Denial is an important psychological mechanism with both good and bad consequences. The positive side is that denial allows people to accept an HCV diagnosis at their own pace. When the time is right and you accept this diagnosis, you may be better prepared to deal with the realities of disclosing your health status to your family, friends and business acquaintances. At the same time, denial can prevent you from seeking necessary medical care and making lifestyle adjustments to stay healthy.

Friends and family may also practice denial. Again, this can be either positive or negative, depending on how denial is used. Be patient with them and respect their need to come to terms with this information. If denial is causing damage to anyone or your relationship, you may want to talk to a counselor, clergy person or other expert.

13. Support

The decision to disclose is a personal one. A good support system can be an invaluable resource during this process. We strongly encourage patients to join HCV support groups. Often the best information and suggestions come from the combined expertise of all the group members. Support groups can make us laugh, lift our spirits, help us manage HCV treatment, and act as an informal referral resource.

One way to use people in your support system is to discuss the details of disclosure. There may be a particularly tricky disclosure situation for which you want feedback. You may want to role-play various disclosure techniques.

A support group can be a good place to hang out while your loved ones are digesting the information you disclosed to them. Our loved ones may need time to absorb what you told them. In the U.S., there are a handful of HCV support groups specifically for family, friends, and other caregivers. This can accelerate your loved ones' absorption process. The sooner they come to terms with your HCV status, the earlier they can support you.

You can find a support group at www.hcvadvocate.org. Just look for the green button labeled SUPPORT groups toward the bottom of the right hand column and click on it.

14. Topics for Thought or Discussion

- Do you tell others that you have hepatitis C? Whom do you tell and whom do you not tell? What are the reasons for withholding this information?
- Have you ever felt that others are uncomfortable because you have hepatitis C? If so, why do you think that is?
- When you do tell others you have HCV, what do you say?

- What advice would you give to newly diagnosed HCV patients on the subject of disclosure?

15. Resources

The Hepatitis C Support Project lists support groups, HCV specialists and has information about hepatitis C in multiple languages. For more information, facts and guides, visit www.hcvadvocate.org

Some HCSP fact sheets and guides:

- *A Guide to Understanding Hepatitis C*
- *Easy C: A Guide to Understanding Hepatitis C*
- *Easy C Facts: HCV and Hygiene Items*
- *Easy C Facts: HCV and Needle Exchange*
- *Hep C Basics: Sexual Transmission of Hepatitis C*
- *HCSP Fact Sheet: Occupational Exposure to Hepatitis C*
- *HCSP Fact Sheet: Preventing HCV Transmission in Personal Care Settings*
- *HCSP Fact Sheet: Sexual Transmission of Hepatitis C*
- *Stigma and Hepatitis C*

Books

- *The First Year—Hepatitis C: An Essential Guide for the Newly Diagnosed*, by Cara Bruce and Lisa Montanarelli
- *Living With Hepatitis C For Dummies*, by Nina L. Paul and Gina Pollichino
- *My Mom Has Hepatitis C*, by Hedy Weinberg, Shira Shump, Gregory T. Everson and Joy Chen

Appendix I

Frequently Asked Questions

Here are some brief answers to some common questions. For more complete information, visit the Hepatitis C Support Project's website at www.hcvadvocate.org

Q What is hepatitis C?

answer

Hepatitis C is a disease caused by the hepatitis C virus (HCV). It primarily affects the liver and over time can damage the liver and health of an individual. Usually it takes a long time to do any damage, especially if the person who has it does not drink alcohol and lives a healthy lifestyle. Sometimes the damage is so minimal that people will go through their entire lives without knowing they have HCV.

Q Is HCV rare?

answer

No. Approximately 3 to 4 million people in the United States have HCV. Some people believe these estimates are low and there may be 5 million or more people in the U.S. living with HCV. Worldwide, more than 170 million people have HCV.

Q Is it serious?

answer

Maybe. It should be regarded as a potentially serious problem. The good news is that for most people, HCV will not create major health problems. Your medical provider will be able to determine the seriousness of your particular situation.

Q Will I die from HCV?

answer

Most people will die **with** HCV and **not of** HCV. Out of 100 people who have hepatitis C, 3 or fewer will die an HCV-related death.

Q Will I need a liver transplant?

answer

This is very unlikely. The majority of people living with HCV will not need a liver transplant.

Q Is there treatment for hepatitis C?

answer

Yes. Currently the treatment involves combining two drugs, pegylated interferon and ribavirin. The effectiveness of these drugs is about 50%. Depending on specific factors, your chances can be as high as 80%. These drugs do have side effects. Talk to your medical provider about whether treatment is right for you.

Q Can "natural medicine help me?"

answer

No herbs, supplements, or alternative treatments have been proven to effectively treat HCV. Some herbs can be harmful and even lethal. Some people have experienced health improvement from acupressure, acupuncture, meditation, Tai Chi, Yoga and other complementary health practices.

Q **Is there anything I can do to help my liver?**

answer

Yes, there is a lot you can do. First, talk to your medical provider. Avoid alcohol. Do not eat raw or undercooked shellfish. Get regular medical care. If you have never had hepatitis A or B, be sure to get vaccines to protect you from these. Try to live the healthiest lifestyle possible. Avoid or exercise caution with potentially liver toxic-drugs, supplements, and chemicals.

Q **How did I get it?**

answer

HCV may be transmitted during activities that involve blood. In order to acquire HCV, a person's blood needs to be in contact with HCV-infected blood. This can happen in various ways. Some common ways are from blood transfusions before 1992, and sharing needles or other injection drug utensils. There is an occupational risk to those who have had a needlestick injury or mucosal exposure to HCV-positive blood. There is low risk of acquiring HCV sexually or for a mother to transmit it to her fetus during pregnancy. There are other ways to acquire HCV and it is important to obtain more information about this. It is normal to wonder how you got hepatitis C. However, it can be unhealthy to obsess about this. Try to focus on what you can do for yourself now, rather than on the past.

Q **How long have I had it?**

answer

Your medical provider can help you determine this. Sometimes it is easy to answer this, but often an educated guess is made based on risk factors, medical history and your current health information.

Q **Is it contagious? Can I give it to my family and friends?**

answer

*Yes, it is contagious, but mostly only through blood. It is usually transmitted when people come in contact with someone's blood, such as by sharing contaminated needles, piercing and tattooing instruments and other blood-related practices. If you do not share these with your family and friends, it is unlikely they will get HCV from you. We do recommend that you do not share razors, toothbrushes and other tools that may have your blood on it. We do not know for sure that sharing personal items is a risk, but it is better to be safe. Always cover any bleeding wounds or sores. It is not transmitted by hugging, kissing, sneezing, coughing, sharing eating utensils or glasses, or by casual contact. Although the risks are low, it is recommended that family members be tested, especially children of women who may have had HCV at the same time they were pregnant. You should not donate blood or semen. Body organ and tissue donation is made on a case-by-case basis. There is a major shortage of donated organs, so sometimes an HCV-positive organ is used for an HCV-positive recipient. **There is no vaccine that protects against hepatitis C at this time.***

Q **What about sex?**

answer

This is a sensitive, complicated and important subject. The research is confusing. The Centers for Disease Control (CDC) does not recommend any changes in sexual practices between monogamous, long-term partners. Sexual transmission rates increase with multiple sexual partners and with risky behavior involving trauma and blood. It is important to get accurate information about sexual transmission of HCV.