

A GUIDE TO: **COPING WITH DEPRESSION AND HEPATITIS C**

Lucinda K. Porter, RN



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

Living with a chronic disease such as hepatitis C can be challenging. Few of us ever think we will develop a chronic condition, so naturally it is not a situation for which we prepare.

A diagnosis of chronic hepatitis C virus (HCV) infection can invoke a wide range of reactions. One common response is depression.

This booklet will discuss various aspects of depression. Hopefully, this information will provide you with tools to gain insight and control over your depression.

Life is indeed too short to spend it feeling depressed.

– Especially since you can do something about it!

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Writer, Hepatitis C Support Project and *HCV Advocate*

Disclaimer: Drug-drug interaction information in this guide is correct as of the time of writing, but testing for potential interactions is ongoing. Before taking any supplements, prescribed drugs or over-the-counter medications, discuss potential interactions with your medical provider.

“Many people with a depressive illness never seek treatment. But the majority, even those with the most severe depression, can get better with treatment. Medications, psychotherapies, and other methods can effectively treat people with depression.”

– National Institutes of Mental Health website

WHAT IS DEPRESSION?

Depression is the most common serious psychiatric illness. It is also one of the most treatable. Depression is a disorder that may affect your feelings and outlook on life. Persistent feelings of sadness, a loss of interest in life, hopelessness, and pessimism are common warning signs of depression. The symptoms can vary from person to person. Anyone can feel sad or blue from time to time. However, a persistent or unexplained bout of malaise—the blues—is not normal and should be evaluated.

The following are some common symptoms of depression:

- Feeling sad or “empty”
- Fits of crying with no reasonable explanation
- Feeling hopeless or pessimistic
- Feelings of guilt, worthlessness, or helplessness
- Feeling anxious, irritable, or restless
- Loss of interest or enjoyment in hobbies, social activities, or sex
- Fatigue or decreased energy
- Difficulty concentrating, sometimes accompanied by decision-making and memory problems
- Insomnia or other sleep-related problems
- Appetite loss and/or weight loss
- Overeating and/or weight gain
- Thoughts of death or suicide; suicide attempts

Adapted from “Depression,” National Institute of Mental Health, www.nimh.nih.gov/publicat/depression.cfm.)

Depression may be accompanied by a number of other psychological as well as physical complaints. Persistent physical symptoms that do not respond to treatment—such as headaches, digestive disorders, and chronic pain—may be related to depression.

Other physical complaints that may be related to depression include:

- Panic attacks or phobias
- Tight chest or throat
- Difficulty breathing or swallowing
- Dizziness
- Shaking or tremors
- Gastrointestinal complaints such as nausea, diarrhea, intestinal gas, and stomach pain
- Muscle aches and pains

DEPRESSION AND HEPATITIS C

The Hepatitis C Diagnosis

Any medical diagnosis can be a jolt. If you were feeling well at the time of your diagnosis, this new information can be especially shocking. An array of questions may be swimming around in your head, such as: What does this mean? Will I die from hepatitis C? What about my family? Is hepatitis C contagious? If so, how?

Your questions will be answered over time. However, the period following initial diagnosis can be very stressful, emotional, and confusing. Fear, anxiety, anger, and denial are common reactions.

Isolation

Feeling isolated is a complicated problem because it can come from both internal and external factors. The part that comes from within can stem from “feeling infectious.” Invisible, pervasive, and hideous, this feeling of having the potential to infect other human beings can be an incredible burden. Isolation can result if a person becomes preoccupied with potential infectiousness.

Society can reinforce this isolation. Sometimes people are ignorant about how to prevent transmission of HCV in particular and of viruses in general. Patients have reported stories of friends and family who would not let them into their homes out of fear that their children would become infected. Hugs and kisses cease. Sexual relationships stop or are never initiated. In extreme cases, marriages and

partnerships have suffered.

It is tragic to witness this unnecessary and avoidable exclusion. Those struggling to live with a chronic disease need more support, not less. For some people with HCV, the isolation is worse than the virus. Just as with other aspects of chronic hepatitis C, finding ways to manage these complexities is a key to learning how to live with HCV infection.

Depression is common in people with chronic HCV. Various studies support the notion that depression is more common in those with HCV than in the general population. This seems to be true regardless of how a person contracted hepatitis C or the severity of the disease. Additionally, those coping with any chronic illness are more likely to report depression compared to the general population. A hepatitis C diagnosis can carry with it a number of issues and reactions. This section explores some of these common concerns.

Note: *The hepatitis C virus is a blood-borne virus. It is most often transmitted through shared needles or other direct blood-to-blood contact. Sexual transmission is uncommon. HCV is not passed easily or casually. For information about HCV transmission, visit www.hcvadvocate.org.*

DEATH

Sometimes a change in our health can be an unexpected reminder of our temporary existence on this planet. A common response upon receiving a diagnosis of hepatitis C is, "Am I going to die from this?" This question arises whether a person has mild disease or more advanced liver damage.

Thoughts and fears about death are common and normal. It is essential to address these concerns so they do not become persistent. Many of our deepest fears can be soothed with accurate information. The majority of people with HCV will die **with** hepatitis C, not **of** hepatitis C. HCV is nonetheless serious and we can't ignore it. Be sure you see your medical provider on a regular basis.

Consider these suggestions if you find yourself wrestling with issues related to death

Talk about it. Tell someone your fears and thoughts. Sometimes the act of speaking the unspoken can be very powerful.

Get the facts. Talk with your doctor about your particular situation. Be specific with your questions. What are my chances of dying from this? How much time do I have? Should I be concerned about the fact that I cannot remember things like I used to? Your physician may not know the answers to these questions, but should take them seriously. You have the right to not be dismissed or made to feel uncomfortable about your concerns.

Compare notes. The key here is to talk to other people without hepatitis C. Choose people close to your age and lifestyle. Ask them how they feel. You might be surprised to learn that many other people your age are feeling tired and achy and find their memory slipping.

Get support. Talk to people with hepatitis C. People with HCV have more health complaints than those not infected with the virus. Many have also developed ways to cope with these problems. They know the best and the worst doctors. They can recommend web sites and literature. Best of all, when you attend a support group you do not have to try to look or act your best.

Control what you can. Although you do not have control over the fact that the virus has taken up residence in your liver, you do have control over factors such as alcohol use. Alcohol and HCV do not mix. Look at your lifestyle. Do you smoke, drive without a seatbelt, or misuse drugs? Do you exercise and are you careful about what you eat? These are areas that you can control. Be aware that permanent lifestyle changes do not happen instantly. Success is more likely to occur if you are gentle with yourself while maintaining your commitment.

Grieve. Grief is a normal part of having a chronic illness. Sometimes grieving is the only way to move on.

Live while you are alive. Focus on the present, not the future. Until breathing stops, you are still alive. How are you going to spend today and the rest of your life?

HCV TREATMENT AND DEPRESSION

The current standard treatment for chronic HCV infection depends on your genotype. Those with genotype 2 or 3 use a combination of peginterferon and ribavirin; genotype 1 patients use that combination along with a protease inhibitor – either boceprevir or telaprevir. Peginterferon injections are self-administered once per week. Ribavirin is a pill, usually taken twice a day. The protease inhibitors are pills taken every 7 to 9 hours.

Patients taking interferon commonly report depression. If you are considering treatment, tell your physician if you have a current or past history of depression or other psychiatric illness. It is especially important to report severe depression, hospitalization for any psychiatric illness, or any suicide attempts.

Sometimes antidepressant medications are used in conjunction with HCV treatment (see Professional Help, page 11). Many patients say that antidepressants make a huge difference in their quality of life while they are undergoing HCV treatment. Some people start on antidepressants prior to HCV treatment. Others start HCV treatment and then begin antidepressant medication if they think they need it. Talk to your doctor about what would be best in your situation.

Approximately 25% of patients with chronic HCV infection are affected by major depression, compared with 7% of the general population. Interferon-based treatment of HCV increases the depression risk to 23% - 44%. The use of HCV protease inhibitors does not increase the prevalence of depression.

WHAT CAN BE DONE ABOUT DEPRESSION

Help for depression can come in a variety of forms. Sometimes mild depression can be reduced with self-help measures alone. Prolonged or severe depression usually requires professional treatment. Sometimes professional intervention and self-help measures can reinforce each other.

The mind and the body are not separate and independent from each other. The body affects the mind, and the mind affects the body. Stress can weaken the immune

system and make it harder to resist diseases. Feeling unwell can lead to increased fatigue and more depression. Breaking the cycle of depression usually involves a holistic mind-body approach.

SELF-HELP

Information

Separating fact from fiction can be enormously reassuring. Patients sometimes hear or read something incorrect that leads them to believe that their health or prognosis is worse than it really is. The Internet is a valuable tool, but it is not always reliable. Know your sources and do not settle for anything less than the most current and accurate information. Write down questions that you have and bring them to visits with your doctor so that you can cover all of your concerns.

Support

The benefits of support cannot be overstated. Support can come from friends, family, and community. Support groups, especially those designed for people with hepatitis C, can be invaluable. Sometimes the process of talking about inner concerns can be healing.

Exercise

Exercise is probably the single most effective self-help antidote for fatigue and depression. This can be hard to fathom, especially if merely getting out of bed seems like an ordeal. Like most things, exercise is best when practiced in moderation.

If you are unaccustomed to exercise, have a complicated medical condition, or are over 50 years old, talk to your healthcare provider before embarking on a new exercise regimen. If you are ready to begin, start slowly.

Five to fifteen minute intervals, two to three times per day, can help fend off relentless fatigue. This is especially true if you can exercise in a relaxing environment such as a park. Remember that five minutes of exercise is better than no exercise! Resist the all-or-nothing temptation.

Also, resist the temptation to over-exercise. Balance is the key. When it comes to exercise, there are many activities from which to choose. Walking is perfect because

it requires no special equipment except comfortable shoes. Biking, swimming, dancing, and gardening can be fun as well as therapeutic. Yoga, Tai Chi, Qigong, and Pilates are highly regarded as beneficial activities.

As you venture into the realm of exercise, include stretching as part of your regimen. Start slowly and increase your activity according to how your body responds. The goal is to find a balance of activity that revitalizes you during the day and promotes sleep at night.

Balance Rest and Activity

Schedule a daily rest period. Rest is like fuel for the body. Just as you plan to put fuel in your car, do the same for your body. Consider resting as a preventative measure and try to plan to rest before you get too fatigued.

During those times when you feel more energetic, resist the temptation to skip a rest break. This will likely only lead to increased inefficiency or fatigue later. Again, balance is the key. Pace yourself, take breaks, plan ahead, and delegate. Ask for help. Create short cuts. Organize your work areas so you can work more efficiently. Break large tasks into smaller ones, set priorities, and do what you can as you are able.

Sleep

Inadequate or poor-quality sleep can lead to feelings of daytime tiredness. Make sure you are getting sufficient sleep. The National Sleep Foundation states that the average adult needs seven to nine hours of sleep per night. If you believe that insufficient sleep is contributing to your fatigue, gather more information and seek help. Sleep issues are well understood and much can be done to improve the quality of sleep.

Positive Thinking

Positive thinking is a learned skill. Performed on a regular basis, positive thinking can replace negative thinking. A recent study evaluated people with chronic fatigue. After interviewing them, it was noted that people often said to themselves and others, "I am tired." Two groups were then formed, and half the group was not instructed to do anything different. The other half was instructed to substitute the phrase, "I am getting my energy back" every time they felt tired. The people in the second group reported a significantly reduced fatigue level.

This example shows how the power of positive thinking can be a useful tool in overcoming inertia.

Hint: *Practice positive thinking even if you do not believe it. Over time, positive thinking can become a habit, and can help improve many aspects of your health.*

Stress Reduction

Too much stress takes its toll on a person's health. Avoiding unnecessary stress is easier said than done. There are a number of measures that can help reduce stress. Some examples are yoga, meditation, visualization, and stress-management techniques.

Substance Use

Alcohol, drugs, tobacco, excess caffeine and other substances of abuse can all cause or worsen depression and anxiety. Alcohol is a depressant and can worsen liver damage in people with HCV. The psychological and physical effects of drug use have been well documented. Tobacco and caffeine are stimulants and can cause increased anxiety. Although reducing or stopping the use of these substances can be difficult, it can be done. There are many types of help available for substance use cessation. Ask your doctor for available resources in your community.

Laughter and Recreation

Finding pleasurable activities that you can participate in may improve your mood and prevent thoughts and feelings that can contribute to depression. Try to pick at least one pleasurable activity and find the time to do it often.

Finally, it is worth promoting something that can be infectious: laughter. Having HCV can be painful and burdensome—if we let it. Laughter is not a cure, but it can lighten the load. It is the one contagious condition that feels good and for which you do not need a doctor's order. Prescribe it for yourself today!

Good Nutrition

Try to eat a low-fat, high-fiber diet. Eat a variety of foods including fruits, vegetables, and whole grains. Eating well does not take a lot of effort, but may involve a bit of planning. There are plenty of healthy food choices available without having to cook from scratch. For instance, vegetables are available pre-cut, and can be tossed into soup, a salad, or an omelet. Most fast food restaurants now offer healthy

alternatives to the usual fried fare. A sandwich made from whole grain bread and piled high with vegetables is simple, healthy, and delicious.

HELP FROM FAMILY AND FRIENDS

Watching a loved one experience depression can be frightening. Feeling helpless is a common reaction to someone else's depression. If you are a friend or family member of someone with hepatitis C, you are already helping the person you are concerned about by reading this booklet. By gaining information and tools, you can be a great source of support.

“The most important thing anyone can do for the depressed person is to help him or her get an appropriate diagnosis and treatment. This may involve encouraging the individual to stay with treatment until symptoms begin to abate (several weeks), or to seek different treatment if no improvement occurs. On occasion, it may require making an appointment and accompanying the depressed person to the doctor. It may also mean monitoring whether the depressed person is taking medication. The depressed person should be encouraged to obey the doctor's orders about the use of alcoholic products. The second most important thing is to offer emotional support. This involves understanding, patience, affection, and encouragement. Engage the depressed person in conversation and listen carefully. Do not disparage feelings expressed, but point out realities and offer hope. Do not ignore remarks about suicide. Report them to the depressed person's therapist or physician. Invite the depressed person for walks, outings, to the movies, and other activities. Be gently insistent if your invitation is refused. Encourage participation in some activities that once gave pleasure, such as hobbies, sports, religious or cultural activities, but do not push the depressed person to undertake too much too soon. The depressed person needs diversion and company, but too many demands can increase feelings of failure. Do not accuse the depressed person of faking illness or of laziness, or expect him or her 'to snap out of it.' Eventually, with treatment, most people do get better. Keep that in mind, and keep reassuring the depressed person that, with time and help, he or she will feel better.”

from the National Institute of Mental Health publication, *Depression*
(www.nimh.nih.gov/publicat/depression.cfm)

PROFESSIONAL HELP

As mentioned previously, depression can be treated. There are a number of types of treatment for depression. The medical specialty dealing with mental health conditions is called psychiatry. Psychiatrists can prescribe medications. Sometimes psychotherapy is recommended. Psychotherapy can be done individually or in groups. There are many types of psychotherapy, and approaches vary widely. Shop around to find a therapist and a style that suits you. Although some psychiatrists offer psychotherapy, patients are often referred to other mental health professionals such as psychologists, marriage and family counselors, licensed social workers, or nurse specialists for this type of treatment.

Important Note

If you have thoughts of suicide or hurting yourself or others, seek immediate professional help.

Antidepressant Medications

Antidepressant medications are commonly used to treat depression. Studies have shown that antidepressants can help reduce depression associated with hepatitis C and interferon-based therapy. There are different types of antidepressants and new ones are on the horizon. Some people have satisfying results with the first medication their doctor prescribes; others need to try a few before they find one that gives them good results. If an antidepressant does not work well within a reasonable time, don't despair. Your doctor may suggest combining two or more medications. Try to be patient. Although it may be a frustrating process, the benefits can be astounding.

HCV and HIV protease inhibitors interact with many medications, including some antidepressants. Desipramine, escitalopram, and trazodone are known to interact, and others, such as citalopram may potentially interact. These antidepressants may be used with protease inhibitors, but they need close monitoring.

Antidepressant Side Effects

Antidepressant medications can cause side effects. Usually these are mild, do not interfere with activities, and often resolve over time. However, some side effects can be serious, and those that are unusual, annoying, or affect your activities should be reported to your doctor right away.

Warning

Consult your doctor prior to stopping antidepressant use. Uncomfortable and potentially serious medical symptoms have been associated with abrupt discontinuation of some antidepressants.

Common side effects of antidepressants include:

- **Headaches** may occur during the first one to two weeks, but usually go away after a short period of time.
- **Nausea** also can occur during the first one to two weeks and usually resolves after a short time.
- **Nervousness** may also occur early on and go away after a couple of weeks.
- **Agitation** or a jittery feeling, occurs less frequently. Notify your doctor if it lasts longer than a day or two.
- **Sexual problems** may occur in both men and women. Although fairly common, these are reversible. Tell your doctor if you experience any sexual problems after starting an antidepressant, as there may be ways for your doctor to help.

Warning

Consult your doctor prior to stopping antidepressant use. Uncomfortable and potentially serious medical symptoms have been associated with abrupt discontinuation of some antidepressants.

Caution

Liver problems have been associated with the use of nefazodone. This problem was significant enough that the manufacturer withdrew their product Serzone (the brand name for nefazodone) from the market. Generic nefazodone is still available and should be avoided or used with extreme caution in patients with liver disease.

Never stop a medication without talking to your doctor first. The abrupt stopping of antidepressants can have serious consequences.

WHAT TO EXPECT DURING ANTIDEPRESSANT THERAPY

Antidepressants often take some time before they are effective. Some people may notice improvement in their depressive symptoms in the first one to two weeks, but

typically the medications must be taken regularly for six to eight weeks before their full effect is felt. Antidepressants should typically be continued for at least six to twelve months, but the length of treatment may vary.

Antidepressants are not “uppers” or “happy pills,” and they are not addictive. In order to be effective, antidepressants should be taken on a regular basis. Never stop a medication without talking to your doctor. If you miss a dose, take the next regularly scheduled dose; do not “double up,” as this may cause increased side effects.

If you are taking antidepressant medications for depression associated with interferon-based therapy, you should work closely with a healthcare provider who is knowledgeable about hepatitis C and interferon. Avoid alcohol, since it can worsen depression and may interact with antidepressants and reduce their effectiveness.

All medications can cause allergic reactions. Tell your doctor about any allergies you might have. Antidepressants can also interact with over-the-counter or prescription medicines, or other conditions. Inform your doctor about any over-the-counter, prescription medicines, herbs, or other drugs you are using, since these may affect how the antidepressants work. Finally, notify your doctor if you experience any unusual or worsening symptoms.

Although antidepressants are often very effective and can significantly improve your symptoms and quality of life, treatment should be individualized. Studies have shown that the best results occur when antidepressants are used in conjunction with psychotherapy. Discuss treatment options with your healthcare provider to find the best treatment for you.

A WORD ABOUT HERBS

The use of herbs and supplements is becoming increasingly popular. However, as with any medication, you should know what you are using and how to use it. Tell your healthcare provider about all substances you are using, including herbs, vitamins, and any drugs. Herbs can interact with drugs, so it is important to provide a complete account of whatever you are taking.

St John's wort is sometimes used to treat mild depression. This herb has the potential to interfere with other drugs, especially if given after surgery. If you do take St. John's wort, stop taking it one week before any surgical procedure. **Do not take St John's wort if you are taking a protease inhibitor, such as boceprevir (Victrelis) or telaprevir (Incivek).**

Some herbs can cause unintended problems. Ephedra is an example of a commonly used herb that can cause increased anxiety. Several common herbs can cause liver damage, especially in people with an existing liver disease such as hepatitis C. If you are taking a mixture of herbs or supplements, check the product label for the various ingredients.

FINAL ENCOURAGEMENT

Feeling Better Takes Time

Do not expect to be free from depression overnight. However, with self-help, support, and professional treatment, it is reasonable to expect gradual improvement. Do not settle for a small improvement—depression can be treated. Aim for feeling great. With professional help, this is a reasonable goal.

"For those who have dwelt in depression's dark wood, and known its inexplicable agony, their return from the abyss is not unlike the ascent of the poet, trudging upward and upward out of hell's black depths and at last emerging into what he saw as 'the shining world.' There, whoever has been restored to health has almost always been restored to the capacity for serenity and joy, and this may be indemnity enough for having endured the despair beyond the despair."

– William Styron, *Darkness Visible*

RESOURCES

Mental Health

Ask your doctor for a referral to a mental health provider. Your local county mental health association may have recommendations. If you have a religious affiliation, ask for suggestions. Some places of employment provide counselling services.

National Mental Health Association

800-969-NMHA (6642)

www.depression-screening.org

National Institute of Mental Health Depression Information

www.nimh.nih.gov/publicat/depression.cfm

National Mental Health Information Center

800-789-2647

mentalhealth.samhsa.gov

Sleep

National Sleep Foundation

202-347-3471

www.sleepfoundation.org

Substance Use

Alcoholics Anonymous (AA)

www.alcoholics-anonymous.org

To find an AA group near you, look for "Alcoholics Anonymous" in any telephone directory or contact AA World Services 212-870-3400.

Narcotic Anonymous (NA)

www.na.org

To find an NA group near you, look in your local telephone directory or contact NA World Services, 818-773-9999.

National Clearinghouse for Alcohol and Drug Information (NCADI)

800-729-6686

www.health.org

Smoking Cessation

American Cancer Society

800-227-2345

www.cancer.org

American Lung Association

212-315-8700

www.lungusa.org

Centers for Disease Control and Prevention

www.cdc.gov/tobacco/how2quit.htm

National Cancer Institute (NCI)

Information specialists are available to answer smoking-related questions in English or Spanish, Monday through Friday, 9:00 a.m. to 4:30 p.m. local time. Call toll free in the U.S., 1-877-44U-QUIT (1-877-448-7848)

www.nci.nih.gov/cancertopics/tobacco/quitting-and-prevention

Hepatitis C Information

Hepatitis C Support Project

www.hcvadvocate.org

American Liver Foundation

800-465-4837

www.liverfoundation.org

Caring Ambassadors Hepatitis C Program

www.hepcchallenge.org

Hepatitis Foundation International

800-891-0707

www.hepfi.org

Hep C Connection

800-522-4372

www.hepc-connection.org

HepCBC

www.hepcbc.ca

Support Groups

To find a hepatitis C, chronic illness, or depression support group in your area, ask your doctor, search the Internet, or contact an HCV advocacy group. The Hepatitis C Support Project can provide information about hepatitis C support groups in many areas.

The information in this booklet is designed to help you understand and manage HCV and is not intended as medical advice. All people with HCV should consult a medical practitioner for diagnosis and treatment of HCV and depression.

This information is provided by the Hepatitis C Support Project. The mission of the Project is to offer support to those affected by HCV. The Project provides information, education, and support groups, and seeks to serve the HCV community as well as the general public.

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