Special Populations

Caregivers and Hepatitis B

Hepatitis B (HBV) doesn’t just affect the infected; it touches family, friends, coworkers and community members. These effects intensify when people experience side effects from HBV treatment, have advanced liver disease or are involved in a liver transplant process.

Those who live with someone who has hep B 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 lend support. This service is usually unpaid; sometimes it’s around-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. Assisting people living with an advanced form of hep B that causes 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 and 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 in your life who is living with hep B doesn’t need hands-on help, 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.

Sometimes the caregiver also has hepatitis B. When giving care to a family member who is dying from hep B, you may be wondering what your own life and death will be like. You may be reluctant to talk about this, particularly with members of your family. Try to find someone to talk to, whether a support group, your medical team or counselor.

Suggestions for Hep B Caregivers

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

- What is Hepatitis B?
- Hepatitis B Progression
- Hepatitis B Transmission and Risks
- Hepatitis B 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 B or who are giving care by joining the Hep Forums. Support groups are packed with information about the latest treatments and tips for living with chronic illness. If your loved one isn't participating in a support group, you may encourage him or her to join one, preferably a different one than the one you belong to.

Here is more information that may help caregivers:

- If the person in your life who is living with hep B is taking medication, learn about the side effects. Medications may affect moods, sex drive and other behaviors.
- Remember that you aren't the only one who is scared. Hep B 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 HBV-related concerns about your loved one, ask whether you can go along to his or her medical appointments.
- We all handle illness in our own way. Open communication is the best way to find out how your loved one feels. However, some people do not want to talk about having hep B. If this is the case with your loved one, it's best to respect this, and get your own support.

Put Your Health First
When on an airplane, we are told to put on our own oxygen masks 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 toward 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 having 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. Seek the help of a mental health professional if you feel depressed, anxious or overwhelmed.
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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