First Steps with Hepatitis C for the Newly Diagnosed

For living positively, being well
As I take my first steps with hepatitis C, I am not alone because of all those who will help me along my journey with their wisdom, encouragement and hope.
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Hello,

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 virus infection (HCV)?
- 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, all of us would rather live without it. Treatment for hepatitis C is effective for about 90% of those who try it so someday, you may have the experience of living without it. However, until that time comes, it is important to learn how to live with hepatitis C.

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 K. Porter, RN
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 maintains 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 another 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. Researchers are trying to develop other ways to measure liver damage, but currently, 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 affects 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, the medications to treat hepatitis C infection can cure it in about 90% of people who take them. These drugs do have side effects. Talk to your medical provider about whether treatment is right for you.

—CONTINUED
Frequently Asked Questions—CONTINUED

“A problem is a chance for you to do your best.” — Duke Ellington

• 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, or the pharmaceutical manufacturer of the drug your doctor prescribes.

• Can “natural medicine” help me?
No herbs, supplements or alternative treatments have been proven to effectively treat HCV. Some herbs may 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. Avoid or be cautious with potentially liver toxic drugs, supplements, and chemicals. Try to quit smoking and other tobacco use. Aim for the healthiest lifestyle you can manage, one that includes regular exercise.

• 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 or “works”. There is an occupational risk for 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 transmitting it to her fetus during pregnancy or delivery. 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 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?
The research is confusing about this sensitive, complicated and important subject. 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 and risky sexual practices where blood may be present. It is important to get accurate information about sexual transmission of HCV.
• **Should I tell my sex partner(s)?**
  Yes. Although sex is a basic part of life, many of us are uncomfortable talking about it. Honesty and openness are important. 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**
  • **Understanding HCV: A Patient Pocket Guide**
  • **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.
Getting Organized for the Health of It

This chapter will help you get your healthcare records in order by maintaining an allergy list, medication log, a health and medical history and emergency contact list. Organizing your information helps you take charge of your own health.

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 navigate the medical system effectively
- 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. 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. Although only a small percentage of people with HCV will die from it, Advance Directives are recommended for everyone.)
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, but check the copyright date to make sure the information is current. 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 major medical centers 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. See the Resource section (page 35) for a list of comprehensive and easy to understand books about hepatitis C and liver disease.

“To know where you can find a thing is the chief part of learning.”

— Source Unknown
Choosing a Medical Provider

This chapter will help you find a new doctor or medical provider. You will learn how to check their backgrounds, ask the right questions and find out what hospitals or medical clinics use physicians in training. Doing some homework up front can make your first appointment go more smoothly.

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.docinfo.org
Searches for malpractice judgments for a fee per physician.

www.hcvadvocate.org
The Hepatitis C Support Project’s physician database. Note: Click on “find a physician” button.

Clinics and hospitals that are affiliated with medical schools may use interns, residents and fellows as part of their team. Interns are in their last year of medical school and 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 hepatology or 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.
Questions to Ask

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?
- 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?

- What are the fees? Does the provider charge for time spent talking to you on the phone?
- 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?
# Medical Provider Information

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<tr>
<th>Provider Type</th>
<th>Provider’s Name</th>
<th>Phone Number</th>
<th>Address</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Primary Care Provider</td>
<td>NOTES</td>
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<tr>
<td>Nurse(s)</td>
<td>NOTES</td>
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<tr>
<td>Specialists</td>
<td>NOTES</td>
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<td>GI/Hepatology</td>
<td>NOTES</td>
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<td>Nurse(s)</td>
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<td>Other</td>
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<td>Other</td>
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<td>Pharmacist</td>
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<td>Dentist</td>
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<tr>
<td>Other</td>
<td>NOTES</td>
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Maximizing Your Medical Appointments

This chapter discusses how to get the most out of your medical appointments. You pay for time spent with your medical provider, so learning how to get the most out of it benefits you.

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

1. Be prepared. Before your appointment 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 who may be involved with 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 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, especially for the complicated appointments. Ask your companion to take notes for you. If it’s all right with your provider, you can also record the appointment. Smartphones, iPhones, iPod touches and similar devices have recording capabilities.

11. If medication is prescribed, ask what the common side effects are and how to take the medication.

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 doctor (or provider) 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 the best way is 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 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.
**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.

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

• 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 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? □ Yes  □ No __________________________________________________________
- Does anything affect the results, such as drugs, alcohol, food, etc? □ Yes  □ No __________________________________________________________
- Are there any risks or discomfort involved with this test? □ Yes  □ No __________________________________________________________
- 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 you 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 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 yes, complete the following:

Name of medication or treatment: ____________________________________________

Is a generic form available?  [ ] Yes  [ ] No______________________________

Does the provider have any samples in the office for you to try them first?  [ ] Yes  [ ] No

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?  [ ] Yes  [ ] No __________________________

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?
_____________________________________________________________
NEW APPOINTMENT FORM SECTION

Newly Diagnosed • Hepatitis C Support Project

SURGICAL OR MEDICAL PROCEDURES

If you have any concerns or reasons 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.

Name of procedure ____________________________________________

Reason for the procedure_______________________________________

What is involved with the procedure? ____________________________

Will you need any anesthesia  [ ] Yes  [ ] No— if yes, 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? [ ] Yes  [ ] No _____________________________________________

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? [ ] Yes  [ ] No ____________________________

How long is the recovery period? _________________________________

Are there any restrictions after the procedure? [ ] Yes  [ ] No __________________________________

Will you have any discomfort after the procedure? [ ] Yes  [ ] No __________________________________

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

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

Where can you get more information about this procedure? _______________

Other questions or comments: ____________________________

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Tip: It is common practice to stop taking any medications that reduce blood-clotting for a period of time prior to most procedures, such as liver biopsies. These include aspirin, ibuprofen, naprosyn, and other common medications. Dietary supplements may also reduce blood-clotting, such as vitamin E, licorice, dandelion, etc. Report all supplement use to your medical provider.
Your Medical History

When you see a new healthcare professional the appointment starts with communicating details about your present and past medical history. The time to talk will probably be short, so use it well.

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 or racial background.
- Any allergies to medications, food, or other substances.
- All dietary supplements and drugs that you are taking or have taken recently. Include prescription, 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 where you may have been exposed to 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.

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 ago. 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.

“I like a good story well told. That is the reason I am sometimes forced to tell them myself.”

— Mark Twain
# NINE

## Medication and Supplement History

<table>
<thead>
<tr>
<th>Name</th>
<th>How Much (Dose)</th>
<th>How Often</th>
<th>How Long</th>
<th>Reason</th>
<th>Prescribing Provider’s Name</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REGULAR</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription Medication</td>
<td></td>
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<tr>
<td>Non-prescription Medication</td>
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<tr>
<td>Dietary Supplements</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>OCCASIONAL/AS NEEDED</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescription Medication</td>
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<td>Non-prescription Medication</td>
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<tr>
<td>Dietary Supplements</td>
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<tr>
<td><strong>RECENTLY STOPPED (PAST MONTH)</strong></td>
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<td></td>
</tr>
<tr>
<td>Prescription Medication</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Non-prescription Medication</td>
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</tr>
<tr>
<td>Dietary Supplements</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medications Taken in the Past Year</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recreational Drugs</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
This chapter discusses ways to manage your medications. Since this can be tricky, particularly medications used for HCV treatment, spending a little time reading and asking questions about your medications will help you take them safely and correctly.

### 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 the 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.

—continued
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

“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
ELEVEN

Tips for Lowering Prescription Drug Costs

This chapter suggests ways to lower your prescription drug costs with cost-saving tips, such as purchasing wholesale or through reliable Internet-based pharmacies.

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.
- Shop for the best drug price, such as through Costco, wholesale, or reliable Internet-based pharmacies.
- Ask if there are any clinical trials in your area using the drug treatment that you need.
- 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.
- 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
TWELVE

Follow-Up Appointment Checklist for HCV Patients

This section suggests guidelines for how to maximize your follow-up appointments with your medical provider. Providing up-to-date information will help make your appointment go smoothly.

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)
- 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? ____________________________
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 who 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 of 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 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?  □ Yes  □ No ____________________________

• Does anything affect the results, such as drugs, alcohol, food, etc?  □ Yes  □ No __________

• Are there any risks or discomfort involved with this test?  □ Yes  □ No _________________

• 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 you 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 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 yes, complete the following:

Name of medication or treatment: ____________________________________________________________

Is a generic form available? □ Yes  □ No_____________________________________________________

Does the provider have any samples in the office so you can try them first? □ Yes  □ No

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? □ Yes  □ No

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? □ Yes  □ No _______________________________

Are there any side effects you should report or that may be potentially urgent? □ Yes  □ No

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

Are there other options? □ Yes  □ No ___________________________________________________________________

Where can you get more information about this treatment? ____________________________________________

Other questions or comments: _____________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________

_____________________________________________________________________________________
SURGICAL OR MEDICAL PROCEDURES

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

Name of procedure: __________________________________________________________
Reason for the procedure: ____________________________________________________
What is involved with the procedure? __________________________________________
Will you need any anesthesia  □ Yes  □ No— if yes, 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?  □ Yes  □ No ______________
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? □ Yes □ No
How long is the recovery period? _____________________________________________
Are there any restrictions after the procedure? □ Yes □ No _______________________
Will you have any discomfort after the procedure? □ Yes □ No ____________________
How are pain and other post-procedure problems treated? _______________________
If a biopsy is involved, how and when do you get the results? _______________________
Where can you get more information about this procedure? _______________________
Other questions or comments: ________________________________________________

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

“As I see it, every day you do one of two things: build health or produce disease in yourself.”

— Adelle Davis
FOURTEEN
Calling your Medical Provider

You may need to call your medical provider for information, to renew a prescription, or to see if it is necessary to be seen in the office. This section offers ways to improve phone communication with your 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 cell 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. Because of privacy regulations, medical providers will not leave messages unless specifically authorized to do so.

EMERGENCY SITUATIONS

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 ______________________________
- Member Identification ______________________________
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.

• 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 minutes 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.

• 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 does.

• 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 you cancel an appointment, try to do so at least 24 hours in advance. You may be charged if you do not cancel within a certain time frame. Remember that other patients may need that time slot.

“"No pessimist ever discovered the secret of the stars or sailed an uncharted land, or opened a new doorway for the human spirit.”"

— Helen Keller
SIXTEEN

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 a few definitions of some 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 Master of Arts.)

**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 those of 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.

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**A NOTE ABOUT HCV MEDICAL SPECIALTIES:**

<table>
<thead>
<tr>
<th>Gastroenterologists</th>
<th>Hepatologists</th>
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<tr>
<td>These physicians specialize in diseases of the digestive system. The liver is part of that system.</td>
<td>These are gastroenterologists who specialize in liver diseases. Hepatologists usually practice in medical centers that have liver transplant programs.</td>
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</table>

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.

“Always laugh when you can. It is cheap medicine.”

— Lord Byron
HCV Laboratory and Diagnostic Tests

This chapter presents information on the most common medical tests associated with HCV.

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** – The qualitative test merely confirms the presence of virus. Since it doesn’t measure the virus, many providers just use the qualitative HCV RNA.
- **HCV genotype**
- **ILB28**
- **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.
Most medical providers recommend regular laboratory follow-up for their HCV patients.

You can keep track of your labs. Ask your medical provider for the results. Look for trends rather than single results. Depending on your health status, labs are done annually. Some providers order labs more frequently. Do not interpret laboratory results on your own. An abnormal result may not be clinically important. Always seek expert advice.

This form targets the most important elements that may indicate liver disease progression. Viral load testing is used only to diagnose HCV and to monitor treatment. It does not need to be done routinely since it is expensive and the results are meaningless. Space has been provided for additional lab results you might want to track.

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**Do’s**

- Join a support group.
- Educate yourself.
- Protect yourself from hepatitis A and B – get immunized (unless you have been previously infected).
- Strive for freedom 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.
- Follow 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.

**Don’ts**

- Try to avoid alcohol.
- Don’t exceed 3000 mg of acetaminophen (Tylenol) daily 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.
- Don’t share anything related to injection or inhaled drugs – needles, syringes, preparation water, cooker, tourniquet, etc. Clean the area where you use these items.
- Don’t eat raw or undercooked shellfish.
- Don’t take iron supplementation or multi-vitamin with iron without discussing this with your doctor.
- Don’t take large doses of any drug or supplement without medical supervision.
- If you use herbs or supplements, familiarize yourself with those that may be harmful.
- Don’t donate blood or semen.
- Don’t jump into immediate treatment without weighing all of your options.
- Don’t obsess over whether or not you can pass HCV to others – be informed, use commonsense and do the best you can.
- Don’t feel guilty about having HCV – you did not intend for this to happen.

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In spite of all of the above, remember to laugh and enjoy life.
TWENTY

Tips For Living Well With HCV

We may not have chosen HCV, but we can choose to live well and be healthy.

• Join a support group.
• Avoid or minimize use of alcohol, tobacco, excess caffeine and illicit drugs. If you want to quit and can’t, 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.
• Follow 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 6 to 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.
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.

**Publications**

- **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
- **Free from Hepatitis C: Your Complete Guide to Healing Hepatitis C**, by Lucinda K. Porter, RN
- **Healing Hepatitis C**, by Christopher Kennedy Lawford and Diana Sylvester
- **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 Polichino
- **Curing Hepatitis C**, by Gregory T. Everson, M.D., F.A.C.P
- **My Mom Has Hepatitis C**, by Hedy Weinberg, Shira Shump, Gregory T. Everson, Joy Chen

**Internet**

- [www.hcvadvocate.org](http://www.hcvadvocate.org)
  This website is packed with information about hepatitis C and has links to many other websites.
- [http://hepcchallenge.org](http://hepcchallenge.org)
  Caring Ambassadors Hepatitis C Program.
- [www.cdc.gov](http://www.cdc.gov)
  Centers for Disease Control and Prevention.
- [www.healthfinder.gov](http://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](http://www.healthypeople.gov/BeHealthy)
  The U. S. Department of Health and Human Services conducts this health promotion program.
- [www.hhs.gov](http://www.hhs.gov)
  This web page of the U. S. Department of Health and Human Services links to other sources of information.
  Links to extensive information courtesy of the National Institutes of Health.
- [http://familydoctor.org](http://familydoctor.org)
  Information and tools provided by the American Academy of Family Physicians.
- [www.labtestsonline.org](http://www.labtestsonline.org)
  Information about laboratory tests.
- [www.mayoclinic.com](http://www.mayoclinic.com)
  Includes tools, information and even some recipes.
- [www.mercksource.com](http://www.mercksource.com)
  Provides information and easy to use health assessment tools.
- [www.prevention.com](http://www.prevention.com)
  Covers nearly every aspect of general health.