

# HCV ADVOCATE

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## HealthWise

### Fatigue

Lucinda K. Porter, RN

Patients with chronic hepatitis C virus (HCV) infection often report that fatigue is a prominent symptom. In one recent study, more than half (56%) of HCV patients complained of fatigue and 70 % had musculoskeletal pain. Webster's defines fatigue as "weariness from bodily labor or mental exertion; lassitude or exhaustion of strength". The on-line medical dictionary Infomedical edited by Kwok Lee describes fatigue as "a sense of losing stamina, a symptom common in depression, cancer, and chronic infection". From a nursing perspective, fatigue is a challenge because it is the one symptom that can keep patients from initiating the changes that ultimately might improve their quality of life. Fatigue can incapacitate motivation. Loss of concentration and feelings of helplessness can accompany exhaustion. The following article addresses fatigue management.

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## Treatment Advocate

Joe Shaw

Tests, tests, tests. How many times have you had your blood taken recently? Sometimes I feel like the health care system is the Vampire Lestat and I'm slowly being bled to feed the voracious appetite for human blood. They take my blood and I don't even get the vampire benefits. Yesiree. It's all right there on the tests: AST, ALT, Albumin, Alk. phos., T-bilirubin and D-bilirubin, bun, creatinine, TSH, amylase, lipase.

What's it all mean? I'm going to share with you this time some explanations of the two main things that are measured, ALT and AST. These two are also known as liver enzyme tests, and they give a somewhat reasonable way for doctors to judge how your liver's doing. They fluctuate naturally. You should not use these as indicative of how your disease is progressing. They are one tool and there are many reasons why your liver enzymes could fluctuate. A more accurate test would be the HCV/RNA test, otherwise known as the viral load.

But this month, let's concentrate on AST and ALT. I'm also including a list of questions you should ask your doctor about medical tests and procedures.

If you have any questions, you can always e-mail me at [joesha@yahoo.com](mailto:joesha@yahoo.com).

### AST (Aspartate aminotransferase serum)

One of the two main liver function blood serum tests (the other being the ALT test). The purpose of this blood test is to detect a recent myocardial infarction (heart attack), to aid detection and differential diagnosis of acute hepatic disease, and to monitor patient progress and prognosis in cardiac and hepatic diseases. AST levels by a commonly used method range from 8 to 20 U/L although some ranges may express a maximum high in the 40s. (Check with your physician.)

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## HCV ADVOCATE

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Most patients find that their level of fatigue is cyclical. For instance, if you are too tired to concentrate on this article right now, wait until you have a bit more energy. However, if you experience constant inertia, gathering momentum might feel impossible. There is a law in physics that states that it takes more energy to set into motion an object at rest than it does to stop an object already in motion. There is another law that states that energy creates energy. These two laws can be powerful tools when trying to overcome inertia. When you do not feeling like moving, move anyway. As the popular advertisement says, “just do it”.

The first order of business is to rule out other causes of fatigue. Fatigue is a symptom of many diseases other than HCV infection. Since fatigue is a common symptom of chronic hepatitis C, it is unlikely that a person has an additional disease. However, it does happen and your health care practitioner will advise you on this matter. Some examples of conditions that cause fatigue are thyroid function, anemia, depression, and perimenopause. Certain medications can cause fatigue. This is especially likely if you are currently on one of the interferon treatments. Again, if you are on an interferon-based treatment, ask your physician to rule out other explanations for your exhaustion. For example, an undiagnosed hypothyroid condition, which can be precipitated by interferon therapy, can exacerbate fatigue associated with interferon treatment.

Inadequate or poor quality of 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 7 to 9 hours of sleep per night. If you believe that insufficient sleep is contributing to your fatigue, gather more information. Sleep issues are well understood and much can be done to improve the quality of sleep.

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. Those times you feel more energy, resist the temptation to skip a rest break. This will only lead to increased inefficiency or fatigue later. Balance is the key. Pace yourself, take breaks, plan ahead, and delegate. Ask for help. My experience is that people want to help each other. It is not clear who benefits more, the person helping or the person being helped. Regardless, it can be mutually beneficial.

When at all possible, create short cuts. Organize your work areas so you can work more efficiently. There are plenty of available healthy food choices without having to cook from scratch. For instance, vegetables are available pre-cut and can be tossed into soup, a salad, or an omelet.

Exercise is probably the single most effective antidote for fatigue. This is hard to fathom, especially if getting out of bed is an ordeal. Remembering what was mentioned about the laws of energy, this is a perfect time to apply the “just do it” principle. I recently read about a study that 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 of the people were not instructed to do anything differently. The other half of the study group was instructed to substitute the phrase, “I am getting my energy back” every time they felt they were tired. The outcome of this study was that the people in the second group reported a significantly reduced fatigue level. This example of the power of positive thinking can be a useful tool in overcoming inertia.

Like most things, exercise is something that is best practiced in moderation. If you are unaccustomed to exercise, have a complicated medical condition, or are over 50 years old, it is advisable to speak to your health care provider before embarking on this. However, if you are ready to take this on, start slowly. As a tool for fatigue management, 10 to 15 minute intervals, 2 to 3 times daily, can really help fend off relentless fatigue. This is especially true if you can practice this in a relaxing environment, such as at a park. Remember that 5 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. There are many activities to choose from that can be re-energizing. 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, and Qigong 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.

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## HEPATITIS C: A Lesbian Issue

Is HCV a lesbian issue? It is if you are a lesbian, and you have the virus. In my case, I didn't always know that I was a lesbian. I suppose I did know, but I didn't choose to accept the implications until my husband was ill with AIDS. When we found out that he was HIV positive, we both went to work in the HIV/AIDS field. He was an outreach worker in San Mateo County and I was an HIV/AIDS counselor in Santa Clara County.

Immediately we were thrown in a gay/lesbian world. It sounds paradoxical, but at the same time he was becoming ill and I was unconditionally in love with him; I also realized that I would probably never be with another man again. When he died in 1993, I came out to the community, to my friends, and to my children.

I had one short relationship in 1994 and then I found out that--although I am HIV negative-I have HCV. I was in another two-year relationship with a woman who also has the dragon, but she wasn't ill like me. We broke up a year ago, partly because I was too fatigued to keep up with her.

I sit here alone today, at my trusty computer, contemplating the future. I'm not quite fifty, but the ravages of this disease have aged me beyond my years. I have early cirrhosis, so I'm probably not in any immediate danger of death. But I am very symptomatic, mostly from cryoglobulinemia, a blood disease caused by the HCV. I have chronic, intractable pain and severe, intermittent fatigue. But I also have my good days, and sometimes even good weeks.

Even though I'm ill and don't have much money, I could still be a good catch in a lot of ways. I'm still fairly attractive (If I do say so myself!), I'm intelligent, well read, and fun. That is, when I'm not too sick to enjoy life. My three children are all grown. I love women. I guess you would call me a femme, although that's mostly just habit from living so many years in a heterosexual world.

Yet, I haven't even tried to date. I know that many people are scared of HCV and I let that scare me off. I have a new appreciation for what HIV positive people go through. Whether we have HIV or HCV, there is definitely stigma out there to overcome. But overcome it we must. Most of us are too young, and too feisty to just pull the covers over our heads and hide. The odds of acquiring HCV from sex are extremely low, and probably non-existent for lesbian sex that doesn't include S/M or sharing menstrual blood. Besides, safe sex, with a little imagination, can be a very pleasurable experience.

Common sense tells me that there are other lesbians out there in the same position. You are possibly sick, lonely, and wistful like me. If you feel that HCV or HIV is your lesbian issue too, and you want someone to talk with, send me a line. I'd love to hear from you.

Bev Davis, ([brezybev@pacbell.net](mailto:brezybev@pacbell.net))

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## **Highlights in Liver Disease -** *From Patients Network Service*

### **Interferon Induction Therapy Increases Response Rate for African-Americans**

In general, African-Americans have more resistant HCV disease, with lower response rates to therapy compared to Caucasians. But a study by Firdous Siddiqui, M.D. at Wayne State University in Detroit shows that high dose induction therapy can clear virus in African-Americans at rates comparable to standard doses in Caucasians.

The study involved 43 previously untreated African American patients. They received induction therapy of 5 million units of interferon alfa-2b daily for four weeks, followed by 3 million units three times a week for eight weeks. Ten patients withdrew from the study before week 12. Results were compared to other African-American and Caucasian patients treated in the same setting with standard therapy (3 million units three times a week).

Dr. Siddiqui tested patients' levels of HCV RNA at 12 weeks. Of the 33 remaining patients receiving induction therapy, 33% (11/33) had cleared the virus from their blood by this time. These results greatly exceeded the response of a control group of African-Americans on standard doses, who had a 9% response rate (5/55). It also compared favorably to the 35% (14/40) response rate of Caucasians who had been treated with 3 million units three times a week.

However, induction dosing caused twice as many patients to withdraw from treatment: 23% vs. 10% of patients on standard doses.

The authors conclude that a more intensive regimen of interferon can improve the response rate for African-Americans, but withdrawal rates increase with the intensified dosing of induction therapy.

### **Anti-Oxidant Vitamins Delay Ribavirin-Related Anemia in Patients on Combination Therapy**

Patients on combination therapy who took the antioxidant vitamins C and E delayed the onset of anemia. Hemolytic anemia is a serious side effect of combination therapy, attributable to the ribavirin component in the combination. This complication necessitates a reduction in the ribavirin dose for about 15% of all patients, according to Edward Piken, M.D., Director of Research at South Bay Gastroenterology in Torrance, California.

"Patients become anemic: they feel short of breath, become weaker, are unable to do their normal workload," Dr. Piken says. One hypothesis is that ribavirin accumulates in red blood cells. "The red cells, because of the medications, are under what's called an oxidative stress, and the red cells break down at an earlier point in their life cycle."

To investigate a solution to this problem, Dr. Piken enrolled 12 previously untreated HCV patients in a study to look at the effects of antioxidant vitamins on anemia. Patients received 1,200 milligrams of ribavirin daily along with 3 million units of interferon alfa-2b three times a week. They also took two common over the counter vitamins daily - 1000 milligrams of vitamin C and 800 IU (international units) of vitamin E. "We chose them because they have essentially no side effects, and many people are already taking them," Dr. Piken says. Results were compared to a control group of 14 relapse patients who received combination therapy without any antioxidants.

According to Dr. Piken, patients receiving the antioxidants showed an initial benefit from the vitamins, but that benefit declined by the end of three months of treatment. The antioxidants "appear to delay the onset and severity of the anemia, and patients receiving antioxidants do not require [ribavirin] dose reductions, compared to 22% of the people in the control group," he says.

Dr. Piken says the results merit further research. "We plan to run a larger study and also are currently making a decision on which type of antioxidant to use," he says. "We would like to use more bio-available and perhaps stronger antioxidants. The forms of the vitamins, particularly C, could be improved to a more bio-available vitamin C."

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Source: <http://www.wellweb.com> - WellWeb - The Patient's Network. A website that covers hepatitis C as well as other health issues. **HIGHLY RECOMMENDED!**

### Treatment Advocate - continued from page 1 -

AST levels fluctuate in response to the extent of cellular necrosis (cell death) and therefore may be temporarily and minimally elevated early in the disease process, and extremely elevated during the most acute phase. Depending on when the initial sample was drawn, AST levels can rise- indicating increasing disease severity and tissue damage- or fall- indicating disease resolution and tissue repair. Thus, the relative change in AST values serves as a reliable monitoring mechanism.

Maximum elevations are associated with certain diseases and conditions. For example, very high elevations (more than 20 times normal) may indicate acute viral hepatitis, severe skeletal muscle trauma, extensive surgery, drug-induced hepatic injury, and severe liver congestion. High levels (ranging from 10 to 20 times normal) may indicate severe myocardial infarction (heart attack), severe infectious mononucleosis, and alcoholic cirrhosis. High levels may also occur during the resolving stages of conditions that cause maximal elevations. Moderate-to-high levels (ranging from 5 to 10 times normal) may indicate chronic hepatitis and other conditions. Low-to-moderate levels (ranging from 2 to 5 times normal) may indicate metastatic hepatic tumors, acute pancreatitis, pulmonary emboli, alcohol withdrawal syndrome, and fatty liver (steatosis).

#### **ALT (Alanine aminotransferase serum)**

ALT, an enzyme appears in liver cells, with lesser amounts in the kidneys, heart, and skeletal muscles, and is a relatively specific indicator of acute liver cell damage. When such damage occurs, ALT is released from the liver cells into the bloodstream, often before jaundice appears, resulting in abnormally high serum levels that may not return to normal for days or weeks. The purpose of this blood serum test is to help detect and evaluate treatment of acute hepatic disease, especially hepatitis, and cirrhosis without jaundice. To help distinguish between myocardial (heart) and liver tissue damage (used with the AST enzyme test). Also to assess hepatotoxicity of some drugs.

ALT levels by a commonly used method range from 10 to 32 U/L; in women, from 9 to 24 U/L. (There do exist differing ranges used by various laboratories.) The normal range for infants is twice that of adults. Very high ALT levels (up to 50 times normal) suggest viral or severe drug-induced hepatitis, or other hepatic disease with extensive necrosis (death of liver cells). (AST levels are also elevated but usually to a lesser degree.) Moderate-to-high levels may indicate infectious mononucleosis, chronic hepatitis, intrahepatic cholestasis or cholecystitis, early or improving acute viral hepatitis, or severe hepatic congestion due to heart failure. Slight-to-moderate elevations of ALT (usually with higher increases in AST levels) may appear in any condition that produces acute hepatocellular (liver cell) injury, such as active cirrhosis, and drug-induced or alcoholic hepatitis. Marginal elevations occasionally occur in acute myocardial infarction (heart attack), reflecting secondary hepatic congestion or the release of small amounts of ALT from heart tissue. Many medications produce hepatic injury by competitively interfering with cellular metabolism. Falsely elevated ALT levels can follow use of barbiturates, narcotics, methotrexate, chlorpromazine, salicylates (aspirin), and other drugs that affect the liver.

Be Aware: Serum liver enzymes can create confusion for both patients and physicians for these tests are highly sensitive, but very nonspecific. Tests commonly referred to as liver function tests or LFTs do not actually determine liver function. Instead, they are static, primarily diagnostic parameters that serve to detect liver disease rather than quantitate liver function.

Rather than liver function tests, it is more useful to refer to these tests as serum liver tests and to mentally categorize them according to the pathophysiologic processes they truly reflect. The serum liver enzyme AST (formerly known as SGOT) and ALT (formerly known as SGPT) are primarily nonspecific markers of necrosis (cell/tissue death) and inflammation, whereas alkaline phosphatase (AP), gamma glutamyl transpeptidase (GGT) and 5'-nucleotidase (5'-NT) are nonspecific indicators of cholestasis (stoppage or suppression of the flow of bile). The serum albumin level and prothrombin time (PT) reflect hepatic synthetic ability, but are too static to quantitate liver function. Likewise, the serum bilirubin level reflects prehepatic, intrahepatic, and posthepatic factors, making the differential diagnosis of jaundice complex. Of the available liver tests, only a handful such as the C-aminopyrine breath test and galactose elimination capacity (GEC) truly quantitate liver function.

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**QUESTIONS TO ASK ABOUT TESTS AND PROCEDURES:**

1. How will this test aid in the diagnosis or therapy of my illness?
2. Will I need to be hospitalized?
3. Will other tests need to be done?
4. Will I need other tests in the future, or will I need this test repeated?
5. Are there simpler or less risky ways to evaluate my symptoms?
6. What if no diagnosis is made? Will you then simply observe me to see if the symptoms go away, or will you possibly have to go as far as exploratory surgery?
7. Do I have any particular risk factors for any of the tests?
8. Will my insurance cover the costs of tests done either inside or outside of the hospital?
9. Please explain to me exactly what you are going to do during this test before you start.
10. How long will it take?
11. Can I expect any unusual feelings, pain, or sensations?
12. Will I need someone to drive me home after the procedure is over, or will it be safe to drive myself?
13. What are the risks of this test, and how often do they happen? Am I at particular risk?
14. Are there special instructions to follow before or after this test?
15. Will I need to be seen after the test is done?
16. Will you call me with the test results, and can I get a copy of them for my personal records?
17. How will I know if a complication is occurring?
18. What should I do if I experience a complication?
19. Are there any side effects I should be concerned about?

**Musculoskeletal pain and fatigue are associated with chronic hepatitis C** -a report of 239 hepatology clinic patients. **OBJECTIVE:** The aim of this study was to identify the frequency of fatigue and musculoskeletal pain in hepatitis C compared with other liver diseases. **METHODS:** Hepatology outpatients were evaluated by questionnaire for musculoskeletal pain and fatigue. Charts were reviewed for diagnoses, aminotransferases, histology, treatment, and presence of hepatitis C by second generation ELISA and/or polymerase chain reaction. The frequency of symptoms in patients with and without hepatitis C were compared. **RESULTS:** In 239 patients, musculoskeletal pain was present in 70% and fatigue in 56%. Backache was the most common complaint (54%), followed by morning stiffness (45%), arthralgia (42%), myalgia (38%), neck pain (33%), pain "all over" (21%), and subjective joint swelling (20%). Diffuse body pain was present in 23% on a pain diagram and was strongly associated with fatigue. There was a significant association between hepatitis C positivity and the presence of musculoskeletal pain (81% of HCV-positive compared with 56% of HCV-negative patients, respectively; and fatigue (67% compared with 44%). Musculoskeletal pain was more frequent among patients with isolated hepatitis C infection than among patients with isolated hepatitis B or alcoholic liver disease (91%, 59%, and 48%, respectively). Similarly, fatigue was more frequent among patients with isolated hepatitis C than among those with isolated alcoholic liver disease or hepatitis B (66%, 30%, and 29%, respectively). There was no relationship between musculoskeletal complaints and possible route of acquiring hepatitis C, levels of aminotransferases, liver disease severity on biopsy, or interferon treatment. **CONCLUSIONS:** Musculoskeletal pain and fatigue are frequent in hepatology clinic attendees, particularly those with hepatitis C and are unrelated to severity of liver disease, route of infection, or interferon therapy **SOURCE:** *American Journal of Gastroenterology 1999 May*

**Pegasys Dosing Comparable For Cirrhotic And Non-Cirrhotic Patients With Chronic Hep C** -Data presented at Digestive Disease Week demonstrate that that Hoffmann-La Roche Inc.'s Pegasys(TM) (Peginterferon alfa-2a), an investigational, longer-lasting form of interferon, when administered once-weekly in cirrhotic patients reaches the same blood levels as non-cirrhotic patients. Twenty percent of people with hepatitis C develop cirrhosis of the liver - a complication that makes those the most difficult hepatitis C patients to treat. Cirrhosis causes the filtering process of the liver to slow down, affecting its ability to process medication

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### *Treatment Advocate - continued from page 6 -*

Sustained response rates for cirrhotic patients treated with currently marketed interferon are substantially lower than in patients without cirrhosis. Forty patients received either 90 or 180 mcg. of Pegasys once-weekly for 48 weeks and were followed by a 24-week observation period. Blood samples were collected after the first dose of Pegasys and after the dose at 48 weeks of treatment. Blood levels of Pegasys in the cirrhotic patients were similar to those reported by healthy volunteers. In Phase II clinical trials adverse events with Pegasys appear to be similar to those seen with traditional interferon regimens, such as fatigue, headache, myalgia/arthralgia, flu-like symptoms, nausea/vomiting, injection site reactions, fever, chills, diarrhea, partial alopecia, abdominal pain, depression, irritability, insomnia, dizziness and anorexia. Although dose-dependent reduction of white blood cells is more frequent with Pegasys than currently marketed interferon, this does not appear to be related to an increased risk of infection. Pegylation is the process of attaching one or more hair-like strands of an inert, synthetic polymer called polyethylene glycol (PEG) to another molecule. The PEG attachment encircles the protein and disguises it from the human metabolic system. Pegylation provides a rapid and sustained delivery of this optimised interferon, changing its absorption characteristics and delaying its metabolism. *SOURCE: Doctor's Guide to Medical News*

**Blood-Letting Improves Hepatitis C Patient Response To Interferon** -More patients infected with the hepatitis C virus (HCV) might respond to interferon if their serum iron levels were reduced prior to the start of treatment, according to a new study presented yesterday by Robert Fontana, MD, of the University of Michigan, Ann Arbor, MI. at Digestive Diseases Week, in Orlando, FL. The study included 82 treatment-naive, non-cirrhotic men and women with abnormal serum alanine transaminase values and detectable serum levels of HCV RNA. Half of the patients in the study received standard interferon therapy (3 MU three times a week for 24 weeks), while the other half received interferon therapy after a phlebotomy performed to induce a state of mild iron deficiency. At the end of treatment, complete virologic response, or total loss of HCV RNA in the blood, was achieved in 55 percent of the patients (22/40) who received the combination regimen compared to only about 17 percent of the patients who received only interferon (seven of 42). These findings validate some previous, smaller studies that suggested lower circulating iron levels improved response to interferon in previously untreated patients, Dr. Fontana said. However, iron reduction will require further study in even larger trials before it can be instituted as a clinical measure. In particular, it would be interesting to see whether the treatment response holds up in the long term, he said.

*SOURCE: Doctor's Guide to Medical News*

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### *HealthWise - continued from page 2 -*

Some other causes of fatigue are poor posture, stress, worry, chronic boredom and grief. Poor nutrition and dehydration can also lead to excessive fatigue. These need to be addressed if any of these are evident in your life. Stress reduction, sufficient water intake, a balanced diet, relaxation, and having fun are all-important factors in maintaining a healthy lifestyle.

If you have tried some of these ideas and you still find yourself exhausted, talk to your health care provider. If fatigue is interfering with your life, you may need medication. Some physicians prescribe antidepressants for fatigue management. A number of patients prefer to look for alternative interventions. These can include Traditional Chinese Medicine, herbs, hypnosis, homeopathy, chiropractic medicine, etc. The research on these treatments is scanty at best. One caveat is to talk to your physician before ingesting any potential remedy. Herbs and supplements are potent, even though they are natural. Arsenic is natural, but it is still poison. Take it upon yourself to be informed about everything that goes into your body.

Attitude cannot cure fatigue, but it can be a powerful ally. When all else fails, laugh. There is no doubt about it; fatigue puts a damper on life. However, humor and fatigue is a more tolerable than misery and fatigue. The choice is yours.

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<sup>1</sup> For more information contact The National Sleep Foundation at 729 15<sup>th</sup> St., NW, 4<sup>th</sup> Floor, Washington D.C. <[www.sleepfoundation.org](http://www.sleepfoundation.org)>