

Chapter 1

Conquering Hepatitis C

In This Chapter

- ▶ Looking at the complications and symptoms of the disease
- ▶ Finding out how hep C is transmitted
- ▶ Testing, testing, testing
- ▶ Taking care of yourself
- ▶ Managing your finances and your medical records
- ▶ Making the best decisions for you

Hepatitis C is called an epidemic because of the numbers of people infected. In the United States, almost 4 million people have hepatitis C virus. In Canada, the number is 240,000. In the entire world, at least 170 million people are currently infected. Hepatitis C virus has infected so many people because of the way that it spreads — through contact with infected blood.

If you or a loved one has been recently diagnosed with hepatitis C, and if you're like most folks, you probably have a lot of questions and a fair number of fears. This book can help answer those questions and, in the process, quiet the fears.



Hepatitis C does *not* have to be a death sentence. Getting medical treatment; staying away from alcohol and other dangers to your liver; and otherwise taking good care of your body, mind, and spirit can allow you to live long and live well.

In this chapter, I introduce the essential concepts about living with the hepatitis C virus. My goal is to quickly answer the most pressing questions you may have and let you know where you can find more information on each matter in the rest of the book.

How Hepatitis C Is Spread



Hepatitis C is a virus, and it spreads from person to person through infected blood. Everyone should know how hepatitis C virus is transmitted so they can take measures to protect themselves.

In the United States and other developed countries, the blood supply wasn't tested until 1992, so if you got a blood transfusion or underwent any type of organ transplant before then, you could've gotten the hep C virus.

The blood supplies in developed Western countries are now safe, but this isn't the case around the world. In developing or transitional countries (as defined by the World Health Organization, or WHO), reuse of injection equipment for medical procedures is the major source of new infections.



Here are the main ways that hepatitis C can now spread in the United States and other developed countries:

- ✓ Use of shared equipment for drug use, tattoos, or piercing.
- ✓ Mother-to-child transmission.
- ✓ Sexual transmission.
- ✓ Sharing items such as toothbrushes or razors with someone with hepatitis C.
- ✓ Occupational exposure.

To read more about transmission of this virus and how to protect others, check out Chapter 2. If you feel that you have a risk factor for hepatitis C virus, go see your doctor, and get a hepatitis C test (I discuss the tests in Chapter 6).

Hepatitis C timeline in United States

Hepatitis C was initially called hepatitis non-A non-B before it was identified. Here's a list of some milestones in the identification of hep C, protection of the United States blood supply, and treatment of hepatitis C.

1980s 242,000 new infections of hepatitis C occurred per year.

1987 Clotting factor protected (because of precautions against HIV).

1989 Hepatitis C virus was identified.

1992 Blood supply in the United States first tested for hepatitis C.

1996 Interferon first used in treatment of hepatitis C.

1998 Interferon plus ribavirin became standard treatment.

2001 25,000 new infections of hepatitis C.

2002 Pegylated interferon plus ribavirin became standard treatment.

Getting Tested for Hepatitis C

Hepatitis C is a silent virus; most people don't know they have the virus until decades after infection. You can find out if you've been exposed to hepatitis C by taking a blood test.



In addition to the risk factors I outline in the previous section, you should get tested for hepatitis C if you've ever been on long-term kidney dialysis or have signs of liver disease.

In Chapter 6, I cover all the tests and the possible results in detail. But basically, hep C tests come in two forms, both of which involve drawing some blood:

- ✓ **Antibody test:** The first level of tests looks for the immune response to the virus, called *antibody*. The antibody test tells if you've ever seen the virus, even in the past. It doesn't tell you if you have the virus now.
- ✓ **RNA tests:** More-direct tests of the virus look for the virus component called RNA, or ribonucleic acid. The RNA test tells if you have the virus right now and how much you have (viral load or quantitative test).



After you know you have hepatitis C, see a liver specialist to get an expert evaluation of your condition. Turn to Chapter 5 for tips on choosing and communicating with your doctor.

Describing the Disease

Hepatitis means inflammation (*itis*) of the liver (*hepa*). The subject of this book is hepatitis C, but actually, a number of viruses infect the liver and cause liver disease — and they're all called *hepatitis viruses*. You can read more about the differences between these viruses in Chapter 2, but for the moment, I concentrate on the one that brought you here.

Hepatitis C around the world

Hepatitis C affects millions of people around the globe — rich and poor. Calling hepatitis C a “viral time bomb,” the World Health Organization (WHO) estimates that

- ✓ About 3 percent of the world’s population is infected with hep C.
- ✓ 3 to 4 million new infections occur each year.
- ✓ Around 170 million people are chronically infected and risk getting cirrhosis and/or liver cancer.

Chronic infections can be treated with medication in developed countries (see the “Choosing treatments” section in this chapter), but unfortunately, the cost of such medications is too high for most of the millions of people living in countries with fewer financial resources.

The numbers

Everyone responds differently to hepatitis C virus. If you’ve been infected with hepatitis C virus, you want to know what’ll happen to you. Your doctor is the best person to advise you on your particular situation. But I’ll present some numbers, here and throughout the book. **Remember:** These numbers are only estimates.

Of the people exposed to hepatitis C virus,

- ✓ 15 to 25 percent clear (get rid of) the virus when they first get infected.
- ✓ 75 to 85 percent develop a long-term, or *chronic*, infection.

About 20 percent of the people who have a long-term chronic infection get *cirrhosis*. Cirrhosis can occur 10 or 20 years or more after you’re first infected. After you have cirrhosis, you’re at risk of getting the most serious illness — liver failure or liver cancer.

If you develop liver failure or have liver cancer, the best treatment is a liver transplant (see Chapter 9). Between 1 to 5 percent of people with hepatitis C virus will die from the disease.

The liver

The hepatitis C virus infects liver cells. For most people with hepatitis C, the main problem is how hepatitis C hurts your liver. The liver processes practically every single thing you eat, drink,

or otherwise absorb into your body. It makes proteins, filters out waste and toxins, stores sugars and vitamins, and converts foods and drugs into usable substances. (See Chapter 4 for more information on the liver and its normal functions.)

The disease

To see the extent of liver disease, your doctor will perform blood tests. You may already have had an ALT (alanine transferase) test, which is commonly used to look for liver damage but is by no means the only test. (See Chapter 7 for a description of other tests that look for liver damage or changes in liver function.)

You doctor will probably suggest a liver biopsy, which gives a direct picture of your liver. The liver biopsy can show two types of damage to your liver from hepatitis C:

- ✓ **Inflammation:** This earlier stage of damage is reversible.
- ✓ **Scarring (fibrosis):** Most experts agree that scarring is probably somewhat reversible in early stages, but continued scarring damages the liver and isn't reversible.

Inflammation causes the disease called *hepatitis*, which gives you symptoms of hepatitis C, but your disease isn't life-threatening unless you get *cirrhosis*. Scarring prevents your liver from performing its crucial jobs to keep your body functioning. When scarring covers most of the liver, you get *cirrhosis*. There are two types of cirrhosis:

- ✓ **Compensated cirrhosis:** Even though you have cirrhosis, your liver is still performing its tasks.
- ✓ **Decompensated cirrhosis:** This is another name for *end-stage liver disease* or *liver failure*. Here, your liver is no longer working properly. You'll die from the damage to your liver, unless you get a liver transplant.

Liver cancer (hepatocellular carcinoma) is a life-threatening disease that sometimes occurs in people with cirrhosis. Your doctor will give you an ultrasound or other imaging test to see if there is evidence of liver tumors (see Chapter 7).

If you have liver cancer (only for some stages, though) or end-stage liver disease, a liver transplant can save your life. Read about treatments for liver disease in Chapter 8 and about liver transplants in Chapter 9.

The symptoms

If you have chronic hepatitis C, your symptoms can be bothersome and, in some cases, debilitating. Chronic hepatitis C disease has many symptoms. The most common are fatigue (which is more than tiredness and persists even after a good night's sleep), nausea and vomiting, muscle and joint aches, itchy skin, fluid retention, brain fog (loss of concentration, ability to focus, or remember), and depression. In Chapter 4, I provide a longer list of symptoms and outline the progression of hepatitis C disease.



Along with problems with your liver, you may have other illnesses that are associated with hepatitis C. These are called *extrahepatic diseases* because they're not strictly liver (hepatic) diseases and include diseases of the skin or kidneys. In Chapter 4, I describe a few of the other types of illnesses you may experience with hepatitis C.

Fighting Hepatitis C

Wherever you are in the battle to heal from hepatitis C, you hold the keys to preventing further liver damage.



Seek the advice and care of qualified healthcare practitioners. I give some tips on finding practitioners in Chapter 5 and on evaluating healthcare choices in Chapter 10.

Choosing treatments



The medical fight against hepatitis C is evolving. At this time, the primary recommended treatment by the U.S. Food and Drug Administration (FDA) for chronic hepatitis C is a combination of two drugs — *interferon* and *ribavirin*. These drugs can stop the hep C virus from growing in your body. The form of interferon that's currently used is called *pegylated interferon*, or the shortened version, *peginterferon*. Therefore, you'll see the treatment referred to as *peginterferon plus ribavirin therapy*. Got all that? Just think: There are more rather strange names waiting for you in Chapter 8, where I discuss this and other Western medical treatments.

But not everyone with hepatitis C undergoes drug treatment. The decision whether to pursue this path now, later, or never is one that you'll make with the help of your doctor. Among other things

to consider about combination treatment (see Chapter 8) are the following:

- ✓ **Combination interferon treatment** can be long and costly, and has the possibility of severe side effects.
- ✓ **Between 50 and 80 percent** of people who go through treatment have success in that the hepatitis C virus becomes undetectable in their body for at least six months after treatment. Some doctors call this a “cure” because it can halt further damage from hepatitis C virus.

Alternative medical systems such as Eastern or traditional Chinese medicine, ayurvedic medicine, and homeopathic and naturopathic medicine also offer treatments that can be used instead of or alongside Western medicine and that are less likely to result in severe side effects. These alternatives, however, are also less likely (as determined by the FDA) to eliminate the virus (see Chapter 10).

Medical care is increasingly incorporating both Western (traditional) medicine and Eastern (alternative or complementary) medicine in what’s called an integrated approach to healthcare.

Choosing healthy living



Regardless of whether you can take medical treatment or whether it’s successful in eliminating your virus, you can still fight the effects of hep C by making wise lifestyle choices, including the following suggestions:

- ✓ **Eat healthful foods.** Your liver and immune system need nutrients from food to fight the virus and build new liver cells (read about healthy eating in Chapter 11). Avoiding fatty, junk-type foods will reduce symptoms of hep C.
- ✓ **Avoid toxins.** Products such as paint thinners, chemical cleaners, pesticides, and many household cleaning products are especially harmful for people with hep C. (See Chapter 12 for more on different types of toxins to stay away from.)
- ✓ **Give up dangerous addictive habits.** Say no to alcohol, smoking, and illegal drugs. Alcohol is especially damaging to your liver. If you need help (and most people do) to end these habits, check with your doctor or look into a substance-abuse program (see Chapter 12 for the details).
- ✓ **Take all medications with care.** Some medicines, including prescriptions and the over-the-counter variety, can harm your liver (see Chapter 12). Check with your healthcare practitioner to make sure they’re not hurting your liver.

What you put into your body is one aspect of staying healthy. Also important is what you do with your body. Movement of some sort, whether it's strenuous exercise, gentle stretching, or a mind-body-spirit movement such as T'ai Chi or Yoga, is essential for good health. Exercising your body keeps you limber and helps fight depression and fatigue, two common symptoms of hepatitis C. Chapter 13 focuses on the power of movement to help you feel better and reduce stress.

Letting others help you

Living with a chronic illness can feel frustrating, scary, and lonely. You don't have to live on an emotional roller coaster. Build a support team that includes the following members:

- ✓ **Your physicians:** See Chapter 5 for tips on finding and communicating with a liver specialist and other doctors.
- ✓ **Friends, family, and neighbors:** All these folks can help out when you're not feeling well. Chapter 19 talks about how friends and family can help you.
- ✓ **Spouse or partner:** Discuss your concerns with your loved ones. See Chapter 15 for tips on communicating with your partner and strengthening other important relationships.
- ✓ **Mental health professional:** When the going gets too tough to handle on your own, seek professional help. I give some tips for finding a therapist in Chapter 14.
- ✓ **A support group:** You can get information and comfort from discussions with other people with hepatitis C — either in person or on the Internet. Chapter 14 tells you how to find a support group near you.



Depression is a serious side effect of hepatitis C virus and the medical treatment (interferon). Don't neglect the signs of depression (see Chapter 14). A professional can determine if you would benefit from an antidepressant and/or counseling.

Getting Financial Support

Chronic hepatitis C symptoms can make you unable to work at your usual pace or job, or even cause you to become disabled. To get the most benefit from your health insurance, read your policy carefully, and ask questions. You don't necessarily have to tell your boss you have hepatitis C. But if you want to be protected against

discrimination, your employer must know about your hepatitis C. Sounds like a Catch-22, doesn't it? See Chapter 16 for more information on facing the financial challenges of hep C and the challenges you may find in the workplace.

You need to know more about your insurance than the name and phone number of the company. You need to know the nitty-gritty details:

- ✓ What's covered and what's not, including medications, tests, hospital visits, and mental health care
- ✓ The type of co-payments or deductibles you have
- ✓ The doctors you can visit
- ✓ How to change doctors
- ✓ A yearly maximum amount that's covered
- ✓ Coverage of liver transplants

If you don't have health insurance, you can get help with medical treatment through clinics or Medicaid or by contacting the pharmaceutical companies that make peginterferon plus ribavirin (see Chapter 22).

Staying Organized with a Hep C Notebook



Keep your medical information and health records in a safe place. You may need to show this documentation if you visit new health-care practitioners or if you apply for life insurance or Social Security disability. I provide a complete description of how to build a hep C notebook in Chapter 5, but for now, here are the types of information to save or record:

- ✓ Copies of all tests, which you should request at the time of the test or from your doctor who ordered the test
- ✓ Dates and outcomes of all doctor visits
- ✓ A running list of your symptoms
- ✓ Medications, dates taken, side effects, and results
- ✓ Vitamins, herbs, and over-the-counter medicines you take (see Chapter 12)



You, and trusted friends or family members, are the true gatekeepers of your health plan. I'm not talking about a health insurance plan, but a plan to get better. Use this book to help you make the choices that are right for you.

You're More Than a Statistic

I kept the idea of individuality in mind as I wrote this book, and I want you to keep it in mind, too. Every person with hepatitis C is a unique individual. From your biological makeup to your lifestyle, you're different from the next person.

Hep C isn't a one-size-fits-all disease. There are real differences in the way different people's disease shows up or the way they respond to treatment. So I provide specific information for children, women and men, African Americans and Latinos, and other folks in Part IV of this book. Make sure that your doctor has experience not only in treating people with hepatitis C, but also in treating people who are similar to you in age, ethnicity, lifestyle, and so on.

Even though I give you facts, figures, and information from studies that are performed on *groups* of people, I still want you to remember that you are more than a number.



Therefore, because you're you, your doctor and other healthcare professionals who have an intimate knowledge of your specific situation are your best source of information. This book is meant to provide you with the information that will let you carry on informed conversations with your healthcare professionals and family members and be your own best advocate.