

## Maintaining a Positive Attitude



Alan Franciscus, Editor-in-Chief

*HCV therapy is not easy for many people. The side effects that people experience on therapy range from mild to severe. In addition to the physical side effects, one may experience a multitude of psychological problems that can be triggered by interferon and ribavirin. In order to get through therapy, sometimes it is simply a matter of equipping yourself with the necessary tools and strategies.*

Maintaining a positive attitude while on treatment may be difficult, but it is essential and should be at the top of your list for side effect management. Although there is no scientific data at this time to support the notion that a positive attitude will have an impact on hepatitis C or treatment outcome, many patients report that attitude was an important part of staying on therapy. Strive to maintain a positive attitude, but it would be unrealistic to assume that you will achieve perfection 100% of the time. The point is that a positive attitude is a process and not the goal. Be realistic and don't set yourself up for failure because this is the time that you need to be gentle with yourself.

### ATTITUDE

How do you maintain a positive attitude? There are many steps you can take:


Before beginning therapy write a list of the reasons why you are being treated and read the list often.

Reasons to undergo therapy are:

- To improve health
- Live longer
- To feel that you have done all that you can do
  - To be alive for your children, grandchildren and loved ones
  - To experience life and all it has to offer
  - To simply get rid of the virus
  - To put the treatment or hepatitis C behind you
  - To have children
  - To reduce symptoms and increase quality of life
  - To help reach personal and professional goals
  - To avoid being a burden to others

Starting the day off with a positive attitude is half the battle. When you wake up in the morning try to think of one thing you are grateful for in your life. Examples:

- I feel grateful that I have the



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opportunity to take this treatment

- I am grateful for the people in my life

- I am grateful I have a roof over my head or a bed to sleep in at night

Try restructuring your thought processes. For example:

- Instead of saying "I'm overwhelmed," say and believe "I am doing the best that I can"
- If you find yourself thinking "I'm tired," try saying to yourself "This will eventually pass"
- When you say "I can't do this," try saying "I can do this because it is only temporary"

In the evening when you are going to sleep, look back at your day and define what made you feel better and what made you feel worse. Congratulate yourself for getting through the day! Remind yourself that you are one more day closer to completing treatment and your goal.

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# What are Fibrosis and Cirrhosis?



Liz Highleyman

*Chronic infection with hepatitis C or hepatitis B virus (HCV or HBV) can lead to long-term liver damage including fibrosis, cirrhosis, and hepatocellular carcinoma (liver cancer). It is estimated that about 20 percent of people with chronic hepatitis C will develop cirrhosis, a process that usually takes 20-30 years.*

## THE FIBROSIS PROCESS

Liver fibrosis refers to the accumulation of fibrous scar tissue in the liver. The formation of scar tissue is a normal bodily response to injury, but in fibrosis this healing process goes awry. When hepatocytes (functional liver cells) are injured due to viral infection, alcohol consumption, toxins, trauma, or other factors the immune system is activated and the repair process swings into gear. The injury or death (necrosis) of hepatocytes stimulates inflammatory immune cells to release cytokines, growth factors, and other chemicals. These chemical messengers direct support cells in the liver called hepatic stellate cells to activate and produce collagen, glycoproteins (such as fibronectin), proteoglycans, and other substances. These substances are deposited in the liver, causing the buildup of extracellular matrix (nonfunctional connective tissue). At the same time, the process of breaking down or degrading collagen is impaired. In a healthy liver, the synthesis (fibrogenesis) and breakdown (fibrolysis) of matrix tissue are in balance. Fibrosis oc-

curs when excessive scar tissue builds up faster than it can be broken down.

## FIBROSIS RISK FACTORS

Liver fibrosis does not occur at the same rate in all individuals, and in some people fibrosis remains stable or may even regress over time. Several factors influence fibrosis progression. Fibrosis occurs more rapidly in men than in women, and also in older people, particularly those over age 50. Progression does not seem to be linear; that is, the process appears to accelerate later in the course of disease. Immune system compromise for example, due to coinfection with HIV or use of immunosuppressive drugs after a liver transplant also has been shown to accelerate fibrosis. Heavy alcohol consumption is strongly associated with worsening fibrosis and cirrhosis. Finally, studies indicate that steatosis (fatty liver) and insulin resistance are associated with more rapid and severe fibrosis. In contrast, HCV or HBV viral load and HCV genotype do not appear to have much effect on fibrosis progression (although genotype 3 is associated with a higher risk of steatosis).

## ADVANCED FIBROSIS AND CIRRHOSIS

Early in the course of fibrosis, a person usually will experience few or no symptoms. Over years or decades, however, the liver can be-

come excessively scarred, developing nodules and thick bands of fibrous tissue (septa) that extend from one area or portal of the liver to another—a condition known as cirrhosis. As cirrhosis sets in, scar tissue replaces working hepatocytes and the basic architecture or structure of the liver changes, affecting the organ's ability to function. One such change is the obstruction of the normal flow of blood through the liver. Early on, this can deprive hepatocytes of nutrients, causing increased cell death. In an attempt to restore circulation, new blood vessels form. But these new vessels do not drain efficiently and accumulating scar tissue may put pressure on other vessels, causing blood to back up in the portal vein (portal hypertension). One symptom is stretched and weakened blood vessels (varices) in the esophagus and stomach, which may burst and bleed. Compensated cirrhosis occurs when the liver is heavily scarred but can still function relatively normally. Decompensated cirrhosis occurs when the liver is so damaged that its vital functions are impaired. The organ loses its ability to filter toxins from the blood and to synthesize important proteins, leading to clinical symptoms such as cognitive dysfunction (hepatic encephalopathy), accumulation of fluid in the abdomen (ascites), and prolonged bleeding. In the most severe cases, cirrhosis may progress to hepato-

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## POSITIVE ATTITUDE

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### SUPPORT

Staying positive while on therapy would be almost impossible if a person did not have a very good support system established and in place well before starting therapy. Support from as many areas as possible is critical. Support comes in many forms, including family, friends, co-workers, and from peers found in support groups. If you do not already attend a support group, consider joining one before starting therapy.

### PERSONAL APPEARANCE

Keeping a positive attitude requires that you take really good care of your body, including your appearance. When you look good you generally feel better. If you wake up in the morning and feel achy and out of sorts generally, it will help you feel better if you take the necessary steps to stay well groomed. Starting your day off feeling fresh will create a positive influence on your emotions for the entire day.

#### Try these strategies:

- Shower or bathe daily. Spoil yourself with bathing products that smell and feel good. Light a candle and listen to soothing music
  - Take care of the hands and nails
  - Moisturize, moisturize, moisturize!
  - Consider getting a different hair style that would be attractive, easy to take care of and flattering in case there is hair loss
  - Brush and floss your teeth

regularly

- Men - shower and shave or trim facial hair
- Women - if you regularly use make-up, then continue while on treatment
- Keep finger and toe nails well groomed
- Get dressed even if you will be laying on the couch (wear comfortable clothing)
- Wear colors that make you feel good

*Starting your day off feeling fresh will create a positive influence on your emotions for the entire day.*

### EXERCISE

Exercise is one of the most important components of health maintenance, even on therapy. It will help you stay positive, focused and improve your general well-being. Moderation is the key to physical activity. Exercise comes in many forms and does not mean that you have to spend an enormous amount of money or run a marathon to stay fit.

#### Examples:

- Stretching
- Walking
- Hula-hooping
- Swimming
- Yoga
- Pilates

### RELAXATION

Being on HCV medication is stressful. Trying to remember to take all of the medications, dealing with side effects, a job and family

can greatly overwhelm most people. It is important that people build in relaxation strategies. Try some of these to help you with relaxing:

- Meditation—try saying "may I be well" while you take a deep breath, say "may others be well" when you exhale
- Prayer—practice your spiritual preference at least once a day
- Light a candle and listen to music
- Many people hold their breath when they are stressed out. During these periods try gently breathing in and out
- Sit or walk in a place of natural beauty, such as a beach, garden, or park

### SOCIAL EVENTS

Treatment-related side effects and the everyday demands of life can create some uncertainty. Maintain a social life but be realistic when scheduling dates or appointments. The surest way to become depressed is to isolate yourself from family and friends. However, it is important to talk with family and friends before starting treatment so that they can be supportive if you need to cancel or adjust any plans. Sometimes just the knowledge that you can cancel or leave a social activity early will help to reduce the stress. Relax and enjoy the time spent with family and friends.

### DAILY STRATEGIES

Engage in activities that make you laugh. Choose movies that are comedies rather than movies with painful themes. Read the comics, watch sitcoms, use humor - use it during the difficult moments to get a better prospective. Indulge in a favorite hobby, but, most of all, learn to pamper yourself.

# HealthWise:



Lucinda K. Porter, RN, CCRC

*The high price of health care is dominating some of my social conversations. Other than gasoline, perhaps nothing more essential is so obviously inflated. Rising health care costs are occurring at many levels. Hospital, laboratory, and professional fees are increasing. Insurance is costing more but covering less. According to a report released by the Kaiser Family Foundation, health insurance premiums rose more than 11% this year. Insurance plan deductibles and co-payment amounts keep rising. Medicare premiums will increase by 17% in 2005. Prescription drug costs are going up.*

These rising costs, particularly of prescriptions drugs are affecting us all, chiseling away at our earnings. Patricia Barry writes poignantly in an article appearing in the October 2003 AARP Bulletin, "A widow recently sold her wedding ring to pay for medicine. Another sometimes begs for prescription drugs left by friends who've died. Another on occasion uses pills prescribed for her dog." The Medicare Prescription Drug Law and the Medicare Prescription Discount card were intended to reduce prescription drug costs and to some extent they have. Unfortunately, these programs are confusing and are not serving those who need the most help.

In my work with patients, I frequently see examples of how the high cost of prescription drugs and health care can drive people to creative or desperate measures. Treatment for chronic hepatitis C virus (HCV) infection is expensive. Patients without insurance and other economic means or with high deductibles and prescription co-pay

amounts, simply cannot afford HCV treatment. Some call Stanford Medical Center and other hospitals in the country, looking for clinical trials that treat their conditions and provide free medication, lab tests, and clinic visits. Although not all clinical trials offer free medication and treatment, when they do this can be an excellent resource. Before participating in a clinical trial, it is important to be informed of the entire process before agreeing to be in a drug trial. In order to judge the feasibility of a study from a financial standpoint, some questions to ask are:

- What is the purpose of the study?
- What is the drug or combination of drugs being tested?
- What are the potential benefits or risks of my participation in the study?
- Will I incur any costs? Will the treatment or tests be free?

- Is a placebo being used? If so, what are the chances of receiving the study drug versus the placebo? If I receive the placebo, will I be offered the study drug at the end of the trial period?

Current treatment for chronic HCV uses peginterferon alfa combined with ribavirin. Peginterferon alfa is currently marketed by two companies, Hoffmann-La Roche and Schering. No generic form of peginterferon alfa is available. Hoffmann-La Roche and Schering

also sell their own brands of ribavirin, but there is a generic form available. At this time, generic ribavirin is not necessarily a cheaper alternative. Hopefully competition will have a healthy in-

*Election Day is Tuesday, November 2, 2004. Exercise your right to vote. If you are not registered to vote, you can obtain a National Mail Voter Registration Form from the Federal Elections Commission web site:  
<http://www.fec.gov/votregis/vr.htm>*

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## FIBROSIS

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cellular carcinoma or end-stage liver disease (liver failure), necessitating a transplant.

## GRADING FIBROSIS AND CIRRHOSIS

Early fibrosis can be difficult to diagnose because it is often asymptomatic. Various techniques are under study to detect fibrosis using noninvasive blood tests, for example by measuring markers of fibrogenesis and fibrolysis. But the current "gold standard" for determining the extent of liver disease is liver biopsy, in which a small sample of tissue is removed with a needle, stained, and examined under a microscope. In order to monitor progression in a timely manner, most experts recommend repeat biopsies every 3-5 years.

Various systems are used to grade fibrosis and cirrhosis. These include the Knodell Histological Activity Index (HAI), a modified HAI known as the Ishak system, and the METAVIR system. All three systems include separate scores for histological activity (necrosis and inflammation) and fibrosis; inflammation itself is not a reliable predictor of fibrosis severity. The Knodell system includes four components, for periportal/bridging necrosis, interlobular degeneration/focal necrosis, portal inflammation, and fibrosis, which are added together to yield a combined score from 0-18. The METAVIR system includes one score for inflammation (grades 0-4) and one for fibrosis (stages F0-F4).

## METAVIR FIBROSIS STAGES

- F0: no fibrosis
- F1: minimal fibrosis in one portal of the liver, with no septa

- F2: some fibrosis in one portal, with rare septa
- F3: bridging fibrosis (septa that extend over adjacent portals)
- F4: cirrhosis with loss of normal liver architecture

Another system, known as Child-Pugh, is used to grade the severity of cirrhosis on the basis of laboratory findings and clinical symptoms including ascites, hepatic encephalopathy, bilirubin and serum albumin levels, and prothrombin time (a measure of blood clotting ability).

## TREATMENT AND FUTURE PROSPECTS

It was once thought that fibrosis was irreversible, but more recent research indicates that treatment for hepatitis C or B can slow or halt fibrosis progression and even reverse existing liver damage. Studies have shown that fibrosis stabilization and regression are most likely when HCV positive individuals treated with interferon-based therapy achieve a sustained virological response (SVR, continued undetectable HCV viral load six months after the completion of therapy), but improvement has also been seen in some partial responders or nonresponders. In the May 2002 issue of *Gastroenterology*, for example, Thierry Poynard and colleagues reported that among patients with repeated biopsies, 80% who achieved SVR with pegylated interferon plus ribavirin as well as 34% of nonresponders showed evidence of improved fibrosis.

It is likely that interferon improves fibrosis by suppressing HCV replication, allowing the liver to repair itself. But other medications and herbal remedies appear to have a direct antifibrotic effect. For example, in the August 1, 2004 is-

sue of the *Journal of Hepatology*, Yukihiro Imanishi and colleagues reported that a traditional Japanese herbal preparation called inchin-ko-to (TJ-135) down-regulated the activity of hepatic stellate cells, suppressed the production of collagen and fibronectin, and inhibited the development of fibrosis in rats. Much research is ongoing in this area, including a study of long-term interferon maintenance therapy called HALT-C. With a better understanding of the mechanisms underlying fibrogenesis and fibrolysis, it may become possible to design specific therapies to prevent or reverse fibrosis and cirrhosis.

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# How to Start an HCV Support Project: *Part 2*



Alan Franciscus, Editor-in-Chief

*Part one of this series discussed the need for hepatitis C specific support groups. In this article I will discuss important questions potential support group leaders need to ask themselves even before starting a support group, and provide some pointers to help identify appropriate resources. There is no reason to “go it alone.”*

## WHY DO YOU WANT TO START A SUPPORT GROUP?

The majority of people who start an HCV support group have very little prior experience with group facilitation or a medical background enabling them to deal with the questions about hepatitis C and psychological issues that may be needed to run a successful support group. It is important to be aware of these limitations when you start a support group. It is always easier to take on the demands of a support group if there is help available from others with a medical background and from those who have experience with running a support group. You do not need to be the expert or a person living with hepatitis C; but it is important to surround yourself with people who can aid you when you face difficult questions or situations.

## MOTIVE

If you are developing a plan of action for starting a support group it is important that you consider

your motive first. It can be very difficult to be honest with yourself about the motivation for running a support group, but it is a very necessary step. Ask yourself these questions:

- Is it to get your own needs met?
- Is it to help support others?
- Is it to help yourself and others?

There is nothing wrong with starting a support group to get your own needs met, but if you are not careful it can sabotage the most important reason for a support group—to help others. Another essential purpose of a support group is to help empower other members to make important life choices, which will be difficult if you do not identify and serve the needs of the entire group, not just your own.

## ARE YOU OPEN-MINDED AND FREE OF BIAS?

Everyone has certain points of view or biases that could potentially affect the level of support that should be available to all support group members. Ask yourself these questions:

- Is there the possibility that I am biased? Would I be open to talking about any issue as it relates to hepatitis C, including:
  - Interferon based therapies
  - Alternative and complementary therapies

- Life style issues
- Gender
- Sexual orientation
- Substance use
- Can I accept all individual members regardless of their ethnic and cultural backgrounds?
  - Am I biased concerning the mode of transmission? Will I accept others who believe they contracted hepatitis C from a blood transfusion, injection drug use, or sexual transmission, etc?
  - Can I put my ego and “my issues” aside for the benefit of the entire group?

All of these questions are extremely important questions that need to be answered, and the answers will be helpful in guiding you in the process. More importantly they will help you fine tune your goals.

## IDENTIFY EXPERTS

Members of a support group look at the facilitator or support group leader as an expert in hepatitis C. This can be troublesome unless the facilitator has a medical background and is thoroughly educated about hepatitis C. However, it may be important from the beginning to emphasize that the role of a facilitator is to assist and direct the support group and is not intended to supply expert medical advice to the members. **This should be left**

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fluence on the ribavirin market. For more information about HCV medications, see "A Simple Guide to Understanding the Cost of HCV Medications," by Alan Franciscus, *HCV Advocate* (May 2003).

Patients are looking for cheaper drugs for all of their medical problems, not just HCV. The following are some cost-saving ideas to consider:

- Ask your doctor if there is a cheaper version of your medication, such as a generic form
- Inquire about free samples
- See if you qualify for a pharmaceutical patient assistance program. For more information contact Needy Meds [www.needy meds.com](http://www.needy meds.com) or try [www.helpingpatients.org](http://www.helpingpatients.org)
- Shop for the best drug price, such as through Costco, wholesale, or reliable Internet-based pharmacies
- Look for discounted drug prices, such as through your insurance plan, or AARP. Insurance pharmacy mail order plans can really cut costs. Some pharmaceutical companies, such as Pfizer, offer discounted drug prices for everyone without prescription drug coverage. For more about this, look for information at the website of the pharmaceutical company that sells the medication you are taking.
- If it's a drug you are confident you will be taking for some time and at a steady dose, see if a 90 day supply costs less than a 30 day supply.
- Join a discount pharmacy program. These programs offer discounted drug prices for an annual membership fee. If you are interested in this option, make

sure the membership fee is reasonable and that the program carries the medications you are taking.

- Compare the price of different strengths of the drug. Ask your doctor if the pill can be prescribed at a higher dose and safely divided in half. For instance, if you are supposed to take a 5 mg dose of a medication every day, it may be cost effective to purchase a 30-day supply of a 10 mg dose and divide it in two. This would stretch the medication over a 60 day time period. Do not do this without your doctor's knowledge because some pills should not be cut.
  - A lesser known option is a program called The Medicine Program. For a fee of \$5.00 per medication, this service is staffed by volunteers who attempt to find free-of-charges prescriptions. This service can be reached at (573) 996-7300 [www.themedicineprogram.com](http://www.themedicineprogram.com)
  - For more information about Medicare programs, call Medicare at 1-800-MEDICARE (1-800-633-4227) or go to [www.medicare.gov/MedicareReform](http://www.medicare.gov/MedicareReform). Kaiser Family Foundation provides some interesting information about this program and other health topics at [www.kff.org](http://www.kff.org).
- Lately there has been a lot in the press about purchasing prescription drugs in Canada, Mexico, or overseas. In some cases this is perfectly legal and other cases it is not. The laws about this vary, depending on the medication and how it is being used. Medication from another country is not always the same or safe and not necessarily cheaper. However, sometimes it can be the same drug priced at a substantial



**Executive Director  
Editor-in-Chief,  
HCSP Publications**

Alan Franciscus  
[alanfranciscus@hcvadvocate.org](mailto:alanfranciscus@hcvadvocate.org)

**Managing Editor, Webmaster**

C.D. Mazoff, PhD  
[cdmazoff@hcvadvocate.org](mailto:cdmazoff@hcvadvocate.org)

**Contributing Authors**

Liz Highleyman  
Lucinda K. Porter, RN, CCRC

**Design and Production**

Paula Fener  
Blue Kangaroo Design  
[blueroodesign@aol.com](mailto:blueroodesign@aol.com)

**Contact information:**

Hepatitis C Support Project  
PO Box 427037  
San Francisco, CA 94142-7037

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## SUPPORT GROUP

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to patients' medical providers. It is not even recommended that the facilitator become the 'expert' since it could potentially derail the purpose of a support group—to support and guide others. This requires that everyone in a support group become actively involved in the process and take ownership of the group.

Having said this, it is important that a support group leader learn as much about hepatitis C as possible, as well as become knowledgeable about running or facilitating a support group. Information about hepatitis C is freely available from many sources, such as the Internet, various governmental agencies, HCV non-profits and published books on the subject.

### IDENTIFY RESOURCES

It is important to develop resources to aid you. You may want to develop a relationship with a local health provider who can serve as a consultant to the support group. It would also be useful to have as many experts as possible to consult with on a wide range of issues, and key people who could potentially present information to the group members.

Medical institutions and non-profit agencies may also provide sponsorship and free space to hold the meetings. This would also help with advertising since the agency could advertise to their clientele.

### DO YOU NEED A CO-FACILITATOR?

It can be very difficult when you realize that *all* of the group members' support falls on your shoulders. It would help to ease

the pressure if you identify a person from the beginning who would be willing to step in or share in the responsibility of running a support group. The benefits of having a co-facilitator will be discussed in more detail later in this series.

### LEARN MORE ABOUT SUPPORT GROUPS

There are many resources to help you learn more about running and facilitating an effective support group:

- Attend other support groups in your area specific to hepatitis C. This will help you learn how others run a support group and will help you find out if the needs of the HCV population in your area are being served. If the need is being filled by another group, perhaps the best use of your time and energy would be to help an existing group. You may also find that certain people are not being served. The potential for HCV support groups is unlimited and many more specific groups can be started to help support the HCV community. These may be groups that serve Veterans, family members, substance users, or any other group with specific needs.

- Visit and attend other types of support groups. There may be 12 step meetings or other disease specific support groups that would help you understand the support group process and how to support people with different needs. It is important that if you do attend other groups for research that you let them know why you are

attending. There is a certain level of trust that needs to be honored at all times.

- Publications on support groups that will help guide you through the process of starting a support group.
- Local agencies may offer services or seminars on running a support group.

### Recommended reading:

- *The Support Group Sourcebook*, by Linda L. Klein
- *Self-help and Support Groups: A Handbook for Practitioners*, by Linda Farris Kurtz

They are both available at [Amazon.com](http://Amazon.com).

*Part 3 of this series will discuss the importance of establishing the type of group and factors such as group size, length of the meetings as well as the physical space needed to run an effective support group.*

*There is nothing wrong with starting a support group to get your own needs met, but if you are not careful it can sabotage the most important reason for a support group--to help others*



**HEALTHWISE**

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savings. One resource that can provide more information about this option is [www.medicineassist.org](http://www.medicineassist.org)

One way to change the direction of health care is through the political process. Election Day is Tuesday November 2, 2004. Exercise your right to vote. If you are not registered to vote, you can obtain a National Mail Voter Registration Form from the Federal Elections Commission web site: <http://www.fec.gov/votregis/vr.htm>. This form can be used by every state in the U.S. to register to vote except New Hampshire, North Dakota, and Wyoming. Each state has particular deadlines and instructions listed on the web site. The form is other-

wise straight forward.

Some prefer to vote by absentee ballot. With the 2000 Florida election results still fresh in our minds, there may be reasons to consider voting by absentee. Each state has its own requirements for absentee balloting. Information about your state's Board of Elections can be found in the telephone Yellow Pages or on the Internet. Whether in person or by absentee, the point is to vote. Together, perhaps we can make a difference, one vote at a time.

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