



Special Populations

# Caregivers and Hepatitis C

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In most cases, hepatitis C (HCV) is a curable disease, and the majority of those who have it will not die from it. In fact, the majority of those who have hep C are still undiagnosed, partly because the symptoms are often vague. People living with hep C may experience fatigue, depression, aches and pains, and other symptoms that aren't severe enough for them to seek a diagnosis. Usually those with mild disease are able to function well enough, and don't need hands-on care giving.

However, even in its early stages, hepatitis C doesn't just affect the infected; it touches family, friends, co-workers and community members. These effects intensify when people are undergoing HCV treatment, have advanced liver disease or are involved in the liver transplant process.

Those who live with someone who has hep C may find themselves thrust into caregiver roles. A caregiver is anyone who provides assistance to those who need it. The majority of caregivers are family members, but friends and others in the individual's social circles may also provide assistance. This service is usually unpaid; sometimes it's round-the-clock. Caregivers may lose income from work or incur out-of-pocket expenses as a direct result of giving assistance.

The caregiver's role may include helping with medications, managing appointments, and dealing with mood swings. Giving assistance to people living with hepatitis C who have a type of dementia known as hepatic encephalopathy can be especially stressful. Perhaps the only harder situation is caring for loved ones who are dying.

Caregiving is hard work. It may mean interrupted sleep, engaging in physically demanding tasks, possibly setting aside one's own needs and wants. The stress of being a caregiver may harm the caregiver's own health. Stories of caregivers who have become ill or died during the course of supporting an ailing partner are all too common.

Even if the person living with hep C in your life doesn't need hands-on assistance, the mere act of caring about that person may stir up strong feelings in you. The emotional side of caregiving often includes feeling powerless or hopeless. It may mean giving up dreams of the future if you are caring for someone who is chronically ill, especially if that person is mentally unavailable or dying.

## Suggestions for Hep C Caregivers

If someone you know has hep C, you may have many questions about the disease. Start by learning a few facts. The following links provide basic information:

- [What is Hepatitis C?](#)
- [Hepatitis C Progression](#)
- [Hepatitis C Transmission and Risks](#)
- [Hepatitis C Prevention](#)

The time you spend informing yourself about the disease will help you be a more effective caregiver. You can also talk to others who have hep C or who are giving care by joining the [Hep Forums](#).

Here is some more relevant information that may help caregivers:

- Some people with hepatitis C may show signs of cognitive impairment. The more common type is a mild form of mental cloudiness that the hep C community calls brain fog. Hep C-related brain fog is usually reversible when hep C is cured. A completely different and more serious form of cognitive impairment is hepatic encephalopathy (HE), a dementia that may occur in advanced stages of cirrhosis. HE is a serious problem needing prompt medical attention.
- Remember that you aren't the only one who is scared. Hep C may be occupying your loved one's mind and heart. If you are a good listener, and not prone to trying to fix other people's problems, offer to listen to your loved one.
- If you have HCV-related concerns about your loved one, ask if you can go along to their medical appointments.

#### Information About HCV Treatment for the Caregiver

People living with HCV often "look good" during treatment. This can create problems, especially if the person feels awful and assumes everyone can see this. Open communication is the best way to find out how your loved one feels. Do not expect too much from the person undergoing HCV therapy, especially if he/she was not a good communicator before treatment. Some people do not want to talk about their experiences, while others want to talk about them a great deal. The two best things you can do for your loved one are to encourage him or her to join a [support group](#) and to take care of your own health.

Here is more information that may help you while the person you care about is undergoing HCV treatment:

- If the person living with hep C in your life is undergoing treatment, learn about the side effects. Medications may affect moods, sexual interest, and other behaviors. Ribavirin is especially

likely to cause mood changes.

- Set limits on unacceptable behavior. If your loved one has anger management issues, you do not have to tolerate outbursts.
- Suicide, harmful threats, or aggressive or abusive behavior are not normal. If you or your loved one is in harm's way, seek immediate help.
- The side effects of HCV medications are not permanent, but it will take some time after the drugs are stopped before the person returns to previous moods.

### Put Your Health First

When on an airplane, we are told to put our own oxygen masks on before helping others. This applies to caregiving too. Be sure you:

- Make a commitment to your own health. Get an annual flu shot and regular health care.
- Eat sensibly.
- Be physically active.
- Aim for a good night's sleep. If sleep is a problem, get some help. You may need to sleep in a different room or have someone stay with your loved one so you can go somewhere to rest.
- Take time every day to do something to recharge. Read a book, watch a sporting event, go for a walk, meditate, pray, play with a pet, do a puzzle, or take a class.

### Caregiver Burnout

The expression caregiver burnout describes a person who is overwhelmed with the responsibility and may be headed towards illness. The symptoms of burnout are much like those for stress and depression: irritability, exhaustion, feeling down, changes in appetite or sleep patterns, and problems with memory or concentration.

The following suggestions may help you to avoid or relieve caregiver burnout:

1. Join a support group.
2. Put yourself first. If you don't take care of your health, you cannot be an effective caregiver.
3. Identify your needs. Compose a list of everything you need, such as more sleep, someone to talk to, time off, help with meals, help with errands, etc. Devise a plan for getting your needs met.
4. Establish a support network. List everyone who may be willing to help. Include everyone who has offered help as well as those who might be good listeners.
5. Ask for help and delegate responsibilities. Ask someone to pick up groceries for you. Ask your kids to mow the lawn or help with household chores.
6. Take a break from caregiving. See a friend, go for a walk, read, go to a movie, nap—anything that revitalizes you. It is all right to go away for a day, a weekend or longer if that is what you need.

7. Set limits for yourself. Remember the word “no” is a complete sentence.
8. Look for signs of [depression](#) and seek help if you think you have it.
9. Practice stress management, meditation and other mind-quieting techniques.
10. Find ways to laugh. Laughter is a proven stress-reliever.

## Resources

Centers for Disease Control and Prevention's [Families with Special Needs: Caregiving Tips](#)

National Library of Medicine's [MedlinePlus](#)

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