

HOPE



First
Steps
with
HCV
for the
Newly
Diagnosed



HCV ADVOCATE
www.hcvadvocate.org

HCSP FOR LIVING POSITIVELY BEING WELL HEPATITIS C SUPPORT PROJECT

First Steps with HCV for the Newly Diagnosed

TABLE OF CONTENTS

1.	Introduction Letter	2
2.	FAQs	3
3.	Getting Organized	7
4.	Choosing a Medical Provider	9
5.	Medical Provider Information	11
6.	Maximizing Your Medical Appointments	12
7.	New Appointment Checklist	14
8.	Your Medical History	21
9.	Medication and Supplement History	22
10.	Medication Guidelines	24
11.	Tips for Lowering Prescription Drug Costs	26
12.	Follow-up Appointment Checklist	26
13.	Medical Appointment “Short Form”	33
14.	Calling Your Medical Provider	34
15.	More Tips about Medical Appointments	35
16.	The Medical Alphabet	36
17.	HCV Laboratory and Diagnostic Tests	38
18.	HCV Lab Tracker	40
19.	Do’s and Don’ts	42
20.	Tips for Living Well	44
21.	Resources	45
22.	Notes Page	47

Letter to Someone, Newly Diagnosed with Hepatitis C

Greetings,

You recently found out that you have hepatitis C. Being diagnosed with this brings up a lot of feelings and questions about hepatitis C.

Some frequently asked questions are:

- What is hepatitis C?
- Is it serious? Will I die?
- Will I need a liver transplant?
- Is there treatment for hepatitis C?
- Can “natural medicine” help me?
- Is it contagious? Can I give it to my family and friends?
- How did I get it? How long have I had it?
- Does this mean I am disabled?
- Where do I get help, information and support?
- What do I do next?

Enclosed is information to help you find answers to your questions. This information is basic and assumes that you have very little knowledge about hepatitis C. Hopefully it reassures you. How can information about a disease be reassuring? We believe that once you get the facts, the future will look a little brighter.

In the beginning, you might be scared or angry. You might feel hopeless or depressed. You might try to ignore the situation, telling yourself that this is not a big deal. These reactions are normal. These feelings will not go away overnight. This is part of the process of living with a disease.

You are not alone. There are millions of people in the United States and the world living with hepatitis C. What you don't know yet is what some of us have learned over time - that hepatitis C can teach you how to live better. Sure, most of us would rather live without hepatitis C. Treatment for hepatitis C is effective for about one-half of those who try it. So someday, you actually may have the experience of living without it. However, until that time comes, it is important to learn how to live with it.

You are embarking on a process that will teach you how to make the best of a bad situation. Some people take better care of themselves after having this “wake-up call.” They become healthier because they know that their lives depend on it.

For now, lean on the rest of us who have faced this for a long time. We probably have experienced some of what you are going through and are more than willing to help. You do not have to go through this alone. Enclosed is information that will get you started.

Lucinda Porter, RN

2. Frequently Asked Questions

Here are some brief answers to some common questions. For more complete information, visit the Hepatitis C Support Project's website at www.hcvadvocate.org

What is hepatitis C?

Hepatitis C is a disease caused by the hepatitis C virus (HCV). It primarily affects the liver and over time can damage the liver and health of an individual. Usually it takes a long time to do any damage, especially if the person who has it doesn't drink alcohol and lives a healthy lifestyle. Sometimes the damage is so minimal that people will go through their entire lives without knowing they have HCV.

Is HCV rare?

No. Approximately 3 to 4 million people in the United States have HCV. Worldwide, more than 170 million people have HCV.

How is hepatitis C diagnosed?

It is diagnosed with a blood test. The first test most people have is an HCV antibody test. If this is negative, it means you do not have hepatitis C, assuming you have not been exposed in the past 6 months. If the results are positive, then you need a different blood test called a viral load test. It is important that you have this second test because some people have a positive HCV antibody test but do not have HCV. Until you have this test, you will not know for sure if you have HCV.

Is it serious?

Maybe. It should be regarded as a potentially serious problem. The good news is that for most people, HCV will not create major health problems. Your medical provider will be able to determine the seriousness of your particular situation.

Will I die from HCV?

Most people will die with HCV and not of HCV. Out of 100 people who have hepatitis C, 3 or fewer will die an HCV-related death.

What are the symptoms of hepatitis C?

Some people have little or no symptoms. This could be because they hardly have any liver damage. Unfortunately, it also could be because the liver is a "non-complaining" organ. This means that there could be a lot of liver damage and hardly any symptoms. The most common symptom of HCV is fatigue. Body aches, flu-like symptoms, depression, and abdominal discomfort are also symptoms of HCV. Since these are symptoms of many medical conditions, it is important to seek medical help.

How do I know if my liver is damaged?

The most accurate and reliable way to find out is by having a liver biopsy. Research scientists are trying to develop other ways to measure liver damage, but liver biopsy is the most reliable.

Does having HCV mean I am disabled?

No, it does not automatically mean you are disabled. The majority of those with HCV are able to work and function well. However, HCV does impact everyone differently and may interfere with work and quality of life.

Will I need a liver transplant?

This is very unlikely. The majority of people living with HCV will not need a liver transplant.

Is there treatment for hepatitis C?

Yes. Currently the treatment involves combining two drugs, peg-interferon and ribavirin. The effectiveness of these drugs is about 50 %. Depending on specific factors, your chances can be as high as 80%. These drugs do have side effects. Talk to your medical provider about whether treatment is right for you.

If I decide to undergo treatment, when should I start?

This depends on a number of factors. It is important to be informed about the treatment, what is involved, the side effects and costs. Also, you need to evaluate the current factors in your life. Talk to your medical provider about this. Treatment decisions do not need to be made instantly. If you need to delay treatment, ask your medical provider if you can do so safely and for how long?

Is HCV treatment expensive?

Yes. However, many insurance plans cover most of the cost. See if you qualify for a pharmaceutical patient assistance program. For more information contact Partnership for Prescription Assistance www.pparx.org or Needy Meds www.needymeds.com

Can “natural medicine” help me?

No herbs, supplements or alternative treatments have been proven to effectively treat HCV. Some herbs can be harmful and even lethal. Some people have experienced health improvement from acupressure, acupuncture, meditation, Tai Chi, Yoga and other complementary health practices.

Is there anything I can do to help my liver?

Yes, there is a lot you can do. First, talk to your medical provider. Avoid alcohol. Do not eat raw or undercooked shellfish. Get regular medical care. If you have never had hepatitis A or B, be sure to get vaccines to protect you from these. Try to live the healthiest lifestyle possible. Avoid or exercise caution with potentially liver toxic drugs, supplements, and chemicals.

How did I get it?

HCV may be transmitted during activities that involve blood. In order to acquire HCV, a person's blood needs to be in contact with HCV-infected blood. This can happen in various ways. Some common ways are from blood transfusions before 1992 and sharing needles or other injection drug utensils. There is an occupational risk to those who have had a needle-stick injury or mucosal exposure to HCV-positive blood. There is low risk of acquiring HCV sexually or for a mother to transmit it to her fetus during pregnancy. There are other ways to acquire HCV and it is important to obtain more information about this. It is normal to wonder how you got hepatitis C. However, it can be unhealthy to obsess about this. Try to focus on what you can do for yourself now, rather than on the past.

How long have I had it?

Your medical provider can help you determine this. Sometimes it is easy to answer this, but often an educated guess is made based on risk factors, medical history and your current health information.

Is it contagious? Can I give it to my family and friends?

Yes, it is contagious, but mostly only through blood. It is usually transmitted when people come in contact with someone's blood, such as by sharing contaminated needles, piercing and tattooing instruments and other blood-related practices. If you do not share these with your family and friends, it is unlikely they will get HCV from you. We do recommend that you do not share razors, toothbrushes and other instruments that may have your blood on it. We do not know for sure that sharing personal items is a risk, but it is better to be safe. Always cover any bleeding wounds or sores. It is not transmitted by hugging, kissing, sneezing, coughing, sharing eating utensils or glasses, or by casual contact. Although the risks are low, it is recommended that family members be tested, especially children of women who may have had HCV at the same time they were pregnant. You should not donate blood or semen. Body organ and tissue donation is made on a case-by-case basis. There is a major shortage of donated organs, so sometimes an HCV-positive organ is used for an HCV-positive recipient.

What about sex?

This is a sensitive, complicated and important subject. The research is confusing. The Centers for Disease Control (CDC) does not recommend any changes in sexual practices between monogamous, long-term partners. Sexual transmission rates increase with multiple sexual partners. It is important to get accurate information about sexual transmission of HCV.

Should I tell my sex partner(s)?

Yes. Sex is a basic part of life. None of us would be here without it. However, many of us are uncomfortable talking about it. Honesty and openness are important. Be honest with yourself and your partner(s). If your partner is uncomfortable with the current sexual practices in your relationship, it is his or her right to express and change this. If you want to practice safer sex, it is your right to express and change this.

What should I tell my partner, family, employer and co-workers?

Legally, you are not required to tell anyone. There are advantages and disadvantages to telling others. For more information about this, see: HCSP's Easy C Facts: Whom Should I Tell? and Hep C Basics: Disclosure.

How do I talk to my children about this?

It depends on their age and your assessment of your children's ability to handle this information. Since children can sense when we have something on our minds, it's a good idea to talk to them so their imaginations don't make things worse than they might already be. Try to find something genuinely reassuring to tell them. Be brief but truthful. Ask them if they have any questions. The CDC recommends that family members be tested. Talk to your children's doctor about this. If your children are adults or old enough to give their assent, talk to them about testing. The most important issue to discuss is prevention. Make sure they know never to use your toothbrush, razor or cuticle clippers. Explain to them that they shouldn't share anyone's personal items.

Is there a vaccine that protects against HCV?

No, not at this time.

What do I do next?

Get accurate information and support. Avoid alcohol. Attend a support group. Try to make healthy choices. Find a medical provider who has a lot of experience working with HCV patients and is someone you trust. If you have any reservations about your medical provider, get a second opinion.

Where do I get help, information and support?

For more information about HCV from HCSP, see:

- Easy C: A Guide to Understanding Hepatitis C
- A Guide to Understanding Hepatitis C
- HCSP's Fact Sheet Series

The Hepatitis C Support Project lists support groups, HCV specialists and has information about hepatitis C in multiple languages. The website is **www.hcvadvocate.org**

3. Getting Organized for the Health of It

Organizing your healthcare records has advantages. These are:

- Allows you to use your time more efficiently
- Will help you get the most out of your medical appointments
- Reduces “where did I put it” frustration
- Maximizes your ability to effectively navigate the medical system
- Ensures that at least someone has “all the information”
- Emphasizes the fact that you are in charge of your own health

How to Organize

Start by asking for copies of your medical records. Although you have a right to copies, it is a common legitimate practice to charge a fee for this. From now on, make it part of your routine to ask for copies of every important piece of your medical records, especially test results. You do not need a copy of everything. The most recent copies are usually sufficient. Important medical documents to have are:

- Hepatitis C viral load (HCV RNA)
- Genotype
- Results from liver function tests, especially ALT and AST values
- Most recent complete blood count (CBC)
- Liver biopsy pathology report
- Ultrasound and imaging reports
- Hepatitis A and B immunization records or lab results or dates for those who have a history of either of these
- All recent lab results that screen for other diseases or conditions

Here is a list of medical information that everyone should maintain, young, old, healthy or living with a chronic disease:

- Allergy list – Include medications, foods, insects, latex, chemicals, etc.
- Your medical history from your perspective (see Your Medical History)
- Medication log (see Medication and Supplement History sheet)
- A list of major diseases in your family
- Notes with dates and purposes of major surgeries or other procedures
- Ongoing journal of major medical events from this day forward
- A list of current health concerns and questions
- Immunization records
- Contact information of all your medical providers (see Medical Provider Information sheet)

- Emergency contact information
- Health screening reminders and results
- Health insurance information
- Medical card or medical identification number
- Advance Directives (Legal documents stating your wishes for end-of-life care and your designation of someone to advocate for these wishes)

Store everything in one place. Use whatever system you prefer - a notebook, file cabinet, computer or a box. The important goal is to make it a habit to keep all your records in one place. If you store information on your computer, make sure you keep a back up copy.

Keep all your appointment information in one calendar or date book. You can also use this to record when you start or stop medications and other medical-related events.

Make it a habit to update your home medical records after each medical visit or event. Do an annual review. Pick a memorable date for this review, such as your birthday, New Year's Day, or the day after you file your income taxes.

Home Health Library

Some communities and hospitals have excellent reference libraries. Kaiser Permanente has many resources for its members. You can also start your own home health library. You can save money by purchasing books at library book sales, used bookstores, and garage sales. See Resources for a more complete list. Here are a few suggestions:

- General medical reference books. Many are written for people without a medical background. The American Medical Association, the Merck Manual and the publishers of the "PDR" offer excellent reference books for people without a medical background.
- Books focusing on health improvement. *The Owner's Manual: An Insider's Guide to the Body that Will Make you Healthier and Younger* by Roizen and Oz is a good one.
- Books about hepatitis C. There are many good ones. Dr. Melissa Palmer's *Guide to Hepatitis and Liver Disease* is comprehensive and easy to understand.

4. Choosing a Medical Provider

Finding a new doctor or other medical professional can take a little effort. Doing some homework up front can make your first appointment go more smoothly. Start by asking for a referral. If you are currently satisfied with one or more of your medical providers, ask that source for a referral. You can also ask family, friends and co-workers for suggestions. If you attend a support group, that is another excellent resource.

Next you can check the provider's background. After you have some names, you can use the Internet to confirm that the provider has a current license. The American Medical Association (AMA), your state's medical board and the county medical association have information about physicians.

www.ama-assn.org/aps/amahg.htm – Can verify a physician's credentials. Also has tips on how to choose a doctor.

www.docboard.org – Keeps records of malpractice judgments for some states and has links to other states.

www.searchpointe.com – Searches for malpractice judgments against physicians.

www.docinfo.org – Searches for malpractice judgments for a \$10 fee per physician.

linux.hcvadvocate.org/cgi-bin/doctor_lookup1.cgi – The Hepatitis C Support Project's physician database.

Some clinics and hospitals that are affiliated with medical schools use interns, residents and fellows as part of their team. Interns are in their last year of medical school. They have a good deal of medical training up to that point. Residents are physicians who are training in a specialty, such as internal medicine or gastroenterology. Fellows are advancing their training in a specialized area beyond residency, such as oncology. The advantage to you is often more time and attention during your medical appointment. Many medical students and new physicians have made a significant impact on their patients' lives. There is also the satisfaction of knowing you are an important part of the medical education process when you see someone during his or her training.

Tip: *Teaching hospitals and clinics rotate new interns, residents, and fellows during the months of July (and sometimes January). Always ask who will actually be performing any procedures. If you have the option to wait and it is medically safe to do so, you may want to avoid complicated elective procedures during July or January.*

Here are some questions to help you choose a medical provider. You can ask these over the phone when talking to the office staff, thus saving precious face-to-face time.

- Ask if the provider is accepting new patients.
- Find out how soon you can be seen. What is the typical wait time for an appointment?

- Is your insurance accepted? If so, be certain you understand any co-pays, deductibles, or other out-of-pocket costs for which you may be responsible.
- Does the office bill your insurance or will you need to pay the fee directly and manage the insurance reimbursement yourself?
- What are the fees? Does the provider charge for time spent talking to you on the phone?
- If you are seeing a nurse practitioner or physician assistant, then who is the physician overseeing his/her practice?
- Will you be seeing an intern, resident or fellow?
- Will you be seeing the provider you have been assigned or will you see other people in that medical group?
- Which hospital is the physician affiliated with?
- Does the medical group have an advice nurse who is available for phone calls?

After you have met with the medical provider, take a moment to reflect on the appointment. Consider the following:

- Did the provider seem knowledgeable and experienced?
- Does this provider communicate well?
- Do you feel the provider gave you his or her full attention?
- Is this a person you would want on your medical team?

A Word of Encouragement:

You are the owner of your body and your health. Choosing a medical provider is like assembling a team. It is up to you to gather experts to advise and support you. If you choose a good team of experts and get reliable advice, then it is up to you to either follow that advice or tell your providers why you are unable or unwilling to follow it. Good communication goes hand-in-hand with good medical care.

5. Medical Provider Information

Provider's Name	Phone Number	Address	Notes
Primary Care Provider:			
Nurse(s):			
Specialists			
GI/Hepatology:			
Nurse(s):			
Other:			
Other:			
Other:			
Pharmacist:			
Dentist:			
Other:			

6. Maximizing Your Medical Appointments

The time we spend talking to our doctors or other medical professionals seems to be getting shorter. Here are some tips on how to maximize the time spent with your care provider.

1. Be prepared. Take the time before your appointment to write down all of your medications, any pertinent allergies, a brief medical history, and your chief health complaints. Include the names, addresses, and phone numbers of your primary care provider and any specialists that might be linked to your current medical issue.
2. You can prepare for your medical appointment by prioritizing and writing down your questions.
3. Maintain your own health records. It can really help expedite matters if you bring copies of your most recent pertinent medical reports.
4. Make eye contact before speaking to your medical provider. Once you begin speaking, your provider may take notes. This does not mean s/he is not listening.
5. Before you start with your list, ask how much time the provider has for questions. Respect these limits and you will benefit in the long run.
6. Prioritize your health issues. Be brief but clear. Start with the most important details and if there is time, you can add the less important information at the end. If you have any fears or feelings, discuss them. It can be reassuring to learn that your symptoms have nothing to do with some disease you have been dreading.
7. When describing your symptoms, begin with the general picture and end with the specifics. Example: My stomach hurts. I feel nauseous in the morning.
8. Ask for clarification. If your doctor uses words or explanations you do not understand, ask her to clarify or simplify her words.
9. Take notes. If the doctor makes suggestions, write them down. Ask him to spell any words you might want to refer to later, such as a diagnosis, medication or procedure. If during the appointment you don't have time to write everything down, write your notes immediately after while sitting in the lobby or your car.
10. Take a friend. This is especially important for appointments that may be long, complicated, or not routine. Ask your companion to take notes for you. If it's all right with your provider, you can also audiotape the appointment.
11. If medication is prescribed, ask what the common side effects are and how the medication should be taken.
12. Express your reservations. If your doctor suggests a treatment plan that you have some concerns about, let her know. Sometimes these concerns can be easily addressed.

13. Ask if there are any alternatives. If your doctor makes a treatment suggestion and it is not one that you are prepared to follow, ask about other options.
14. Keep an open mind. This can be your strongest ally. It is amazing how many people will avoid a medication because of their fear of side effects, only to find out later that the reality was not anywhere near what they imagined.
15. Ask the physician if there are resources or support groups she would recommend.
16. Discuss the follow-up plan. If diagnostic tests are ordered, ask the provider when you can expect the results and how these results will be conveyed to you. When does your provider want to see you next? Ask if there are any signs or symptoms that could be urgent and need immediate reporting. If the results are going to be disclosed at your next appointment, and if there is going to be a long interval between appointments, ask how you can obtain earlier results. Additionally, ask the physician what is the best way to contact his office should a need arise that may not require an office visit.
17. If this is a follow-up appointment, ask for copies of diagnostic test results and surgical reports. This sets a standard that you are the manager of your health care. It also makes it easier to give copies to other health practitioners.
18. If you run out of time and still have more questions on your list, ask how you might be able to get the answers to your questions without disrupting the physician's schedule. Ask if you can leave a copy of the questions along with the request that they call you back within a specified time frame.

Knowledge is Power

How can the average patient with little or no medical training separate fact from fiction? Start by looking for genuine experts whom you trust. Ask your doctor or nurse for reliable resources. Support groups can be a great place for finding trustworthy information. Ask what websites and literature other people depend upon. Be objective and patient. Learning to think critically is a skill. Practice this as much as possible and in time you will be forming opinions based on evidence and reason. This is knowledge.

7. New Appointment Checklist for HCV Patients

It is highly recommended that you bring an advocate with you to your first few or any complicated medical appointments. This can be a friend, family member or someone from your support group.

Complete part A of this form and bring it with you when you see a medical provider for the first time. If you can, bring copies rather than your own copy of your records. Complete part B during or after your medical appointment.

PART A

Bring the following if you have them:

- Your advocate
- Laboratory test results
- Liver biopsy pathology report(s)
- Liver ultrasound or imaging report(s)
- Hepatitis A and B immunization records or lab results (if available) for those who have a history of either of these
- Allergy list – Include medications, foods, insects, latex, chemicals, etc.
- Your medical history from your perspective. Start with your current medical problems. (*see Your Medical History*)
- Medication and Supplement Log (*see Medication and Supplement History Log*)
- A list of major diseases in your family
- Notes with dates and purposes of hospitalizations, major surgeries or other procedures
- Emergency contact information
- Contact information of all your medical providers
- Health insurance information
- Medical card or medical identification number
- Appointment book or calendar
- For women – date of last menstrual period

What is your main health concern? _____

What questions or concerns do you want to cover during this appointment?
List in order of importance, starting with the most important:

If you have symptoms, what are they? _____

Do these symptoms interfere with anything, such as sleep, exercise, eating, or quality of life? _____

If you are experiencing pain, how much pain are you having? Rate this on a pain scale of 1 to 10, with 1 being the least and 10 being the most pain. _____

How long have you had these symptoms? What makes them worse? What makes them better? _____

PART B

MEDICAL PROVIDER'S COMMENTS

Summary of visit: *You or your advocate can complete this during or immediately after your appointment.*

Note: This is a very thorough form. If your medical provider does not have time to answer all your questions, ask for the best way to get these answers. There may be someone else in the office that can help you. Some providers will call or email you later when they have more time.

Write down information from assessments, such as blood pressure and weight:

What is the name for your medical problem (diagnosis)? _____

What is the likely course (prognosis) of your medical problem? _____

Are there any symptoms you should watch out for or need to call the provider for?

What does your medical provider want to do next? _____

(If medication, treatment, surgery, or medical tests are ordered, see the next few pages.)

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment.

Is there anything you can do to help your problem or improve your health? _____

If your medical provider wants you to see another specialist, nurse, dietician, etc, what is the name and reason? _____

Where can you get more information or support about this problem? _____

Does your medical provider want you to return for an appointment? Yes No

If yes, when? _____

Other Comments or Notes

LABORATORY AND OTHER MEDICAL TESTS

(Make multiple copies of this page in case your medical provider orders multiple lab tests)

If you have any concerns or reasons why you might not be able to have these recommended tests, state them during the appointment.

Do you need laboratory or other diagnostic tests? Yes No

If yes, when should you call or return for test results? _____

If yes, complete the following:

Name of test: _____

Reason for the test: _____

What is involved? _____

Do you need to do anything prepare for it? _____

Does anything affect the results, such as drugs, alcohol, food, etc? _____

Are there any risks or discomfort involved with this test? _____

Who will do it? _____

Where will it be done? _____

How soon does it need to be done? _____

When and how do you get the results? _____

Where can I get more information about this test? _____

Other comments:

MEDICATIONS AND TREATMENTS

(Make multiple copies of this page in case your medical provider orders multiple medications or treatments)

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment.

Note: When you pick up your medications, read the label and make sure it states the same information your medical provider told you.

Do you need any medication or treatment? Yes No

If so, complete the following:

Name of medication or treatment: _____

Is a generic form available? _____

Do the provider have any samples in the office for you to try them first? _____

Reason for the medication or treatment: _____

How much should you take? _____

How often should you take it? _____

When should you take it? _____

How long will you need to take this medication for? _____

Will it interact with any other medications or supplements you are taking? _____

Should you take it with or without food? _____

What should you avoid while taking it, such as alcohol, grapefruit juice, drugs, certain foods, or activities? _____

What are the potential benefits? _____

What are the chances it will work? _____

What are the major risks and side effects? _____

How common are these risks or side effects? _____

How soon should you expect to see results? _____

If there are side effects, are there ways to manage these? _____

Are there any side effects you should report or that may be potentially urgent?

What might happen if you avoided or delayed taking this medication or treatment?

Are there other options? _____

Where can I get more information about this treatment? _____

Other questions or comments:

SURGICAL OR MEDICAL PROCEDURES

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment.

Remember: *It is your right to ask for a second opinion. It is often a good idea to get a second opinion if the surgery is complicated, or if you have reservations about the procedure or surgeon.*

Tip: *Teaching hospitals and clinics rotate new interns, residents, and fellows during the months of July (and sometimes January). Always ask who will actually be performing any procedures. If you have the option to wait and it is medically safe to do so, you may want to avoid complicated elective procedures during July or January.*

Name of procedure: _____

Reason for the procedure: _____

What is involved with the procedure? _____

Will you need any anesthesia and if so, what kind? _____

What are the possible benefits of the procedure? _____

What are the possible risks or complications? _____

How common are these? _____

What are the chances it will work? _____

How soon should the procedure take place? _____

Are there other effective but less invasive options? _____

What might happen if you avoid or delay the procedure? _____

What do you need to do to prepare for the procedure? _____

Name of person performing the procedure: _____

How much experience does the surgeon/doctor have with this procedure?

Will a resident be working with the surgeon or doctor? _____

Who will actually be performing the procedure? _____

Where will the procedure be performed? _____

How long will the procedure take? _____

How long will you have to stay after the procedure? _____

Will you need someone to drive you and care for you after the procedure? _____

How long is the recovery period? _____

Are there any restrictions after the procedure? _____

Will you have any discomfort after the procedure? _____

How are pain and other post-procedure problems treated? _____

If a biopsy is involved, how and when do you get the results? _____

Where can I get more information about this procedure? _____

Other questions or comments:

When you see a new healthcare professional the appointment starts with communicating details about your present and past medical history. The time you will have to talk will probably be short. You can maximize your time by preparing for the appointment. Keeping a written record of your medical history will help you use the time more efficiently. Bring a copy of this with you to the appointment. You can give your healthcare provider a copy or you can refer to it during the appointment.

What to include in a medical history:

- Your name, date of birth, and ethnic background.
- Any allergies to medications, food, or other substances.
- All dietary supplements and drugs that you are taking or have taken recently. Include prescribed, over-the-counter, etc.
- If you are pregnant or breastfeeding.
- Childhood illnesses and immunizations you have had and when.
- Any major illnesses you have been diagnosed with, especially those that are still active or have been diagnosed recently.
- Any surgeries you have had.
- Lifestyle - Are you married? Any children? What are their ages? What is your occupation? What is your birthplace?
- Describe your drinking, smoking, eating and exercise habits.
- Places you traveled to recently that may have exposed you to any health risks.
- Family illnesses and cause of death of close relatives.
- Any recent life changes, such as divorce, job change, death or illness of family member or close friend.
- The names, address, and phone numbers of all healthcare providers and pertinent past providers.
- Any recent diagnostic results or other medical reports.

8. Your Medical History

When listing your illnesses and surgeries, start with the most recent and work backwards. Your wisdom teeth removal when you were 15 years old is far less important than last year's gall bladder surgery. A recent diagnosis of thyroid disease is more important to mention than the bladder infection you had two years. The exception to this is if you are being seen for a current bladder infection and you get them frequently.

Try to be honest. It takes time to build trust. However, medical professionals who don't have all the information can't make informed recommendations. If a concern influences your ability to be truthful, state that. For example, "I don't want to tell you that I smoke tobacco because I don't want to be lectured about it. The truth is I smoke, I know it is bad for me, and I am not ready to quit at this time. If I need your help with this in the future, I will bring it up." This is a clear message. It tells the healthcare provider that you are a smoker, aware of the risks and relieves you of the fear of a lecture.

Stay current. Review your medical history annually and every time you have a change in your health. Pick an annual date for this review, such as around your birthday or after you file your income taxes. Keeping your medical history up to date before you have an urgent medical need will help you when you will need it the most.

9. Medication and Supplement History

	Name	How Much (Dose)	How Often	How Long	Reason	Prescribing Provider's Name
Regular						
Prescription Medication						
Non-prescription Medication						
Dietary Supplements						
Occasional/as needed						
Prescription Medication						
Non-prescription Medication						
Dietary Supplements						
Recently stopped (past month)						
Prescription Medication						
Non-prescription Medication						
Dietary Supplements						

Other						
Major medications taken in the past year						
Recreational drugs						

10. Medication Guidelines

Know the following about your medications:

- Generic and brand names of medication
- Reason you are taking the medication
- The dose of the medication
- The frequency you should take the medication
- The time of day you should be taking your medication
- If it will interact with any other medications or supplements you are taking
- If you should take it with or without food
- If you should avoid anything while taking it, such as alcohol, grapefruit juice, drugs, certain foods or activities
- The length of time you will need to take this medication
- If you need to finish the entire prescription
- The drug's expiration date
- The storage instructions for the medication
- The major risks and side effects
- If these risks or side effects are common
- If there are side effects, ways to manage these
- If any side effects should be reported or that may be potentially urgent
- How soon you should expect to see results
- What to do if you are late or miss a dose
- How to refill the medication
- How many days before you run out should you request a refill
- What this medication will cost you
- Where to get more information about this medication

Guidelines for Managing Medications Safely

1. Ask your medical provider if there are ways you can care for yourself that may help you avoid or reduce need for medications, surgery, or any invasive procedures.
2. Understand the correct instructions for taking your medication. Make sure these exactly match the prescription label. If the two instructions are not identical, clarify this before taking the medication.
3. Know the medication's side effects before you start taking it.
4. Before taking a new medication, ask if there are any medications or foods that should not be mixed with it.

5. Take the minimum effective prescribed dose unless advised otherwise.
6. Take medication with a full glass of water unless otherwise directed.
7. Ask if you are supposed to take all of your prescription. For instance, always take the entire prescription of antibiotics even if you feel better.
8. Never break, crush, or dissolve a pill, tablet, or capsule without making sure this is all right to do. Some medications need to be intact so stomach acids do not destroy them. If swallowing pills is difficult for you, tell your medical provider.
9. Do not take medication in the dark or without your glasses if you need them to read the label.
10. For liquid medications, use standard measuring spoons rather than eating utensils.
11. Try to take your medications on time. Find out what you are supposed to do if you are late or miss a dose. Never double up on a dose unless you are clearly instructed to do so.
12. If you have trouble remembering to take medication, ask a pharmacist, nurse or other health provider for tips. Calendars, alarms, computer reminders, notes and daily pill cases can provide reminders.
13. Do not take a medication that has expired, smells or looks odd to you. This is especially important for liquid medications.
14. If you pick up a prescription and the medication looks different from the last time you took it, talk to your pharmacist to make sure there has not been an error.
15. If you did not take the medication as prescribed, tell your medical provider.
16. Do not use someone else's medication or give your medication to anyone else.
17. Keep medications in their original container with a secure cap.
18. If the cap is difficult to remove, ask your pharmacist for a different type.
19. Store medications as directed.
20. If you are traveling by air, carry medications with you in the cabin. Keep them in their original containers with the prescription label.
21. Do not leave medications in a hot car.
22. Keep medications away from children's reach.
23. If you are or may be pregnant, tell your provider this before you take any medication. Also, mention if you are breastfeeding.
24. If you are hospitalized or in a position where someone else gives you your medication, look at what you are taking before you take it. If something does not look right, ask for clarification or assurance.
25. If you think you are having an allergic reaction to a medication, seek immediate medical help.
26. Formulate an emergency plan in case of accidental overdose or medical

emergencies. In the United States, 911 is the standard emergency phone number. If you use a cell phone, calls go to a central dispatch location. This can cause delays. Near your phone, post the numbers of your local poison control center, police, fire, physician, and hospital emergency room.

Poison Control Center: 1 (800) 222-1222

11. Tips for Lowering Prescription Drug Costs

Prescription drug costs are going up. Don't be embarrassed if you can't afford a medication. Nearly everyone has been hit by rising healthcare prices. The following are some cost-saving tips 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 Partnership for Prescription Assistance www.pparx.org or Needy Meds www.needymeds.com
- 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.
- 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.
- Ask if there are any clinical trials in your area using the drug treatment that you need.

12. Follow-Up Appointment Checklist for HCV Patients

It is highly recommended that you bring an advocate with you to your first few or any complicated medical appointments. This can be a friend, family member or someone from your support group.

Complete part A of this form and bring it with you when you see a medical provider for the first time. If you can, bring copies rather than your own copy of your records. Complete part B during or after your medical appointment.

PART A

Bring the following if you have them:

- Your advocate
- Any new test results that were ordered by another medical provider
- Medication log (see Medication and Supplement History Log)
- Any new information or allergies to add to your medical records
- Medical card or medical identification number
- Appointment book or calendar
- For women – date of last menstrual period

What is your main health concern? _____

What questions or concerns do you want to cover during this appointment? List in order of importance, starting with the most important. _____

If you have any new medical problems or symptoms, what are they? _____

Do these symptoms interfere with anything, such as sleep, exercise, eating? _____

If you are experiencing pain, how much pain are you having? Rate this on a pain scale of 1 to 10, with 1 being the least and 10 being the most pain. _____

How long have you had these symptoms? _____

What makes them worse? What makes them better? _____

Have you had any changes in your life that may have affected your health, such as death of a loved one, divorce, insomnia or substance use? _____

PART B

MEDICAL PROVIDER'S COMMENTS

Summary of visit: *You or your advocate can complete this during or immediately after your appointment.*

Note: This is a very thorough form. If your medical provider does not have time to answer all your questions, ask for the best way to get these answers. There may be someone else in the office that can help you. Some providers will call or email you later when they have more time.

Write down information from assessments, such as blood pressure and weight:

If you have a new medical problem, what is the name for your medical problem (diagnosis)? _____

What is the likely course (prognosis) of your medical problem? _____

Are there any symptoms you should watch out for or need to call the provider for?

Is there new information or treatment about your medical problem? _____

What does your medical provider want to do next? _____

(If medication, treatment, surgery, or medical tests are ordered, see the next few pages.)

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment. _____

Is there anything you can do to help your problem or improve your health? _____

If your medical provider wants you to see another specialist, nurse, dietician, etc, what is the name and reason? _____

Where can you get more information or support about this problem? _____

Does your medical provider want you to return for an appointment? Yes No

If yes, when? _____

Other Comments or Notes

LABORATORY AND OTHER MEDICAL TESTS

(Make multiple copies of this page in case your medical provider orders multiple lab tests)

If you have any concerns or reasons for why you might not be able to have these recommended tests, state them during the appointment.

Do you need laboratory or other diagnostic tests? Yes No

If yes, when should you call or return for test results? _____

If yes, complete the following:

Name of test: _____

Reason for the test: _____

What is involved? _____

Do you need to do anything prepare for it? _____

Does anything affect the results, such as drugs, alcohol, food, etc? _____

Are there any risks or discomfort involved with this test? _____

Who will do it? _____

Where will it be done? _____

How soon does it need to be done? _____

When and how do you get the results? _____

Where can I get more information about this test? _____

Other comments:

MEDICATIONS AND TREATMENTS

(Make multiple copies of this page in case your medical provider orders multiple medications or treatments)

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment.

Note: When you pick up your medications, read the label and make sure it states the same information your medical provider told you.

Do you need any medication or treatment? Yes No

If so, complete the following:

Name of medication or treatment: _____

First Steps with HCV for the Newly Diagnosed

Is a generic form available? _____

Do you have any samples in the office so you can try them first? _____

Reason for the medication or treatment: _____

How much should you take? _____

How often should you take it? _____

When should you take it? _____

How long will you need to take this medication for? _____

Will it interact with any other medications or supplements you are taking? _____

Should you take it with or without food? _____

What should you avoid while taking it, such as alcohol, grapefruit juice, drugs, certain foods, or activities? _____

What are the potential benefits? _____

What are the chances it will work? _____

What are the major risks and side effects? _____

How common are these risks or side effects? _____

How soon should you expect to see results? _____

If there are side effects, are there ways to manage these? _____

Are there any side effects you should report or that may be potentially urgent? _____

What might happen if you avoided or delayed taking this medication or treatment? _____

Are there other options? _____

Where can I get more information about this treatment? _____

Other questions or comments:

SURGICAL OR MEDICAL PROCEDURES

If you have any concerns or reasons for why you might not be able to follow the treatment recommendations, state them during the appointment.

Remember: *It is your right to ask for a second opinion. It is often a good idea to get a second opinion if the surgery is complicated, or if you have reservations about the procedure or surgeon.*

Tip: *Teaching hospitals and clinics rotate new interns, residents, and fellows during the months of July (and sometimes January). Always ask who will actually be performing any procedures. If you have the option to wait and it is medically safe to do so, you may want to avoid complicated elective procedures during July or January.*

Name of procedure: _____

Reason for the procedure: _____

What is involved with the procedure? _____

Will you need any anesthesia and if so, what kind? _____

What are the possible benefits of the procedure? _____

What are the possible risks or complications? _____

How common are these? _____

What are the chances it will work? _____

How soon should the procedure take place? _____

Are there other effective but less invasive options? _____

What might happen if you avoid or delay the procedure? _____

What do you need to do to prepare for the procedure? _____

Name of person performing the procedure: _____

How much experience does the surgeon/doctor have with this procedure? _____

First Steps with HCV for the Newly Diagnosed

Will a resident be working with the surgeon or doctor? _____

Who will actually be performing the procedure? _____

Where will the procedure be performed? _____

How long will the procedure take? _____

How long will you have to stay after the procedure? _____

Will you need someone to drive you and care for you after the procedure? _____

How long is the recovery period? _____

Are there any restrictions after the procedure? _____

Will you have any discomfort after the procedure? _____

How are pain and other post-procedure problems treated? _____

If a biopsy is involved, how and when do you get the results? _____

Where can I get more information about this procedure? _____

Other questions or comments:

13. Medical Appointment Checklist: The Short Form

Before your appointment

Prepare for the appointment by bringing the following:

- Brief summary of your main health concern
- Questions or concerns to cover during the appointment. Prioritize, starting with the most important
- Results of all lab or other procedures ordered by another medical provider. If you can, bring copies rather than your own copy of your records
- List of all medications and supplements you take (see Medication and Supplement History Log)
- Any new information or allergies to add to your medical records
- Medical card or medical identification number
- Appointment book or calendar
- It is highly recommended that you bring an advocate with you to your first few or any complicated medical appointments. This can be a friend, family member or someone from your support group.

During your appointment

Start with your main problem. Be brief and clear. Describe your symptoms and how these affect you. If this is a recurring problem, explain how it affected you and what was done.

If you have more questions or concerns, tell your medical provider. Ask your provider if you should state all your concerns now or after you have discussed the main problem first.

If medications, tests, surgery or other procedures are ordered, write down:

- Name of the medications, tests, surgery or procedures
- The reason for the medications, tests, surgery or procedure
- The risks involved
- The potential benefits
- What happens if you delay or avoid the medication, test, surgery or procedure
- How to take the medication or prepare for the test or procedure
- If you are referred to another specialist, nurse, dietician, etc, what is the name and reason
- How will you find out your test results

At the end of the appointment

- Are there any symptoms or danger signs to be aware of
- Is there anything else you need to know
- Does your provider want you to call or return for another appointment

After your appointment

During or immediately after the appointment, you or your advocate should write down the following:

- The name of your medical problem (diagnosis)
- What the medical provider wants you to do next
- What changes you can make that may help your problem
- Everything you can remember that your provider told you

14. Calling your Medical Provider

Here are a few tips when calling your medical provider:

- In one or two sentences, write down the reason for your call.
- List your symptoms and how long you have had them.
- Have calendar, pen, and paper available before you make the call.
- If the call is for a prescription refill, leave the name of the medication, the dose, amount, prescription number and the name and phone number of your pharmacy.
- Make your call first thing in the morning.
- Write down the name of who you spoke with. This may be a nurse, receptionist or answering service.
- Ask when you might expect a return call.
- Leave the phone number that has the best chance of getting through to you over the course of a day. For many people this is a mobile phone number. Few of us are in one place all day.
- Keep the phone line clear as much as possible.
- If the reason for your call can be resolved with a return message, state clearly if it is okay to leave a recorded message or to give the message to someone else who answers your phone. Some medical providers will not leave messages because of privacy regulations.

If your problem is serious or potentially life-threatening, call 911 or have someone take you to the nearest hospital. Examples of emergency situations that usually require an ambulance:

- Any symptom of a heart attack: severe chest pain, sweating, shortness of breath
- Severe bleeding or blood loss

- Breathing difficulties or unconsciousness
- Seizures
- Severe injury or poisoning

Some useful numbers to have near the phone:

- 911
- Poison Control Center: 1 (800) 222-1222
- Medical Provider
- Hospital
- Pharmacy
- Health Insurance Company and Member Identification

15. More Tips about Medical Appointments

Time spent seeing your medical provider is short. Here are some tips on how to set up a good appointment:

- Mondays and Fridays are often busier than the rest of the week. The best times to call for appointments are usually between 10 a.m. to noon and from 2 p.m. to 4 p.m.
- Have your medical number, insurance information and calendar on hand.
- If seeing your medical provider on time is important, ask for the first appointment of the morning or afternoon.
- If your condition is complicated or if having extra time is important to you, explain this at the time you make the appointment. It can be frustrating to find out that you were scheduled for a 10-minute time slot when you actually needed 45 minutes.
- You may also try asking for the last appointment of the day. However, keep in mind that you may have to wait longer because if others arrived late, that will accumulate by the day's end. Also, remember that on busy days, your medical provider may not have had a minute to eat or sit down. Even if you are sick, try to be considerate.
- When making the appointment, state if the appointment is routine or urgent. If you think it is urgent, be prepared to explain why you think so. For instance, "I have been vomiting for the last 48 hours" is urgent. "For the last two years I get a mild stomach ache every time I eat" may feel urgent but it probably is not.
- If the appointment you are given seems too far off, ask if you can be put on a cancellation waiting list. Cancellations are more common than you may think.
- Confirm your appointment a few days before and then keep the appointment. It is amazing how often people do not show up for appointments.
- Be on time. Being early is even better. Planning to arrive 15 minute early is a good rule of thumb.

- If you know you are going to be late, call the office. Sometimes you can still be seen.
- Be prepared to wait. Bring something to occupy yourself. There are many reasons why medical providers can run behind in their schedules.
- If your provider seems habitually late, call in advance and see if he or she is running behind. If appointments are running an hour behind, ask if you can arrive 45 minutes later than your scheduled time.
- Do not take frustration out on the staff. If you have been waiting excessively long you can request an explanation. Good manners go farther than irritability.
- If you know in advance that your time is short, tell the staff when you arrive or even call in advance. If you have an appointment and need to be across town in two hours, say so. Explain, “Something has come up and I need to leave here by such and such time. Have I allowed enough time to see the doctor?”
- If your provider wants you to return for a follow-up, make the appointment before you leave the office. Ask the staff to write the date and time down on a card with the office phone number so it is handy should you need to change the appointment.
- If you need to change or cancel an appointment, try to do so at least 24 hours in advance. Remember that other patients may need that time slot.

16. The Medical Alphabet

Our health is in the hands of numerous people with a variety of letters trailing their names. For instance, nurses can have over 50 different abbreviations after their names. What do these letters mean and what do these people do? Here are some definitions of some of common abbreviations for medical occupations you may encounter:

M.A. Medical Assistant – MAs perform routine clinical and clerical tasks. The MA may be the person who escorts you to the examining room, takes vital signs, and asks you some general questions. MAs are usually trained through a formal program, but are not licensed. MAs are supervised by physicians or nurses. (Note: Outside of medicine, “MA” generally means Masters in Art.)

N.A. Nursing Assistant – NAs work in hospitals at the same level as MAs. NAs may give patient baths, take vital signs, and help with patients’ basic needs. NAs are supervised by nurses and are not licensed.

R.N. Registered Nurse – RNs work in hospitals, clinics, homes and other community settings. They perform many tasks such as making patient assessments, educating patients, administering medications and other treatments. There are many types of nurses such as advice nurses, public health nurses, clinic nurses, surgical nurses, home health nurses and psychiatric nurses. RNs receive their training in a number of ways and may have a bachelor’s degree, associate’s degree, or nursing school diploma. The addition of a “C” followed by other letters signifies that the nurse is certified in a specialty. RNs are licensed and usually report to physicians or other advanced level practitioners.

L.V.N. or L.P.N. Licensed Vocational Nurse or Licensed Practical Nurse – These nurses function in much the same way as RNs. They are licensed, but have less education. The roles of LVNs and LPNs are slightly restricted from RNs, but there is a great deal of overlap. They are usually supervised by RNs, physicians, or other advanced level practitioners.

N.P. Nurse Practitioner – NPs are highly trained advanced practice RNs, who usually have at least a master’s degree. Sometimes NPs may have RNP, FNP or other letters following their names. These simply signify a focus in their education. The laws describing the scope of responsibility differ between states. NPs can work independently, but they usually work under a physician’s supervision. Usually the physician does not need to be immediately present in order for an NP to function. They can prescribe medications, order lab tests, and in certain cases, perform some surgical procedures and administer anesthesia.

P.A. Physician Assistant – PAs are highly trained mid-level practitioners who practice under the license and supervision of physicians. They usually have at least a bachelor’s degree. In general, PAs can practice in all medical and surgical specialties provided they are properly trained and supervised. Usually the physician does not need to be present in order for a PA to function. They can write prescriptions, order lab tests and do other medical tasks often performed by physicians.

M.D. Medical Doctor – MDs have attended medical school and passed rigorous licensing exams. They can be physicians or surgeons. There are a host of other letter combinations that can follow MD. These are earned when the doctor has obtained some advanced training, education or certification.

A note about HCV medical specialties:

- **Gastroenterologists** – These physicians specialize in diseases of the digestive system. The liver is part of that system.
- **Hepatologists** – These are gastroenterologists who specialize in liver diseases. Hepatologists usually practice in medical centers that have liver transplant programs.

There are many other combinations of letters that designate professional distinction. Pharmacist (PharmD), dentist (DDS), doctor of osteopathy (DO), doctor of chiropractics (DC) physical therapist (PT), respiratory therapist (RT) and so on. Professions such as Chinese medicine, naturopathy, etc. also have their own letter designations. If you see unfamiliar abbreviations following a name, ask about them. Professionals have earned those abbreviations and are usually happy to explain the meanings.

Each member of your healthcare team has a role. Although some have more training than others, their training makes them more suited for specific tasks. Learn how each is involved in your care. For instance, most of your phone conversations might be with the nurse, but it is actually the nursing assistant who talks to you at your appointments. If you see a physician assistant or nurse practitioner, ask if they will be your primary practitioner or if there will be certain times when you will interact with a physician. Knowing who does what can help streamline your care while at the same time build your medical support system.

17. HCV Laboratory and Diagnostic Tests

Medical providers frequently order these common tests for HCV patients. Keep track of your results. If your provider did not order some of these tests, you can request an explanation. Every person is different and your provider will tailor your care according to your condition.

- HCV antibody test
- HCV RNA – quantitative or qualitative (sometimes referred to as a viral load or viral count) Note: The qualitative is the more sensitive test. It tells you whether you have HCV. The quantitative test measures the amount of the virus you have. If quantitative HCV RNA is non-detectable, then a qualitative HCV RNA test should be done to confirm this. Some providers will order the qualitative test first and if that is positive, then perform the quantitative to measure the viral load.
- HCV genotype
- Liver or hepatic panel
 - ALT (alanine aminotransferase)
 - AST (aspartate aminotransferase)
 - Albumin
 - Alkaline Phosphatase
 - Bilirubin
- PTT, PT [INR]
- Complete Blood Count (CBC)
 - Platelets
 - Hemoglobin (HGB)
 - Hematocrit (HCT)
 - White Blood Cells (WBC)
 - Absolute Neutrophil Count (ANC)
- Hepatitis B tests (HBsAg, HBsAb, HBcAb)
- Hepatitis A antibody test (Some providers prefer to skip this and recommend vaccination.)
- Liver Biopsy
- Other

It is also important to rule out other diseases, especially other liver diseases. A thorough “work up” may include the following tests:

- Comprehensive chemistry panel – Can detect many abnormalities
- Thyroid tests (TSH)
- Iron tests: Ferritin, FE/TIBC
- Lipid panel or total cholesterol
- Ceruloplasmin if <50 years old
- ANA if female and globulin (total protein-albumin) greater than 4 g/dL
- AMA if itching is a major symptom, or if alkaline phosphatase known to be abnormally high
- HIV
- Urinalysis
- Pregnancy test (urine) if female of childbearing capacity
- AFP – Alpha-fetoprotein (usually not ordered if the patient does not have cirrhosis)
- Abdominal ultrasound
- Other

Many other tests may be ordered. Your medical provider will assess your symptoms and order what is necessary to evaluate your condition.

ALT = alanine aminotransferase

AST = aspartate aminotransferase

ALB = Albumin

AP = Alkaline Phosphatase

BIL = Bilirubin

PLT = Platelets

PT/INR = ProThrombin Time/International Normalized Ratio

19. Do's and Don'ts of Hepatitis C

Do's

- Join a support group
- Educate yourself
- Protect yourself from hepatitis A and B – get immunized (unless you have been previously infected)
- Stay away from alcohol, tobacco, excess caffeine and illicit drugs
- Find and maintain satisfactory medical care
- Be as physically active as you can
- Aim for 7 to 9 hours of sleep every night
- Learn to manage stress
- Eat a low-fat, low cholesterol, low sodium high-fiber diet with lots of fruits and vegetables
- Everything passes through the liver – if you don't want something to go through your liver, don't put it in your mouth, inhale it, or apply it to your skin unless medically ordered
- Discuss vitamin, mineral and herbal supplements with your doctor
- Maintain a healthy weight
- Drink generous amounts of water – 6 to 8 glasses a day
- Develop moderation in all aspects of life
- Keep copies of your medical records, especially current lab and biopsy results
- Notify your dentist and medical provider that you have hepatitis C
- Carry info in your wallet or purse listing your medications, medical providers and basic health information
- Tell family and friends that if your organs or tissues are needed for other HCV-positive people, you are willing to donate upon death
- Apply adhesive strips to cover wounds
- Use care when disposing of sanitary products
- Practice safer sex when appropriate
- Perform careful breast care when nursing

- Floss your teeth
- Label personal hygiene items, such as your toothbrush and razor, and remind others not to use
- Balance work, play and rest
- Look at the positive side of life
- Help others
- Wear your seatbelt. You may be in for a great ride
- In spite of all of the above, laugh and enjoy life

Don'ts

- Do not drink alcohol
- Healthy people should not exceed 4000 mg of acetaminophen (Tylenol) daily. Many medical providers recommend that people with liver disease should take less than the recommended daily amount of acetaminophen. Do not take acetaminophen without first consulting with your medical provider. Some prescription and over-the-counter drugs have acetaminophen as an ingredient, so include this in your calculation
- Do not share anything related to injection or inhaled drugs – needles, syringes, preparation water, cooker, tourniquet, etc. Clean the area where you use these items
- Do not eat raw or undercooked shellfish
- Do not take iron supplementation or multi-vitamin with iron without discussing it with your doctor
- Do not take large doses of any drug or supplement without medical supervision
- If you use herbs or supplements, familiarize yourself with those that may harm be harmful
- Do not donate blood or semen
- Do not jump into immediate treatment without weighing all of your options
- Do not obsess over whether or not you can pass this to others – be informed, use commonsense and do the best you can
- Do not feel guilty about having HCV – you did not intend for this to happen

20. TIPS FOR LIVING WELL WITH HCV

- Join a support group.
- Stay away from alcohol, tobacco, excess caffeine and illicit drugs. If you can't quit, cut back or ask for help.
- Keep your vaccinations current. Be immunized against hepatitis A and B.
- Aim for 7 to 9 hours of sleep every night.
- Strive to be as physically active as you can be on a regular basis. There are many choices, such as walking, bicycling, gardening, dancing, swimming, stretching, Yoga, Tai Chi or strength training. Just keep moving.
- Maintain a healthy weight.
- Eat a low fat, high fiber diet. Include fruit, vegetables, and whole grains. Avoid trans-fatty acids and saturated fats.
- Balance rest and activity.
- Cultivate a positive attitude.
- Avoid or reduce stress.
- Engage in activities that give you pleasure and make you laugh.
- Choose activities that stimulate your brain.
- Engage your spirit in meaningful ways, such as meditation, a walk in the woods, prayer.
- Learn to laugh at yourself.
- Drink at least 8 glasses of water every day.
- Maintain friendships and social contacts.
- Help others. Volunteer your time.
- Remind yourself of the things in your life to be grateful for or that you appreciate.

21. Resources

Community

Find out if your health provider offers resources. Some medical groups and health maintenance organizations (HMOs) maintain libraries and web-based resources. Kaiser Permanente has excellent books and resources for their members. Some hospitals maintain community libraries and the public library usually carries medical books and reference material. Employers and insurance companies frequently provide health improvement services. Some counties offer guides, identifying community resources.

Internet

www.hcvadvocate.org – This website is packed with information about many issues relating to hepatitis C disease management, treatment and support, and has links to many other websites.

www.healthfinder.gov – This is filled with health information. There are over 50 “on-line check-up” tools, including one that will help you create a heart-healthy diet.

www.healthypeople.gov/BeHealthy – The U. S. Department of Health and Human Services conducts this health promotion program.

www.hhs.gov – This web page of the U. S. Department of Health and Human Services links to other sources of information.

<http://health.nih.gov> – Links to extensive information courtesy of the National Institutes of Health.

<http://familydoctor.org> – Information and tools provided by the American Academy of Family Physicians.

www.mercksource.com – Provides information and easy to use health assessment tools.

www.mygoals.com – Offers tools for setting goals.

www.mayoclinic.com – Includes tools, information and even some recipes.

www.prevention.com – Covers nearly every aspect of general health.

www.osophs.dhhs.gov/ophs – Maintained by the Office of Public Health, this has links to other health-related websites. Be sure to visit the Office of Disease Prevention and Health Promotion’s website.

Publications

HCV and Liver Disease

Dr. Melissa Palmer’s Guide to Hepatitis and Liver Disease, by Melissa Palmer

The First Year-Hepatitis C: An Essential Guide for the Newly Diagnosed, by Cara Bruce, Lisa Montanarelli

The Hepatitis C Help Book – A Groundbreaking Treatment Program Combining Western and Eastern Medicine for Maximum Wellness and Healing, by Misha Ruth Cohen, Robert Gish, Kalia Doner

The Liver Disorders Sourcebook, by Howard J. Worman

Living With Hepatitis C For Dummies, by Nina L. Paul, Gina Pollichino

Living With Hepatitis C: Everything You Need to Know, by Jenny Heathcote, Colina Yim, Quynh Thai, Averell Sherker

Living with Hepatitis C: A Survivor's Guide (Third Revised Edition), by Gregory T. Everson, Hedy Weinberg

My Mom Has Hepatitis C, by Hedy Weinberg, Shira Shump, Gregory T. Everson, Joy Chen

Hepatitis Magazine www.hepatitismag.com Phone: 281-272-2744; Fax: 281-847-5440; info@hepatitismag.com

General Medical Reference

American Medical Association Complete Medical Encyclopedia, by American Medical Association

American Medical Association Family Medical Guide, 4th Edition, by American Medical Association

The Merck Manual of Medical Information: The World's Most Widely Used Medical Reference - Now In Everyday Language, 2nd edition by Mark H. Beers

Harvard, Johns Hopkins and the Mayo Clinic also publish general family medical reference books.

General Health Improvement

Lifelong Health from A To Z, by David A. Lipschitz

The Owner's Manual: An Insider's Guide to the Body that Will Make you Healthier and Younger, by Michael F. Roizen, Mehmet Oz

Spontaneous Healing: How to Discover and Embrace Your Body's Natural Ability to Maintain and Heal Itself, by Andrew Weil

A Word of Encouragement:

“The secret of health for both mind and body is not to mourn for the past, worry about the future, or anticipate troubles but to live in the present moment wisely and earnestly.” - Buddha

