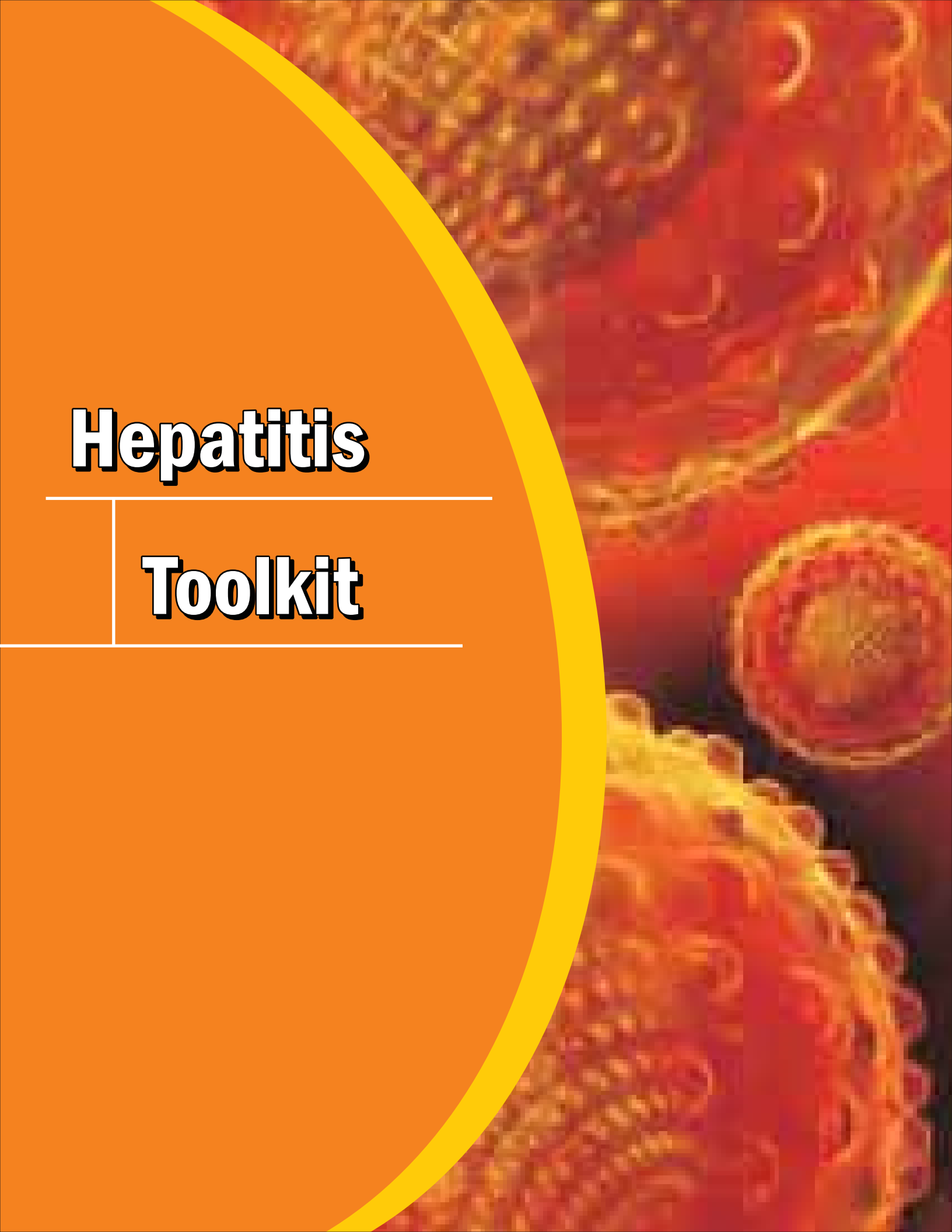
Hepatitis

Toolkit



Hello,

My name is Evelyn McKnight and like you or someone you know, I was infected with viral hepatitis. I was infected with Hepatitis C through the reuse of syringes during chemotherapy for stage III breast cancer. I used my malpractice settlement award to begin a nonprofit patient advocacy foundation called HONOReform, which stands for Hepatitis Outbreaks' National Organization for Reform. HONOReform is committed to preventing transmission of blood borne pathogens like hepatitis and HIV through healthcare procedures.

I am very sorry for the losses you are experiencing now perhaps the loss of good health, peace of mind and/or confidence in our healthcare system. In your grieving, you may be experiencing many of the same emotions that I did when I was diagnosed. I was frightened, confused and angry. I was overwhelmed with the amount of new information I had to process and the decisions I had to make regarding my health, my family's welfare, my finances, and possible legal recourse.

Because we care about you, HONOReform Foundation has provided this toolkit to help you gather important information. This information will empower you to make sound decisions about the important issues that you face now. As you thoughtfully make your decisions one by one, the anxiety, anger and grief will have less power over you. You may not notice it today or tomorrow but it WILL happen.

Please know that you are not alone there are many, many others who have contracted viral hepatitis, and unfortunately many who contracted it through healthcare procedures. Please visit our website www.HONOReform.org to connect with others who have contracted viral hepatitis.

On the website you will also see ways that you can work with thousands of others to stop the spread of hepatitis through healthcare procedures. HONOReform is active in initiating and shaping public policy. Please join us in our ongoing efforts on Capitol Hill. When we all work together to stop the spread of hepatitis through healthcare procedures, our suffering becomes an honorable way to influence lawmakers and others.

Our warm wishes go out to you for good health and peace of mind.

Sincerely,

Evelyn

Evelyn V. McKnight, Aud
President, HONOReform/HONOReform Foundation
www.HONOReform.org
www.OneandOnlyCampaign.org
Twitter:honoReform
www.ANeverEvent.com

HONOReform Compassionate Response Toolkit

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Hepatitis Education

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What is Hepatitis C?

Hepatitis C is a liver disease that results from infection with the hepatitis C virus (HCV). The disease can range in severity from a mild illness lasting a few weeks to a serious, lifelong illness that damages the liver. The infection can be acute or chronic.

Acute: hepatitis C viral infection can be a short-term illness that occurs within the first 6 months after exposure to the hepatitis C virus. For reasons that are not known, 15%-25% of people "clear" the virus without treatment and do not develop chronic infection. Approximately 75%-85% of people who become infected with the hepatitis C virus develop chronic infection.

Chronic: hepatitis C viral infection can be a long-term illness that occurs when the hepatitis C virus remains in a person's body. Chronic infection can last a lifetime. Over time, it may lead to serious liver problems, including liver damage, cirrhosis, liver failure, or liver cancer.

Source: CDC (2007)

How is Hepatitis C Spread?

Hepatitis C can be spread in any one of the following ways:

- Blood to blood contact
- Delivery of a baby to a mother with hepatitis C
- Exposure to contaminated needles, syringes, or other equipment. This may occur in healthcare settings or with recreational drug use.
- Sex with multiple partners or rough sex
- Tattooed or pierced with non-sterile needles or equipment
- Accidental needle stick with a needle that was used on an infected person
- Using the same razor or toothbrush that an infected person used

Source: http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez/ and C DC (2007)

What is the rate of transmission?

According to the Centers for Disease Control and Prevention (CDC), in 2007, an estimated 17,000 new cases of hepatitis C were expected for the United States.

The actual reported number of cases is much lower because people might not know they have been exposed and/or never develop symptoms and therefore do not get tested.

Approximately 75%-85% of people infected with hepatitis C will develop chronic infection.

An estimated 3.2 million people in the United States are infected with chronic hepatitis C.

Source: http://www.cdc.gov/hepatitis/C/cFAQ.htm#statistics

Is there a vaccine for hepatitis C?

There currently is no vaccine for hepatitis C, although research is being conducted to develop vaccines. There are however vaccines available for hepatitis A and hepatitis B.

Source: http://www.cdc.gov/hepatitis/C/cFAQ.htm#statistics

Who should get tested for hepatitis C?

Anyone who:

- Received donated blood or organs before 1992
- Has been notified of a healthcare exposure
- Currently injects drugs recreationally
- Has abnormal liver test results or liver disease
- Is HIV+ or has AIDS
- Is on long term hemodialysis
- Has been exposed to blood on the job through a needlestick or other injury with a sharp object

Source: http://www.cdc.gov/hepatitis/C/cFAQ.htm#statistics

What are the symptoms of Hepatitis C?

People infected with hepatitis C may not have symptoms until advanced liver damage has occurred. Although this may be true for some people, others may develop acute infection and begin to develop symptoms rapidly, within 2 weeks to 6 months.

Symptoms include:

- Fever
- Easy bruising
- Loss of appetite
- Nausea
- Abdominal pain
- Tiredness
- Longer than usual amount of time to stop bleeding
- Fatigue
- Light or clay colored stools
- Dark urine
- Vomiting
- Joint pain
- Jaundice (yellow tint) of the eyes and skin

Source: http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez/, CDC (2007)

If I've been diagnosed with hepatitis C, what questions should I ask my doctor?

1. Do I have acute or chronic hepatitis C?
2. Should I receive treatment for hepatitis C? What are my chances of clearing the virus if I receive treatment?
3. What is the chance of me developing cirrhosis or liver cancer if I do not receive treatment?
4. What treatment do you recommend? What do I need to know about my treatment?
5. How long will I need to be treated? When can I expect to see the results from the treatment?
6. How will you assess whether the treatment is working for me?
7. What should I do if I have side effects? Is there anything I can take to help the side effects go away?
8. Do I have to stop drinking alcohol even if I only have a few beers or a glass of wine once a week?
9. How will my hepatitis C affect my family and friends?
10. Should I take any special precautions to avoid infecting others?

Source: http://www.liverfoundation.org/education/info/hepatitisc/

How do I find out if I have Hepatitis C?

You can find out if you have hepatitis C by taking an antibody test. Initially your blood may be tested for the presence of hepatitis C antibodies (i.e. an antibody test). If this comes back positive, it means that you have been exposed to the virus at some time. If it is negative, then you may be required to have another test a few months later. This is called the window period, the time it can take from initial exposure until the antibodies to the virus become detectable in your blood.

If the antibody test is positive, then a further test to check for the active virus will be necessary. If this is negative, then you have had hepatitis C but are no longer infected (this happens to one in five people and is called "spontaneous clearance"). If it is positive, then you have a hepatitis C infection. You may have an acute infection or chronic hepatitis C (sometimes referred to as CHC).

How did I get it?

There are a number of ways you may have contracted hepatitis C. Maybe you already suspect how you were exposed to the virus. For some people it is not important, others need to know. It can be useful to have an idea of exposure because then you can estimate how

long you have been infected. However, the truth is that some people will never be able to be sure how they were infected. There are a number of ways you may have been exposed to the virus and many people are not diagnosed until many years after the initial infection.

Source: http://www.liverfoundation.org/education/info/hepatitisc/
For more information about testing for HCV: http://cdc.gov/hepatitis/C/cFAQ.htm#tests

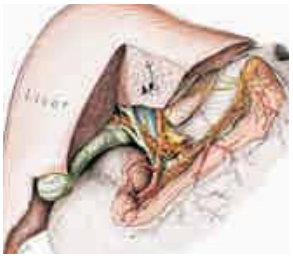
The Liver and Hepatitis C

Hepatitis or the inflammation of the liver disrupts the normal function of the liver. To understand hepatitis C and its progression, one must first understand the liver and its function.
Source: http://www.hepctrust.org.uk/hepatitis-c

The Liver

1. Transforms the food we eat into energy to build cells and tissues in our body.
2. Detoxifies all the poisonous chemicals that enter our bodies such as alcohol, drugs and pollutants.
3. Stores vitamins, fat, sugars, and minerals and sends them out around the body as and when they are needed.
4. Makes a digestive juice called bile so that fats can properly be broken down and absorbed by the body.
5. Produces hormones that regulate sexual desire and function.
6. Is engaged in so many activities that the energy it creates carrying them out warms the blood that passes through it and helps maintain the body's temperature.

The immune system, digestive tract, kidney, brain and cardiovascular system all depend on a healthy and well-functioning liver. Due to the affects on all major systems and organs by a diseased liver, liver diseases such as hepatitis C can have varied symptoms. It is because of this that it is important to understand both how the liver works and how to keep a healthy liver.
Source: http://www.hepctrust.org.uk/The+Liver/#headingAnchor1



Liver damage can be decreased and managed through lifestyle modification.

Decrease or cease smoking, drinking alcohol, using drugs or exposures to other harmful chemicals.

The management of hormones is compromised in hepatitis C. This may affect immunological, emotional and sexual aspects of your life. Talk with your health care provider about how to optimize your health, and protect the health of your family.

The storage of vitamins may be impeded - vitamins A, D, E, K, B12, iron and copper. Talk with your health care provider about supplements.

If I have chronic hepatitis C, what can I do to help keep myself and others healthy?

With proper management, many people with hepatitis C can lead full and active lives. If you are infected with hepatitis C, you should:

- Be under the care of a doctor who specializes in the liver (called a hepatologist).
- Stay on any prescribed medications and keep all your medical appointments.
- Get hepatitis A and B vaccinations to protect you from another liver infection.
- Maintain a healthy lifestyle by eating nutritious meals, getting exercise, resting when you feel tired and avoiding alcohol and illegal drugs.
- Use only drugs and supplements that your doctor has approved.
- Consider joining a hepatitis C support group, either in your community or online. Your local American Liver Foundation chapter may be able to refer you a support group in your area.

Avoid spreading your blood to others. Don't share razors, toothbrushes insulin pens or nail clippers.

Source: http://www.liverfoundation.org/education/info/hepatitisc/

Hepatitis and Nutrition

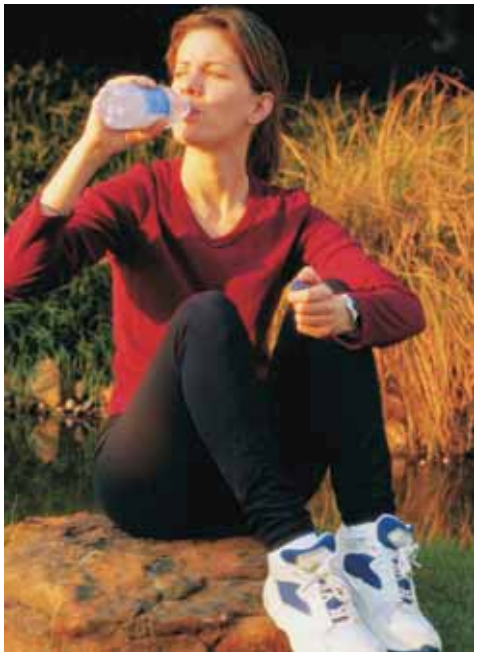
Foods to eat moderately or avoid:

- Raisins
- Processed foods
- Iron-rich or iron-fortified foods
- Caffeine (including colas, coffee, chocolate and some teas)
- Hydrogenated oils
- Artificial sweeteners
- Fatty or fried foods
- "Junk" foods calorie-rich but nutrient empty foods

Source: http://www.liverfoundation.org/education/info/hepatitis

Foods to eat:

- Fiber
- Low sugar
- Whole wheat bread
- Brown rice
- Vegetables
- Low fat
- Baked chips
- Baked potatoes
- Pizza (whole wheat crust)
- Chicken, tuna or salmon salad
- Whole wheat waffles or pancakes
- Flaxseed oil or virgin olive oil
- Whole grains and whole grain cereals
- Fresh fruit
- Pasta
- Yogurt
- High fiber
- Beans



Helpful Tips

The Goal: Take stress and strain off the liver! Eat 4 small meals per day. Avoid eating too many rich foods at one time.

1. Avoid eating right before bedtime.
2. Try new foods, you may just like them.
3. Drink water throughout the day.
4. Prepare your foods ahead of time, if possible, so they are ready when you are hungry. A helpful way to do this is to prepare soups, beans, chili beans, for example, and freeze them in microwave containers. Then when you are ready, just pop them in the microwave.
5. Chew, chew, chew, chew, chew. The digestive process starts in the mouth. The chewing action begins the release of digestive juices. Chew, chew, chew, chew. Are you finished chewing? Great...

Support: Social and Family

Included in this section:

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- Dealing with grief 9-10
- Developing coping skills 11-13
- Living with HCV and defeating stigma 14-17
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The Importance and Accessibility of Grief Counseling

Living with a serious or chronic illness can change every aspect of your life. You may be experiencing emotions, such as anguish or anger, or feeling physical changes, including pain. You may be asking questions about your health, your religion, and your future. Remember that information and support is available to you. In this section you will learn about what changes you may experience, how to support yourself and hear that any changes or reactions you experience are real and valid.

Managing Symptoms

Understanding how to manage the symptoms of a serious illness can seem overwhelming. Whether the serious illness is a new diagnosis for you or if you have been living with your illness for some time, you may be experiencing a range of emotions and may be wondering how you will face the challenges having a serious illness brings. Learning about the emotional, physical and spiritual changes you may face and where you can turn to for support may help enhance your quality of life and manage the symptoms of your serious illness.

Physical

Physical symptoms that you may experience include:

- Becoming tired more easily
- Having difficulty participating in your regular activities
- Having a renewed sense of energy as effects of previous treatment go away

Things you can do:

- Taking naps so that you have energy throughout the day
- Finding new activities that take less energy (for example if you like to cook, you may want to read some cookbooks and ask others to make the meals while you watch)
- Pace yourself as your energy returns after treatment and focus on those activities which give you the most joy or help you prepare for what is to come

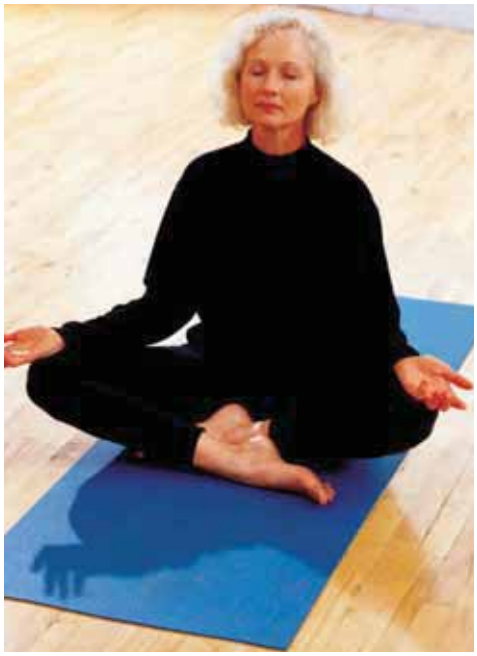
Spiritual

Physical symptoms that you may experience include:

- A deeper sense of faith and hope for each day
- Questioning of your faith beliefs and what your life has meant
- A new understanding of spirituality that you did not have before

Things you can do:

- Exploring your faith through readings or discussions with family members, friends or faith leaders
- Reflecting on the role of faith throughout your life and ways that you have found comfort in the past
- Talking with people who are or have been in a similar situation who may have advice for you



Emotional

Emotional changes that you may experience include:

- Fear about what will happen as your illness progresses, or about the future for your loved ones
- Anger about past treatment choices, about the change in diagnosis
- Grief about the losses that you have had and those to come
- Anxiety about making new decisions and facing new realities
- Disbelief about the changes that will be taking place
- Relief about ending difficult treatments and setting new goals for care

Things you can do:

- Sharing your feelings with friends, family members, healthcare professionals, faith leaders and others you respect
- Talking with people who are or have been in a similar situation who may have advice for you
- Writing about your feelings in a journal

Developing Coping Skills

Children learn how to cope with life events and stressors primarily through watching and observing their parents or other family members. During a tragic event like the one you are going through it is important to remember that your child is experiencing it, too.

Here you will find some helpful tips for how to help your children cope and some resourceful websites.

Communication

1. Be observant of non-verbal communication, including but not limited to clenching teeth and fists, acting out, fidgeting, and eye movements.
2. Encourage the sharing of feelings with an "I" statement instead of "you" statements. "I" statements encourage a relationship whereas "you" statements can sound like accusations or stifle communication.
3. Give feedback or clarify what is said.
4. Tell how you are affected: "because."

   Source: http://www.extension.org/pages/Teaching_Children_Coping_Skills

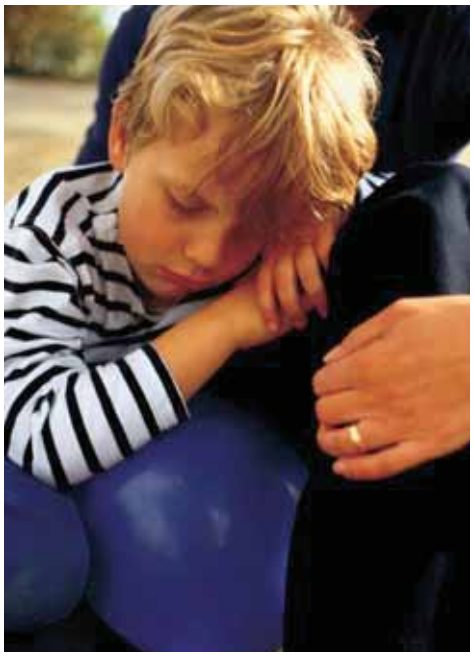
Helping Children Cope with Stress

1. Talk with children about their feelings and concerns
2. Allow children to have their feelings and listen to them.
3. Let children know that you are afraid or nervous sometimes, too.
4. Be honest with children about what is going on.
5. Teach children relaxation exercises to use when they feel tense.
6. Love, hug, and be direct with children.
7. Help children use their imagination to think positively.
8. Praise children for accomplishments and efforts.

   Source: http://www.extension.org/pages/Teaching_Children_Coping_Skills

Ways to prepare your children for changes

1. Check your local library for books related to the change that will be affecting them. Reading a book with them and allowing them to ask questions about what they are reading is a great way to teach them about the change and find out what they know and how much they understand it.
2. Keep child care providers and teachers informed of family changes that might affect child care or school behavior. When parents and teachers work together, children can usually cope with most daily stress.



3. Don't sugar-coat the truth when talking to them about the changes that will be happening. Children can see through it to the truth. Talk with them about the pros and cons.
4. Prior to a change or stressful event, encourage your child to write, tell, or draw a story of what he thinks might happen. This will give you a view into your child's perceptions and feelings. After hearing your child's story, you can confirm information that's correct. But more importantly, you can clarify misconceptions that may cause your child unnecessary concern. For instance, a child facing hospitalization for corrective leg surgery may silently worry his leg will be cut off. If he is allowed to verbalize this, parents or a doctor can provide invaluable reassurance by explaining the actual surgical process in understandable terms.
5. Role-play or put on a puppet show to act out the changes that will be happening.
6. Change can make us all feel insecure and helpless. During change, let children make as many of their own decisions as possible. Autonomy offsets anxious feelings. It gives life balance and reminds kids they have control over some things in life, just not all things

Source: http://www.oh-pin.org/articles/pex-02-ways-to-teach-children-po.pdf

For Parents

1. You can help your children best by first helping yourself. Try to gain control of your own stress; then you are ready to help your children cope.
2. Provide your children with information about your family's situation in a way that is within the child's understanding. Do not keep the income loss a secret from children and other family members, despite the urge to spare them or "save face."

3. Recognize symptoms of stress that may affect your children: sleeplessness, diarrhea, withdrawal, headaches, and/or angry outbursts. Encourage the child to share feelings and fears. If you feel ineffective in helping your children manage stress, talk to the children's teacher, a school psychologist, clergy member, or contact a mental health professional.
4. Promote a balanced diet, get adequate rest, and plenty of exercise to guard against health problems.
5. Try to keep other major changes to a minimum. Too many changes at once can be overwhelming. However, some changes are unavoidable, such as a move, so try to keep the changes in perspective.
6. Help your children focus on the positive aspects of their lives. Look at family and personal strengths and draw on talents and contributions of all family members. Recognize these contributions, no matter how small.
7. Hold a family discussion on how the income loss affects money available for extra activities and allowances. Talk about family spending priorities. Discuss how each person will help control family spending.

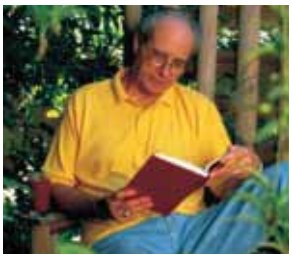
Source: http://www.extension.org/pages/Teaching_Children_Coping_Skills

Additional Resources

Open Leaves Bookshop
Online bookstore
http://www.openleaves.com.au/

Karen Stephens: The Complete Parent Exchange Library
For information, enrolments and requests contact
45 Helston Road, Johnsonville
Wellington, New Zealand.
(+64 4) 461 7076 phone
(+64 4) 478 3986 fax
http://www.childspace.co.nz/index.html

Coping Skills for Kids: Brain Works Project
http://www.copingskills4kids.net/



Living with HCV

Living with the Label start with yourself: Do you label yourself? Do you expect to be shunned? Do you fear that others will reject you in some way? Do you have your own fears about HCV? If so, the best place to share your feelings is at an HCV support group and learn how others live and deal with HCV. Recognize that HCV is not a punishment for past behavior and it doesn't matter how you acquired it. Guilt and remorse may have a negative effect on your health. If you struggle with negative emotions, you may need some counseling so talk to your medical provider.

Who Are You?

1. Labels often define us they say a lot about who we are, encompass our values/beliefs, and describe our relationship with others.
2. In saying, "I'm a hepatitis C patient", it says "I'm sick"
3. If you imagine or describe yourself as an HCV patient, try substituting more powerful images and words. Imagine yourself as strong and calm. Say to yourself, "I am living with hepatitis C, but I am so much more than this." How does this feel compared to "I am a hepatitis C patient."
4. It is important to identify with your illness because you can't move forward without first accepting it.
5. An important part of the process is to acknowledge it, reflect on it, and recognize its meaning.
6. There is a fine line between finding the meaning in your illness versus letting the illness define you
7. If you focus on illness, that is where your energy will go. Try to live positively, not negatively.

Consider making the following points:

- Make sure you know the truth. Get accurate information about hepatitis C. Some people mistakenly believe hepatitis C is an automatic death sentence. The truth is, the majority will die with hepatitis C, not of hepatitis C.
- Don't make things worse by imagining a future with pain, disability or loss. Improve your odds by visualizing your future the way you want it. Visualizing health, not illness, is a powerful tool for self-transformation.
- Maintain perspective of the big picture. Focus your attention on something that brings peace, joy, laughter and meaning. Tell yourself that difficult moments will pass.

- Watch your words. If you hear yourself talking negatively, substitute positive phrases. Say, "I will find a way to live with hepatitis C" rather than "hepatitis C is ruining my life."
- Practice gratitude. Make it a habit to find things for which you are grateful.
- Learn what you can control and what you cannot. There are things you cannot control, such as the fact that you have hepatitis C. However, there are things you can control, such as your attitude and what you say to yourself about having hepatitis C.
- Learn from the virus. Ask yourself what hepatitis C can teach you about living.
- Get support. Being with others who are dealing with the same issues can bring encouragement and hope.
- Help others. When it come to stepping outside of ourselves, probably nothing works as well as reaching out to others who are also struggling.

If you have hepatitis C, the first step in breaking the stigma is to start with your own attitude toward your illness. Some questions to ask in uncovering this include:

- Do you label yourself as a sick person?
- Do you expect to be shunned from co-workers, friends and family?
- Do you feel like you deserve to have hepatitis C?

Honestly examining your own feelings of shame and working to shift those feelings into pride makes a tremendous difference when facing the world with any illness. Living in the present and looking to the future are the best ways to leave negativity in the past. By learning how other people live with the disease, many people find help in discussing their feelings at hepatitis C support groups. In order to garner the respect from others, it is absolutely necessary to first develop respect for yourself. Additionally, feeling good is the single most important factor in living a long, healthy and rewarding life.

By cultivating self-respect through a positive attitude and through active participation in educating your community on hepatitis C, you can take an active role in breaking the hepatitis C stigma and helping those diagnosed with the disease to finally receive the compassion they deserve.

Adapted From: http://hcvadvocate.org/hepatitis/factsheets_pdf/stigma_guide.pdf

Facts and Compassion to Defeat Stigma

1. Many believe people die of HCV, but most die with HCV
2. Stigma of HCV often goes unnoticed but is a painful part of the process "For some, the stigma of HCV hurts more than HCV itself."
3. Stigma definitions:
    - "a mark of shame or discredit; an identifying mark or characteristic; a specific diagnostic sign of disease" Merriam Webster
    - "a sign of social unacceptability; the shame or disgrace attached to something regarded as socially unacceptable." Encarta
4. Reasons for stigma:
    - HCV is a blood borne pathogen and thus, potentially infectious causes fear of disease
    - People are uncomfortable being around others with a disease or seen as being "sick", so they avoid them
    - HCV is associated with injection drug use (society lacks sympathy for drug users in general and jump to the conclusion that all HCV patients engaged in injection drug use)

Effects of Stigma

- Job and healthcare discrimination
- Decreased quality of life
- Alienated by friends and family
- Reduced self-esteem
- Diminished mental health
- Fear of disclosure which can lead to decreased social support

Breaking the Stigma

You can help break the stigma through education and self-respect. Educating yourself and others can help break down the process of hepatitis C because until all of society is aware of the facts about HCV, inaccurate stereotypes driven by fear will continue.

Adapted From: http://hcvadvocate.org/hepatitis/factsheets_pdf/stigma_guide.pdf

Recommendations and Solutions to Decrease the Negative Public Perception

Research: It is clear that HCV is under studied and there is a great need for further research in biology, social science, and treatment. Policy suggestions are listed below to improve the state of HCV research.

1. Research endeavors to understand patterns and trends related to HCV transmission are needed.
2. Epidemiological and social science research that accurately estimates the prevalence of HCV and the intricacies of risk behaviors among potentially hidden populations will provide intervention specialists with more information to develop targeted primary and secondary prevention programs.
3. Research must assess social drug and sex networks that may exacerbate risk for HCV.
4. Researchers should evaluate best practices regarding HCV acquisition among persons who are newly initiated into injection drug use.
5. Researchers must investigate the transition from experimentation with drugs to injection drug use among youth. They should evaluate syringe exchange programs and their effectiveness in deterring the transmission of blood borne pathogens.
6. Secondary prevention strategies are needed to support healthful living with HCV for marginalized persons who may not gain appropriate access to medical care.
7. Drug treatment facilities should be studied as secondary HCV prevention/ intervention sites.
8. The efficacy of peer-education models for prevention of HCV transmission among the extremely marginalized should be explored.

Prevention

Many people living with chronic HCV do not know of their infection. A lack of knowledge perpetuates transmission and decreases the opportunity for individuals to take liver health preventive measures necessary to decrease the likelihood of severe liver disease. While there is no magic bullet for most blood borne pathogens, harm reduction programs that acknowledge people's current social circumstances may reduce drug and sex-related harms and can support positive health choices for marginalized persons. The following policy recommendations may help to prevent the spread of HCV.

1. Testing should be accessible to all high risk persons, especially PWID, those who are incarcerated, and all persons at high risk for HCV infection.
2. A new harm reduction approach to drug use and safer injection practices among PWID is needed.

3. Safe syringe access and disposal programs should be available in all decrease the HCV transmission through sharing injection drugs.
4. More accessible treatment options are necessary to prevent the health complications of HCV disease.

Education

Political disenfranchisement of PWID in the United States maintains the isolationist policies that exacerbate the HCV epidemic. It is suggested that through efforts to educate all strata of our society including medical providers, allied health care, social service providers, and the public, that a destigmatization may occur such that people infected with HCV will no longer have to die in the shadows of our communities. The following recommendations can help with HCV education.

1. Launch extensive and comprehensive education programs designed for target audiences including educational messages regarding disease transmission, risk assessment, behavior modification, treatment options, and harm reduction strategies.
2. Develop specific programs for healthcare providers, dentists and oral hygienists, pharmacists, persons working in substance abuse and mental health, corrections staff, and others working in social services for disadvantaged persons.
3. Develop basic educational programs aimed toward the general public.
4. Evaluate and assess information given to persons diagnosed with HCV to ensure persons have the appropriate knowledge to make decisions about their health.

Management

While HCV is an equal opportunity infectious disease, it is the subpopulations that are marginalized socioeconomically and morally in our society that will have the worst outcomes. Those most likely to progress with HCV-related liver disease are people on the fringes of society. People who may be infected with HIV, HBV, who consume significant amounts of alcohol, and who are marginally housed, are all less likely to be linked to a medical care system and thus, more likely to progress with HCV related liver disease. The following are policy suggestions that will help manage HCV more effectively.

1. Provide access to basic health care.
2. Facilitate alcohol and drug treatment (when necessary).
3. Administer viral hepatitis A and B vaccines to high-risk adults. Make treatment for HCV available for all persons, but especially persons who are incarcerated and PWID.
4. Provide accessible and integrated care structures for persons with HCV.

Adapted From: http://www.sssp1.org/File/Agenda_For_Social_Justice_2008_Chapter_11_.pdf

Useful Hotlines

- **Hepatitis C Association Support Line**
  866-437-4377 (toll free). Mission is to educate the public and provide emotional support to patients living with hepatitis C.
- **Hep-C ALERT Hotline**
  877-HELP-4-HEP-(877 435 7443). Toll-free national hotline ran by Hep-C ALERT, a nonprofit organization that seeks to provide information and assist people affected by hepatitis C.
- **HIV/AIDS/Hepatitis C Nightline**
  Hotline providing support for people with HIV or hepatitis C and their caregivers during the evening and nighttime hours. Call 1-800-273-AIDS or 415-434-AIDS, 5 pm - 5 am Pacific Time. Also offers Spanish-language hotline at: 1- 800-303 SIDA or 415-989-5212.
- **National Immunization Information Hotline**
  CDC specialists provide up-to-date immunization information, including vaccine schedules, side effects, contraindications, recommendations, and more. English and Spanish: 1-800-232-4636; TTY: 1-888-232-6348. TTY Service: 10 am - 10 pm, Eastern Time.

Informative and Supportive Websites

- **United States Department of Veteran's Affairs**
  The goal of the VA is to provide excellence in patient care, veterans' benefits and customer satisfaction. The department continues to offer their dedication and commitment to help veterans get the services and resources they have earned.
  Http://www.hepatitis.va.gov/
- **Hepatitis Central**
  A website dedicated to all the information you need about living with Hepatitis C, including the latest news about infection, transmission, symptoms, treatment breakthroughs and medical progress.
  Http://www.hepatitis-central.com/

- **American Liver Foundation**
  A national nonprofit organization dedicated to the prevention, treatment, and cure of hepatitis and other liver diseases through research, education, and advocacy. Web site features a database directory of hepatitis clinical trials, lay-oriented facts sheets, and links to additional resources.
  Http://www.liverfoundation.org/
- **Centers for Disease Control and Prevention: Viral Hepatitis**
  Information on all types of viral hepatitis from the CDC's National Center for Infectious Diseases. Site features related CDC guidelines and recommendations as well as training materials, slide sets, fact sheets, and key CDC hepatitis documents.
  Http://www.cdc.gov/hepatitis/index.htm
- **HIVandHepatitis.com**
  Commercial site with conference coverage, news stories, and links on hepatitis B, hepatitis C, HIV, and viral hepatitis/HIV coinfection.
  http://www.hivandhepatitis.com/
- **Hepatitis Foundation International**
  http://www.hepfi.org/
- **Hepatitis C Connection**
  http://www.hepc-connection.org/

Hepatitis Resources in Southern Nevada

Included in this section:

Patient Resources & Clinics 21-24

Hepatitis C Screening and Medical Care Locations

- **Great Basin Primary Care Association / AccessHealth Program**
  2801 S. Valley View Blvd., Suite 12
  Las Vegas, NV 89102
  (702) 430-3580

  If you are un-insured or underinsured please contact AccessHealth Program to find out if resources are available to provide health care assistance.

- **Bridger Health Center**
  310 S. 9th St., Suite 110
  Las Vegas, NV 89101
  (702) 220-9932

- **Cambridge Family Health Center**
  3900 Cambridge St., Suite 101
  Las Vegas, NV 89119 (702) 307-5415

- **NLV Family Health Center**
  2320 McDaniel St., Suite C North
  Las Vegas, NV 89030
  (702) 214-5948

- **MLK Family Health Center**
  1700 Wheeler Peak Dr.
  Las Vegas, NV 89106
  (702) 383-1961

- **Eastern Family Medical and Dental Center**
  2212 S. Eastern Ave.
  Las Vegas, NV 89104
  (702) 735-9334

  Nevada Health Centers, Inc. provides medical and dental care to all patients. It accepts most insurance programs, Medicaid, Medicare, Nevada Check-Up, Women's Health Connection and it offers a sliding fee schedule to uninsured patients.

  Appointments are strongly recommended; some sites do see walk-ins for emergency needs. Call the medical center to check on walk-in availability and to confirm the necessary documents

  required for the sliding scale program; such as a proof of income, proof of home address, proof of dependents, and picture I.D.

  Each facility has a physician on duty. There is a pediatrician at NLV Family Health Center, a pediatrician at the Medical and Dental Center, and a pediatrician at Cambridge Family Health Center. There is also a dentist at the Medical and Dental Center.

Depending on income, the fee to see a physician may be as low as $25 and $15 for each lab test. The minimum payment for the dental care is $45.

- **Hepatitis C Treatment Clinic for Veterans**
  Dr. Farooq Shaikh
  3880 S. Jones Blvd.
  Las Vegas, NV 89103
  (702) 636-3005

  Veterans may call for both medical and counseling services eligibility. The VA provides a wide range of medical, counseling and support services.

Hepatitis C Support Groups

- **Community Counseling Center**
  1120 Almond Tree Ln., Suite 207
  Las Vegas, NV 89104
  (702) 369-8700
  Contact person: Bob Barone

  Support group is held every Tuesday from 3 p.m. to 4:30 p.m.

- **Sunrise Hospital and Medical Center**
  Physician's Conference Room
  3186 S. Maryland Pkwy.
  Las Vegas, NV 89109
  Contact person: Sandra Hart
  (702) 796- 9111

  A hepatitis C support group meets the first Monday of each month from 6 p.m. to 7 p.m.

Hepatitis C Support and Resource Programs

- **Be In Charge program and the RediPEN Answer Line**
  Be In Charge program and the RediPEN Answer Line 1(888) 437-2608 (24-7 nurse support) Website: www.beincharge.com

  Be In Charge Program is sponsored by Schering-Plough Corporation. It offers free personal support to people diagnosed with hepatitis C who are either not yet on therapy or who are

  Receiving PEG-INTRON (peginterferon alfa-2b) Powder for Injection alone or in combination with REBETOL (Ribavirin, USP) Capsules; or INTRON A (interferon alfa-2b, Recombinant) for injection therapy. People enrolled in the program have access to specially trained nurses and educational materials. If participants choose, a personal nurse counselor will be assigned to them who will call them

periodically to answer their questions and encourage them throughout their therapy.

- **Pegassist Resource Center**
  1 (877) 734-2797 (24-7 nurse support)
  Website: www.pegassist.com Local Representative:
  Richard Mayorga (702) 233-9057

  Pegassist is a comprehensive patient education and support program. It provides important information about hepatitis C, treatment options, and tips for daily living when you have hepatitis C. The program also provides a toll-free telephone number to talk to nurses—24 hours a day, 7 days a week—who will provide guidance throughout your treatment with PEGASYS alone or in combination with COPEGUS® (Ribavirin, USP). This program is supported by Hoffmann-La Roche Inc.

Hepatitis C Patient Assistance Program

- **Commitment to Care**
  1 (800) 521-7157

  Commitment to Care is a program sponsored by Schering-Plough. It assists hepatitis C patients in providing lifesaving drugs at no cost to eligible individuals. These medicines include PEG-INTRON (peginterferon alfa-2b) Powder for Injection; REBETOL (ribavirin, USP) Capsule; and INTRON A (Interferon alfa-2b, recombinant) for Injection.

- **Roche Patient Assistance Foundation**
  1 (877) 75ROCHE (877-757-6243)

  Roche Patient Assistance Foundation is a program which provides Pegasys (peginterferon alfa-2a) free to patients who lack prescription coverage and the means to pay for the medications they need. Roche does not charge a co-payment and does not limit the time a patient may receive free medication.

- **Caminar**
  3233 W. Charleston Blvd. #110
  Las Vegas, NV 89102
  (702) 471 6360

  Caminar/Nevada provides both community living and assisted living programs for people with HIV/AIDS, including those with HIV/HCV co-infection. Caminar/Nevada also operates several smaller housing facilities in the Las Vegas area and extends HIV/AIDS support services to families as well as to individuals affected by the disease – with the goal of keeping family together in supportive environments. Caminar provides individualized services based upon client need and choice. Support services include: housing, transportation, assistance with medical appointments, shopping, meal preparation and planning, advocacy, access to community resource and supportive counseling.

- **Clark County Social Services**
  Main Office 1600 Pinto
  Lane Las Vegas, NV 89106
  M-F 6 a.m. - 5 p.m.
  (702) 455-4270
  (800) 492-3177 - Rural Clark County

  Clark County Social Services has additional locations, but they suggest an early arrival for "screening" to determine eligibility for Medical Assistance Services.

  Some of the services that may be provided are medical assistance, financial assistance, long-term care, counseling, and homeless services etc.

  Specialty Pharmacy Services

- **Consumer Health Assistance**
  555 E. Washington Ave., Suite 4800
  Las Vegas, NV 89101
  (702) 486-3587
  (888) 333-1597
  www.govcha.state.nv.us/

  Consumer Health Assistance offers prescription medication assistance for people who can't afford medication. Manufacturers provide free miedication to patients who are unable to afford it. Consumer Health Assistance helps clients determine alternate options.

- **Walgreens Option Care**
  3920 W. Charleston Blvd. Suite H
  Las Vegas, NV 89102
  (702) 258-0011

  Option Care provides specialty pharmacy therapies for hepatitis C.