

FOR YOUR HEALTH —Start Forgiving Others

Human feelings or emotions can cause stress on a regular basis when they consist of anger or resentment towards someone. Although these are natural emotions which we will all experience, hanging on to any one of these emotions may have a negative impact on your health. Several research studies point towards the Power To Forgive, as reflected in the web site we found on Forgiveness Research at www.forgiving.org.

According to some of the findings in their 46 funded research projects on various aspects of forgiveness, an observation demonstrated that the person who forgives is happier and healthier. Richard Fitzgibbons, author of "Anger and the Healing Power of Forgiveness: A Psychiatrist's View" cites these benefits to the one who forgives—*decreased levels of anger and hostility; increased feelings of love; improved ability to control anger; enhanced capacity to trust; freedom from the control of events of the past; no longer repeating negative behaviors; improved physical health; significant improvement in psychiatric disorders. One the other hand, one who cannot forgive may continue to suffer endlessly.*

Living with chronic liver disease, or any other health issue, has promoted each person to look at many aspects of their own lives and how health might be improved. Many with hepatitis C have been treated by their liver specialist with interferon, others have looked at complimentary or alternative approaches, even religion and spirituality may have entered ones life where it was not in existence before. Since anger and resentment are truly stress causers, we can only assume that they indeed adversely affect both physical and mental health and would interfere with our body's immune system's attempt at doing the best job for us.

Visit the web site www.forgiving.org and pledge forgiveness. Feel relief and a sense of a new beginning to your health and happiness.

Social Security Disability Thoughts

Claim Approval Rates Decline Slightly at SSA

Social Security disability claim approval rates declined slightly in 2003, according to figures published by the U.S. General Accountability Office (GAO) July 2, 2004.

- | | | |
|----------------------------|--------------|-------------------------|
| • Initial claim decision | 37% approved | 63% denied |
| • Reconsideration | 15% approved | 85% denied |
| • Administrative Law Judge | 61% approved | 39% denied or dismissed |

For comparison, the 2002 figures were:

- | | | |
|----------------------------|--------------|-------------------------|
| • Initial claim decision | 38% approved | 62% denied |
| • Reconsideration | 16% approved | 84% denied |
| • Administrative Law Judge | 61% approved | 39% denied or dismissed |

As of July 2004, approximately 10,562,000 people were receiving Social Security disability benefits in the United States, according to the Social Security Administration (SSA).

Sometimes a patient with hepatitis C cannot work because of the problems associated with the liver disease. Disability may be the only option to secure financial assistance.

The submittal and review of all responses from the government are critical to the outcome. According to one attorney, Alan J. Nuta (www.ssbenefits.com), the following are the most costly mistakes that can result in not receiving deserved benefits:

- Not applying for SSDI or SSI benefits soon enough.
- Taking "no" for an answer—not appealing a denial
- Not reapplying at a later date (after the appeal time has run out), just because there was a previous denial.
- Not requesting prior applications be reopened, gaining access to many months or years of back benefits.
- Not considering psychological aspects of physical illnesses and conditions.
- Not considering the side effects or medications.
- Not verifying that all medical records are in the file.
- Believing that a simple note from a doctor saying you are disabled is enough to win.
- Not going for regular treatments for claimed disabilities.
- Not applying for other benefits, e.g. veterans disability benefits, at the same time a Social Security claim is pending.
- Not reading denial notices carefully enough and thereby missing appeal deadlines.
- Thinking that it is too expensive to hire a lawyer.

Here are some very important resources to get you started:

Social Security home page:

<http://www.ssa.gov/disability/>

Online application forms:

<http://www.ssa.gov/disability/forms.htm>

How to contact Social Security:

<http://www.ssa.gov/reach.htm>

Over-the-Counter Medications Can Be Harmful Too!

Make sure that you inform your doctor about both prescription and non-prescription medications you are taking. Check to make sure that you are not duplicating a medication, like Tylenol for example, that may be contained in more than one medication you are taking. A good resource for your medication questions is your local pharmacist. They will be able to help you with answers to these questions, including drug interactions.



SUPPORT

ADVOCACY

COURAGE

HOPE

FAITH

COMMITMENT

PATIENT ADVOCACY COUNCIL

Volume IV, Issue 1

February 2005

PUBLISHED BY HEPATITIS FOUNDATION INTERNATIONAL

Is Treatment Part of Your New Year Plans?

For many people, a New Year is the time to reflect on many things, and health is no exception. For those with hepatitis C, it is often a treatment decision that has been held over due to the holidays and special vacations.

Being prepared for treatment and identifying all potential resources for support is important. Your family members and friends who you feel comfortable in confiding about your diagnosis should be well educated to help you by being understanding of some of the changes that may temporarily occur in your life during treatment.

Here are some great resources:

1. Depending on the treatment you have been prescribed, it is important that you recognize the pharmaceutical resources as a positive presence in your care. If you have been prescribed Peg-Intron, take a look at their treatment center online at <http://www.all-about-hepatitisc.com>. If you have been prescribed Pegasys, go to www.pegassist.com. Both companies also provide a toll-free number so that you can speak to a registered nurse, 24-hours per day. If a Starter Kit was not provided to you by your doctor or pharmacy, please contact the applicable pharmaceutical to order one. Great tools inside the kit.
2. Contact the *Hepatitis Foundation International* at 1-800-891-0707 to identify a support group in your area. Although you may not feel you would attend, having the information handy may be useful to you when you want support and education from a facilitator and other patients.
3. A telephone list of other patients who are willing and ready to talk by telephone is available from the *Hepatitis Foundation International*. Find out how this system works and in days you could be in phone contact with someone going through just what you are. Call 1-800-891-0707 and ask about PATS (Patient Advocacy Telephone System).
4. Log on to the internet and go through a classroom course on treatment at www.hcvandme.org. You can actually hear an audio presentation about side effects, understanding your liver, self-injection training and care of the medications. Supplies are free of charge.
5. Consider using a "Specialty Pharmacy" for your prescriptions. This group of pharmacies is becoming ever popular because of the services they offer not available through a local pharmacy. Specialty Pharmacies offer assistance with insurance authorization, direct shipment of your medications to your home, nursing support, and more at no additional cost to you. For a resource list of specialty pharmacies, please call the *Hepatitis Foundation International* at 1-800-891-0707.

ALT—Albumin-Lab Tests

Alanine aminotransferase (ALT) is an enzyme found mainly in the liver, but also in smaller amounts in the kidneys, heart, muscles, and pancreas. ALT formerly was called serum glutamic pyruvic transaminase (SGPT). ALT is measured to determine whether the liver is damaged or diseased. Low levels of ALT are normally found in the blood. However, when the liver is damaged or diseased, it releases ALT into the bloodstream, causing levels of the enzyme to rise. Although ALT is found in organs other than the liver, most increases in ALT levels are due to liver damage. The ALT test often is done along with other tests that can determine whether the liver is damaged, including aspartate aminotransferase (AST), alkaline phosphatase, lactate dehydrogenase (LDH), and bilirubin. Both ALT and AST levels are reliable indicators of liver damage.

Albumin is produced mainly in the liver. It helps keep the blood from leaking out of blood vessels. When albumin levels drop, fluid may collect in the ankles (pedal edema), lungs (pulmonary edema), or abdomen (ascites). Albumin also helps carry some medications and other substances through the blood and is important for tissue growth and healing. Albumin is one of several liver function tests.

Featured Resources

on the Web

Centers for Disease Control and Prevention - Hepatitis Branch www.cdc.gov/hepatitis/

National Institute of Diabetes & Digestive and Kidney Diseases (NIDDK) www.niddk.nih.gov

Hepatitis Foundation International www.HepatitisFoundation.org

American Liver Foundation www.liverfoundation.org

National AIDS Treatment Advocacy Project (NATAP) www.natap.org

California Hepatitis Resource Center www.hepatitisresources-calif.org

Hepatitis C Support Project www.hcvadvocate.org

Department of Veterans Affairs National Hepatitis C Program www.va.gov/hepatitisc

Finding current news on viral hepatitis:

California Hepatitis Resource Center (Home Page) www.hepatitisresources-calif.org

PR NewsWire (search keyword "hepatitis C" from Home Page)

www.prnewswire.com/news/

PATIENT ADVOCACY COUNCIL

Chair & CEO: Thelma K. Thiel

A project of:



504 Blick Drive
Silver Spring, MD 20904
(800) 891-0707
(301) 622-4200
www.hepatitisfoundation.org

Editor: Carol Craig

Supported through an unrestricted educational grant from Roche

Hepatitis C – A Sneaky Virus!

About 80% of infected people don't have any symptoms at all, and their liver shows only a little damage. Many of these people are diagnosed with hepatitis C after showing abnormal liver enzymes on routine blood tests. Other people—about 15% of those infected with the virus—develop cirrhosis after having the infection for 20 or 30 years. This is when the normal functioning liver is replaced by scar tissue. A smaller number of people develop liver cancer 20 to 40 years after infection. Some symptoms of hepatitis C are similar to flu symptoms. They can include:

- Feeling tired
- Feeling sick to your stomach
- Poor appetite
- Stomach pain
- Diarrhea
- Muscle and joint pain
- Dark yellow urine
- Yellowish eyes and skin

Reference: Medscape Patient Education

Positive Thoughts Help

Our lives are not determined by what happens to us but by how we react to what happens, not by what life brings to us, but by the attitude we bring to life. A positive attitude causes a chain reaction of positive thoughts, events, and outcomes. It is a catalyst, a spark that creates extraordinary results.

Fact Sheets Updated

Visit the HFI web site at www.hepatitisfoundation.org for 2005 updated Fact Sheets on liver disease and wellness.

Flu Vaccine May Be Available

Contact your primary doctor if you have not had a flu vaccine to see if this is right for you. Prior shortages which limited the availability to many patients, including some with compensated liver disease, may have resolved in some areas.

There are many ways to help take care of your emotional needs when diagnosed with hepatitis C. Here are just a few ideas: talk about your feelings with your doctor, friends, family members, or other supportive people; try to find activities that relieve your stress, such as exercise or hobbies you enjoy; try to get enough sleep each night to help you feel rested; learn relaxation methods like meditation, yoga, or deep breathing; Limit the amount of caffeine and nicotine you use; Eat small, healthy meals throughout the day; Join a support group.

Liver Transplant Updates

As of 12/31/2004, 17,739 people were candidates registered with OPTN. Of these, 4,868 were hepatitis C patients. In 2004, 5,135 liver transplants were performed in the United States for cirrhosis related to hepatitis C.

Thank You for Acts of Kindness

GLAXOSMITHKLINE OFFERS AID TO TSUNAMI VICTIMS

Following in the footsteps of other drug-makers, GlaxoSmithKline (GSK) has joined relief efforts to help victims of the recent earthquake and tsunami that have devastated countries in Asia and along the east coast of Africa.

Be Added to the PAC Newsletter Mail List

We appreciate the many individuals, support groups and medical offices that have been distributing this Patient Advocacy Council newsletter. If you would like to receive a directly copy to your email or mailing address, call the HFI office at 1-800-891-0707 and request to be added to the list.

Create a School Project

If you have school-age children or a great contact in your community, try to get involved by reaching our most vulnerable and precious population through liver wellness education. HFI has the tools available and we can help you with your effort. A new 3-D animated video/DVD helps kids value their liver and know how to protect it. Call HFI or order on our website at www.HepatitisFoundation.org.

Physician Referral

Contact the Hepatitis Foundation International for a physician referral at 1-800-891-0707.

Check It Out Before You Sign Up For Any Weight Loss Program

Americans as a general statement are overweight and obesity has become a major health concern. For people with liver disease, fat in the liver often caused by being overweight is a significant problem. Losing weight must be on the list of goals in 2005 for many.

Some people lose weight on their own; others like the support of a structured program. Overweight people who are successful at losing weight, and keeping it off, can reduce their risk factors for heart disease. If you decide to join any kind of weight control program, here are some questions to ask before you join.

- Does the program provide counseling to help you change your eating activity, and personal habits? The program should teach you how to change permanently those eating habits and lifestyle factors, such as lack of physical activity that have contributed to weight gain.
- Is the staff made up of a variety of qualified counselors and health professionals such as nutritionists, registered dietitians, doctors, nurses, psychologists, and exercise physiologists? You need to be evaluated by a physician if you have any health problems, are currently taking any medicine, or plan on taking any medicine, or plan to lose more than 15 to 20 pounds. If your weight control plan uses a very low-calorie diet (a special liquid formula that replaces all food for 1 to 4 months), an exam and follow up visits by a doctor are also needed.
- Is training available on how to deal with times when you may feel stressed and slip back to old habits? The program should provide long-term strategies to deal with weight problems you may have in the future. These strategies might include things like setting up a support system and establishing a physical activity routine.
- Is attention paid to keeping the weight off? How long is this phase? Choose a program that teaches skills and techniques to make permanent changes in eating habits and levels of physical activity to prevent weight gain.
- Are food choices flexible and suitable? Are weight goals set by the client and the health professional? The program should consider your food likes and dislikes and your lifestyle when your weight loss goals are planned.

There are other questions you can ask about how well a program works. Because many programs don't gather this information, you may not get answers. But it's still important to ask them:

- What percentage of people complete the program?
- What is the average weight loss among people who finish the program?
- What percentage of people have problems or side effects? What are they?
- Are there fees or costs for additional items, such as dietary supplements?

Remember, quick weight loss methods don't provide lasting results. Weight loss methods that rely on diet aids like drinks, prepackaged foods, or diet pills don't work in the long run. Whether you lose weight on your own or with a group, remember that the most important changes are long term. No matter how much weight you have to lose, modest goals and a slow course will increase your chances of both losing the weight and keeping it off.

Is Clinical Research Right For You?

People participate in clinical research for a variety of reasons. One of the most common reasons to volunteer for a trial is access to promising drugs before these drugs are approved for the general public. A trial might also provide free medical care. Before you participate, there are some important questions to ask the study personnel, and important facts that you should understand before signing a consent form to participate.

A good educational resource is on the web at www.centerwatch.com. Not only does this site provide you with an understanding about clinical research, it has a clinical trials listing center by disease and by State. No special log-in is required to access the details of the trials or contact information. However, if you would like to be notified of a clinical trial for hepatitis, as example, you can receive direct email notifications from CenterWatch.

Another excellent web based resource for clinical trials listings can be found at <http://clinicaltrials.gov>. The purpose of this web site is to link patients to the information they are seeking about available clinical trials.

If you live in an area that has a University Medical Center, contact their GI department to locate the liver disease research contact person. Ask to be included on a contact list should they have any new clinical trials for hepatitis C. This does not obligate you to participate, but may be a good way to be notified of something to consider close to home.