

HCV ADVOCATE

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Hepatitis C Support Project

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HealthWise

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Living with chronic hepatitis C infection often brings a vast array of symptoms. The extremes seem to range from those who are totally asymptomatic to those with constant health problems. These extremes also apply to the side effects of interferon monotherapy and interferon plus ribavirin therapy. At least one side effect is reported by 90% of patients on interferon monotherapy. There is no reason to believe that this percentage would be any less for patients being treated with combination therapy, which in fact is associated with more prominent side effects. The purpose of this is to review a few suggestions on how to manage some of the symptoms and side effects associated with treatment of chronic HCV infection. For those interested in herbal therapy, speak to your care provider and try to find an expert in herbs.

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LOVE IN THE TIME OF HEPATITIS C

My birth name is Richard Matthew Nolan. I'm Irish and Italian. My father was a newspaper writer straight out of Lowell, Mass and my mother was an Italian daughter within a well-known family in Pittsburgh, PA.

I went to parochial schools in the City and everybody I knew held names like Gallagher, Vallanoti, Firshia, Murphy and the like. My whole life was steeped in the Catholic culture and childhood was alive with all the varied events a kid in SF would naturally encounter in childhood and adolescent adventures.

In my late adolescence, some few years after my family's flight to the suburbs, I was a vigorous participant in the love, peace and happiness years of the sixties. This of necessity involved and re-involved my life in pursuit of traveling, girls, music, and general misadventure with chemicals. The consequences of youth eventually led to my induction physical for the Viet-era Army, and subsequent dismissal from consideration. The reason: a virulent case of an odd hepatitis called in those days for the hepatitis it wasn't; Non-A, Non-B.

For the next ten years after 1967, the chapters of my young history became varied incarnations of substance addiction ranging from amphetamine and alcohol to

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HCV ADVOCATE

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Hep A & Hep B vaccines - It is strongly recommended that people with Hep C get vaccinated against hepatitis A (HAV) & hepatitis B (HBV) since severe HAV & HBV infections have been reported in people with hepatitis C. The hepatitis A vaccine consists of two doses within a six month period and the hepatitis B vaccine requires three doses within a six month period. Both vaccines are considered safe and effective - *Source: HCSP Information Packet*

The most commonly reported adverse events due to interferon related therapy are the initial flu-like symptoms that occur after the first injection. Fortunately, these usually subside quite quickly and often occur only once.

Here are a few suggestions:

- Ask your care provider about premedicating with acetaminophen (650mg).
- Drink lots of water throughout day.
- Put layers of blankets and clothes near your bed to manage chills.
- Have water and crackers near your bedside for nausea and dry mouth.
- Do not schedule first injection the night before a major event.
- Remember these initial reactions are only temporary.

Fatigue is another commonly reported side effect. Next month, there will be a more in depth article on fatigue management. A few tips until then:

- Rule out other causes of fatigue, such as thyroid abnormalities, diabetes, anemia, depression, sleep disorders, dehydration, etc.
- Adjust your injection time to accommodate your fatigue cycle.
- Make sure you are getting sufficient sleep. The National Sleep Foundation states that the average adult needs 7 to 9 hours a sleep per night.
- Drink sufficient water and other nutritional liquids (10 to 16 glasses per day).
- Use moderate exercise to reenergize. A ten-minute walk can work wonders, particularly a walk in a scenic area. Stretching, especially for those confined to a desk for hours, can be helpful.
- Consider Qigong, Tai Chi, or Yoga.
- Cut back on responsibilities.
- Look for short-cuts.
- Ask for help.
- Try meditation.

Headaches, muscle aches, and joint aches are sometimes reported. Suggestions for these side effects are:

- Rule out other causes for the complaints.
- Ask your care provider about the use of nonprescription medications such as acetaminophen, as well as prescription medications.
- Consider one of the many different types of massage therapy.

Skin complaints are common. These include itching, rashes, dry skin, and injection reactions.

- Drink sufficient water.
- Use hypoallergenic lotions, especially immediately following bathing.
- Report rashes to your care provider; rule out allergic reaction to interferon.
- Rotate injection sites; report any unusual injection reaction such as inflammation.
- Use sun protection.

Hair loss:

- Avoid harsh chemicals and tight braiding.
- Avoid over-drying hair with frequent washing and sun exposure.

Nausea, decreased appetite and weight loss:

- Notify your care provider of any significant weight loss.
- Eat small frequent meals.
- Avoid acidic food.
- Sip weak tea, ginger ale, chicken broth.
- Try popsicles, dry toast or crackers.
- Boost your nutritional intake with fruit, yogurt, and soy protein-based smoothies.
- Add powdered milk to milk shakes, hot cereal, regular milk, soups, and mashed potatoes.
- Spread peanut butter on bananas, apples, celery, rice cakes, etc.
- Consult a nutritionist for more ideas.

Depression, malaise, cognitive changes, impaired concentration:

- Discuss these issues with your care provider; the use of prescription antidepressants or
- St. John's Wort might be warranted.

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Treatment Advocate

Joe Shaw

At first when I was diagnosed with Hep C in January 1998, I had no idea where to turn for answers and no idea what questions to ask my doctor. I was scared and didn't know what was going to happen to me. I'm sure my experience is not so different from most other people. Although Hepatitis C has been around for a long time, it was only identified and labeled as such about ten years ago. It has just begun to be studied and there's not a lot of information out there for recently diagnosed patients. What is out there can be confusing or contradictory. I suggest trying to find out all you can about Hep C. The internet is a good place to start. If you don't have a computer or can't afford internet service, most libraries provide access for their patrons. You can also search out medical journals that relate to Hepatitis C such as the Journal of Hepatology. We're our own best advocates and armed with knowledge, we can better fight this disease. Some friends of mine with Hep C know more about their disease than most doctors do. And I've had the opportunity to share new treatment knowledge with several physicians. You should see the surprise in their eyes when you know some little tidbit that they think patients don't know about. So get started gathering information. Make a file with your medical records in it. Make another file with treatment information, copies of medical studies and other pertinent Hep C info. I keep my old issues of the Hep C advocate in their own file. You never know when you may have to refer to something you've read when you talk to your doctor.

To that end, I am offering a couple of lists of questions that are helpful during a doctor's visit. These questions come from Peppermint Patti's website, an amazing source of information for those with Hep C. You can find her site at: <http://members.bellatlantic.net/~clotho/>

SOME QUESTIONS TO ASK THE DOCTOR:

1. Is there a possibility the diagnosis is incorrect? It does happen occasionally you know.
2. Are there any tests (or additional) tests available to confirm the diagnosis or to show the severity of the illness?
3. What organs of my body are involved and in what way? Will the damage to these organs be progressive? If the damage will be progressive, be sure to ask the usual time course over which this occurs. Ask for drawings and down-to-earth terms to help you better understand what is going on with your body.
4. What other organs of my body can I expect to become involved as a consequence of the illness?
5. What are the possible ways I could have gotten this illness?
6. What are the possibilities of my passing this illness on to others, and in what ways? Should I worry about my family catching it? What about sexual transmission? How can I minimize the risk to others?
7. What complications am I at risk for and at what stage of the disease?
8. What symptoms or change in symptoms should I be concerned about? You need to gain some perspective on your illness and not become obsessed with every little ache and pain or change in symptoms. Find out which symptoms are important, and which you need to watch out for.
9. Are there any organizations that can provide more information about my illness or help with the problems that result from my disease? There may also be local support groups which your doctor can direct you to. He may also know of certain medical centers and research facilities who have compiled sources of information about your disease or who can inform you of new or experimental therapies.
10. What medications are available to control the disease? Do you ever conduct or can you refer me to someone who performs experimental or research trials?
11. What are the risks and benefits of taking this medication at this point in my illness?
12. If I am unable to tolerate this medication or if it is ineffective, are alternative therapies available?
13. How will I know if I am responding to treatment and how long will I need treatment?
14. Is transplant an alternative at my stage of the illness? Would you or when would you recommend it?

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15. Are there diet changes or other measures I can take to lessen the effects of the disease?
16. How frequently do I need to be seen by a doctor?
17. How do I contact you in an emergency?
18. Can I do any home monitoring of my illness that might reduce the need for office visits?
19. Will I be able to continue working?
20. Can I expect to have to take many sick days?
21. Will this illness affect my ability to obtain life or health insurance?
22. Ask questions about the specific hobbies, sports, family and social activities that the disease may have an effect on.
23. Will the drugs I am taking interact with other medications or impair my ability to have sex?
24. What are your recommendations regarding alcohol, smoking, aspirin/tylenol/motrin, other prescription or non-prescription drugs?
25. Will the illness or the treatment interfere with my ability to have children?
26. Will the disease or the treatment be disfiguring? (Weight gain/loss, hair loss, etc.)

QUESTIONS TO ASK ABOUT YOUR MEDICATION

1. What types of drugs are used in this disease, and how do they work?
2. Why are you choosing these particular drugs for me?
3. What are the chances that the drugs I am receiving will "cure" me?
4. If the drugs do not cure my illness, what effect should I expect from them?
5. How long will I have to take medication?
6. Can you give me a plan for what we will do if this treatment doesn't work?
7. What is the dosing interval? What are the best days/best time of day to take the drug?
8. Are there any special instructions for taking the drugs?
9. Are there interactions with other drugs, foods, sunlight, alcohol?
10. What are the side effects of this drug and how often do they occur?
11. What are the toxic effects? Be sure to clarify what the dangerous side effects are, how common they are, and if you are in a high-risk group and how to recognize it.
12. Is there a wide gap between toxic and therapeutic amounts of this drug?
13. If someone accidentally takes my drug, or I accidentally take too much, what is the best course of action?
14. Can I take generic drugs?
15. Is there any other way to reduce the expense of taking this drug? Many medications are very expensive and are not covered under most insurance plans. The cost may be a hardship for you. Many states and pharmaceutical companies have Pharmacy Assistance Programs. Both Schering-Plough Corporation (800-822-7000) and Amgen (888-508-8088) have patient assistance programs.
16. What if I become pregnant while taking this drug?
17. Does this drug interfere with sex in any way?

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Love in the Time of Hep C - continued from page 1 -

opiates and Valium. After a minor arrest or two I found myself rather shoehorned into long-term residential treatment. I was in the treatment program for almost three years, and having established a good, solid recovery, I worked as a counselor within drug treatment.

I went to school, eventually earning a Doctorate and licensure as a Psychotherapist. All during the first twenty years of my recovery the one thing I dismissed out of hand were periodic physicals, the results of which always yielded high enzyme levels and lowering platelet counts. I was told not to worry about it and so I didn't, assuming that my liver was, as Dylan Thomas said, "A sly organ, that I may have damaged just a little bit, but not enough so's to notice."

I was working at the VA Hospital when I switched to a UCSF position there and was tested positive for Hep C (In 1990 the test for hepatitis having then arrived). Still, I had no symptoms whatsoever. In 1994 I began to notice a sense of fatigue, but looking around me at the Federal Civil Service workers, who themselves seemed fairly drowsy to begin with. I thought I just must be getting older and -unwelcome thought - maybe acquiring the fabled Civil Service malaise. Who knew?

In 1996 my fatigue symptoms worsened to the point that I would actually fall asleep in a stall in the men's room which became a brief respite from the demands of so many patients and tasks. My joints ached quite a bit and the sense of tiredness was beyond fatigue. It felt almost painful.

In the Fall of 1996 I told my Medical Director how I felt and she recommended a liver guy. I learned with my first biopsy I was Stage IV with cirrhosis. Also, I was losing platelets rapidly and my doctor was concerned. He told me about interferon, but was not very enthusiastic about it. His presentation, in fact, was so lackluster I decided to contact UCSF for their opinion. That's when I was screened and accepted onto a protocol using combination therapy.

The Interferon/Ribavirin combo was pretty gruesome. Most of my Hep C friends consider the treatment miserable at best, but in my case, sticking a "rocket" in my leg or arm was a very unsettling experience and brought unwelcome echoes from distant days of addiction. I attempted to see patients and teach classes but I was not running with the traffic.

My Medical Director was concerned that I was shaking and rattling around in my chair at staff meetings. Combination therapy really smacks my cognitive processing. I would conduct a class driven by that adrenal energy imparted by anxiety and the loathsome spasms of Interferon running up and down my back were...well...forget about it!

At the VA, Dr. Teresa Wright and Karen Cohen, RN really gave me a good deal of support and help. And they are wonderful. I got through one protocol and then into another for partial or non-responders. The day I met my Hep C Support Group friends was the first day of real hope and instant camaraderie. I've gotten a lot of good support and had a lot of good laughs hanging with HCV folks.

I also began attending 12-step meetings at noon, and they have been my mainstays for support not only in remaining clean, but also in dealing with this illness. So many of my old friends now have the virus. In the crowd or "crew" I ran around with, almost everyone has Hep C, and some have died from it. We were all young, just eighteen and nineteen years old. Ironically, the illness which would have prompted the Draft Board to induct my Grammy before me ended up thirty years later to become the dragon we HCV cats know as the roar of hepatitis C.

I may have led a bit of a reckless life as a youngster, but I'm not responsible for my disease of addiction. Rather, I'm bound by life's dictates to be responsible for continued recovery. And, I can carry out those orders. The same with Hep C. I'm responsible in seeking the best treatment I can afford and I don't get mobbed over by doctor's opinions. I find information out, too, and work with my doctors.

Two years ago, in my Fellowship, I didn't hear too many recovering people talk about their Hep C. Now, they do. And I'm pleased to say that in 12-step meetings I attend, people there offer the help we all need. Although my Hep C has clotheslined my therapist career, I can still help by volunteering. For anyone with Hep C, support groups really help.

Hep C recovery depends not only on the medicine but also on the goodwill and friendships of others in similar straits. I'm really grateful that I've run into Alan, Barry, and the great staff of UCSF out at Ft. Miley. I treasure my new friends and my spiritual higher power.

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18. Do the medications cause sterility?
19. Can the drug be stopped suddenly or doses missed without any ill effects?
20. What should I do if I suffer a side-effect or a drug?

Research Findings Suggest Potent, Broad-Spectrum Antiviral Activity for Vertex's Investigational IMPDH Inhibitor VX-497 Jerusalem, Israel, March 25, 1999 - The investigational drug VX-497 may have potent, broad-spectrum antiviral activity, according to laboratory results presented by scientists from Vertex Pharmaceuticals Incorporated at the 12th International Conference on Antiviral Research held in Jerusalem, Israel. VX-497's activity against viruses in cell culture was compared to that of the antiviral compound ribavirin, both alone and in combination with interferon-alpha. Vertex is evaluating VX-497 in Phase II clinical trials for HCV infection and as an immunosuppressant for psoriasis. In one comparative study of the activity of VX-497 versus ribavirin against selected DNA and RNA viruses in vitro, VX-497 was found to be 15-to 186-fold more potent than ribavirin against hepatitis B virus, human cytomegalovirus, respiratory syncytial virus, herpes simplex virus type 1, parainfluenza-3 virus, and Venezuelan equine encephalitis virus. Preliminary data suggests VX-497 may be more potent than ribavirin against bovine viral diarrhea, a flavivirus. Hepatitis C virus (HCV), also a flavivirus, is closely related to BVDV in genome organization. SOURCE: Vertex Press Release

U.S. Organ Donation Up 5.6 Percent - Organ donations rose 5.6 percent last year, aided by recruitment of more older donors and closer cooperation between hospitals and transplant coordinators, the government reports. The increase to 5,479 donors enabled about 600 more transplants in 1998 than in 1997, the Department of Health and Human Services said. About 4,000 people die each year waiting for a transplant. At the end of 1998, there were 64,423 people waiting, a number that has been growing much faster than donation has. The increase was most dramatic among donors age 60 and older, jumping 10.8 percent to 782 donors. Donations also rose 9.6 percent for donors aged 40 to 59. It edged up only slightly for younger groups. HHS also credited a new federal rule that requires hospitals to report all deaths to the organ banks that are responsible for approaching families about donation and coordinating transplants. Experts believe some 3,000 to 4,000 potential donor families are never asked about donation. The rule aims to ensure that hospitals do not overlook patients who may make suitable donors.

Long-term administration of interferon-alpha in non-responder patients with chronic hepatitis C: follow-up of liver fibrosis over 5 years In chronic hepatitis C, previous data have shown that short-term treatment with interferon-alpha (IFN-alpha) can reduce collagen deposition in the liver independently of the viral response. The aim of this work was to determine, in non-responder patients, the long-term effect of IFN-alpha on liver fibrosis according to the total administered dose and the fibrotic stage. Regardless of the dose and duration of IFN-alpha therapy, a slight decrease of fibrosis was observed in patients 5 years after starting treatment, In cirrhotic patients, a short treatment induced an improvement followed by a relapse of fibrosis in 57%, and only 43% of patients showed constant collagen regression over the 5 years of follow-up. On the contrary, after prolonged therapy, a progressive and significant decrease occurred throughout the follow-up period in all patients. Long-term treatment with IFN-alpha is therefore associated with regression of liver fibrosis particularly in cirrhotic patients. SOURCE: JOURNAL OF VIRAL HEPATITIS MARCH 1999

Severe exacerbation of asthma: A new side effect of interferon-alpha in patients with asthma and chronic hepatitis C. Interferon-alpha is used by physicians to treat numerous common medical disorders; however, therapy is often limited by side effects, Pulmonary complications, such as interstitial pneumonitis and bronchiolitis obliterans organizing pneumonia, have been described in patients receiving interferon-alpha therapy. Two patients with mild asthma in whom treatment with interferon-alpha for chronic hepatitis C resulted in exacerbation of the underlying asthma. The severe asthmatic symptoms resolved promptly after use of interferon-alpha was discontinued and corticosteroid therapy was initiated. Repeated treatment with interferon-alpha several months later resulted in a rapid, more severe exacerbation of asthma in both patients. Patients undergoing therapy with interferon-alpha, especially those with chronic asthma, should be monitored closely for pulmonary symptoms. If these symptoms develop, patients should be instructed to discontinue use

Love in the Time of Hep C - continued from page 5 -

I've gone through the death of my father, a painful breakup with a really stand-up young woman, the loss of my profession, blindness in my left eye. At times even my recovery has been in peril, but today I'm feeling better.

I've won some acceptance of my lot. I get pissed off at some newer limitations I encounter, but I'm adapting and within this adaptation, believe it or not, I'm grateful for many new adventures.

Rich Nolan
June, 1999

HealthWise - continued from page 2 -

- Join a support group.
- Consider meditation, moderate exercise, Tai Chi, Qigong, Yoga, stress management
- Reserve your "best times" for activities that require the most concentration.
- Find ways to laugh. Humor therapy has no side effects except perhaps a few laughs.

A word about impaired sexuality and self-injection concerns. These two areas are sometimes difficult to talk about. Those with a history of injection drug use may have some very strong feeling about self-injection with interferon. This is a normal, healthy response. For those who have worked hard to maintain recovery from substance use, self-injection may pose a slight hurdle. Attendance at support groups and talking about it have helped some people. The same applies to sexuality issues. In this case, talk to your care provider and rule out other causes of impaired sexual function. A reminder that reliable birth control needs to be practiced by both males and females undergoing interferon monotherapy or interferon plus ribavirin. Ribavirin is known to cause birth defects, and birth control is strongly recommended for 6 months following treatment.

Some side effects of interferon therapy that need to be reported immediately to the physician:

- Suicidal thoughts
- Chest pain or shortness of breath
- Excessive diarrhea or vomiting
- Seizures
- Hearing loss or ringing in the ears
- Eye pain or vision problems
- Any other abnormal occurrences of concern

This brief overview of symptom and side effect management is meant to be a resource rather than a remedy. The potential value of support groups cannot be overstressed. Patients are among the world's experts on how to manage this disease and its treatment. Your health care provider can also provide you with useful information. Some other resources are:

- The Hepatitis C Helpline (415) 834-4100 This is staffed by HCV+ volunteers who will try to answer messages left on the helpline's voice mail.
- Amgen's Compass program – 888-508-8088 A toll-free resource sponsored by Amgen that offers educational resources and therapy support materials to anyone who calls.
- Schering's Be in Charge program – 888-437-2608 This toll-free program is sponsored by Schering and is open to enrolled patients on Intron-A or Rebetron.

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