Living with Hepatitis C FOR DUMMIES®

by Nina L. Paul, PhD

Foreward by Gina Pollichino, RN

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About the Author

Nina L. Paul, PhD, has worked in the field of science and health communication for 22 years. She started down this path at SUNY Purchase, where she received her bachelor's degree in biology and performed research in the field of neuroimmunology.

After working in medical publishing at Rockefeller University Press *(Journal of Clinical Investigation),* she received her master's degree and PhD in infectious disease epidemiology and immunology from Yale University.

After leaving Yale, Nina pursued postdoctoral research in England. Nina's research focused on human immunodeficiency virus (HIV) and related viruses and their interaction with the immune system. As part of her research, she published research articles and presented her results at scientific conferences around the world.

Nina also taught science to schoolchildren in New Mexico and volunteered at a hospital-based Cancer Information Centre in England. She worked in the field of evidence-based medicine and contributed to the Cochrane Library (a medical database).

Nina believes in a multifaceted approach to health. She became a master of reiki, which is a universal life-force energy that is transmitted through the hands. Check out Nina's Web site at `www.ninapaul.info`.

Dedication

I dedicate this book to my mother, Harriet Paul.

Author's Acknowledgments

Here is the place where I thank the "village" that helped me to write this book.

I'm grateful for the support of loving family and friends: the Paul clan — Marvin (my father), David, and Joshua; The Kasmanoff's — Caryn, Sam, Nathan, Noah, and Anna; The Sularski's — Suzette, Allan, and Rebecca; Thelea Fudim, Bunny Kunin, and Henry Gotthelf; the four Barbaras, Annette, Sue, Patti, Cindy, Robin, Lily, Gus, and Burton, and all my other friends and Reiki angels.

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Foreword

I'm thrilled to be writing the foreword for *Living with Hepatitis C For Dummies*. Nina L. Paul, PhD, has written a comprehensive guide to living with this illness. Nina has studied epidemiology, immunology, and viruses extensively, and her vast knowledge and experience have made her the ideal author for this book. She covers every issue of living with and managing hepatitis C — from diagnosis to treatment. The *For Dummies* series of books has been around for quite some time, and it's refreshing to see hepatitis C written about in such an insightful way. Having a well-written, user-friendly book that can educate people with this diagnosis is a godsend.

I know firsthand how important it is to have a guide like this. When you have hepatitis C, it seems all you have are questions and not many answers. Being diagnosed with this illness can create much confusion and fear, and you may feel powerless over the disease. By learning all you can about hepatitis C and how best to deal with it, your overwhelming anxiety is lessened. Reading *Living with Hepatitis C For Dummies* can do just that!

Many people have no symptoms from hepatitis C, yet they often worry about the uncertainty of what the disease will bring in the future. In addition, hepatitis C patients often deal with the stigma surrounding the disease. A large portion of our society knows nothing about hepatitis C, and those who do often have many misconceptions. This book not only educates the patient with clear, concise, and accurate information, but it can also be shared with family and friends to help them understand what the patient is dealing with. Having any chronic illness creates many challenges, but you can learn to face them head on and learn how to deal with them in a more positive way. When you arm yourself with knowledge, you empower yourself and ultimately gain some sense of control over your illness. You may not be able to control the outcome, but you have the power to control how you deal with it. The information and knowledge this book provides will help to give you the power to face this disease head on.

When I first started running support groups for hepatitis C patients, I saw a great number of people with many misconceptions about the disease. Much has been learned since the early '90s. Early on, I saw many people struggle through interferon monotherapy, yet I saw very few people respond to the treatment regimen. Over time, with the addition of ribavirin, I saw many more patients respond and remain virus free at the end of treatment. The next leap forward was pegylated interferon. As the research chronicled a much better response rate, I saw those results firsthand with the patients in my support groups. Witnessing this great advance in hepatitis C treatment has been wonderful, and I feel very fortunate to work with patients who are benefiting from these advances. But the most important message here is that there is hope for someday living a life free of the hepatitis C virus. Of course, not everyone can take treatment for various reasons, and not all of those who do will respond. With ongoing research, many more drug regimens will be used, and ultimately many, many more people will be cured.

My personal journey with this disease began in 1994 with acute hepatitis C. As an RN, I knew what hepatitis was, but beyond that, I knew very little. If this book were available at the time of my diagnosis, it would have been much easier to understand the disease and overcome the fear and uncertainty. Just like everyone else with this illness, I wish that I didn't have hepatitis C. However, the glass is still half full for me, and it can be for you, too. I have hepatitis C, but it's just one aspect of my life, of which there are many. It is possible to deal with adversity with grace and dignity, and out of this struggle comes personal growth. When you have hepatitis C, it changes some of the ways that you view your life and the decisions you must make, but you can learn to deal with the changes this disease brings about. Living with hepatitis C is an ongoing journey, and you will get all the information you need to move forward in this journey right here in this book. Bravo, Nina Paul, for writing *Living with Hepatitis C For Dummies!* It's the ultimate hepatitis C guide, and I applaud your efforts!

— Gina Pollichino, RN

Introduction

Millions of people in the United States and all over the world have been infected with hepatitis C. Many don't even know they have it, because symptoms may not appear for decades.

The sooner you know that you have hepatitis C, the sooner you can begin medical treatment and start making lifestyle changes to protect others from infection and keep yourself healthy.

Hepatitis C infects the liver and causes a range of disease from none-at-all to life-threatening liver disease that can only be treated with a liver transplant. Most people fall within these two extremes.

Hepatitis C virus spreads through contact with infected blood. You could've received hepatitis C from a blood transfusion or from sharing any type of needle or sharp instrument for medical, cosmetic, or drug use.

But how you got your hepatitis C is nowhere near as important as what you're doing now to help yourself stay well. Use this book to help you build a support network and make *informed* choices about your healthcare and lifestyle.

About This Book

While writing this book, I've tried to focus on the friendly advice given to me by a woman with hepatitis C:

> *"I want choices. I need info. I want to defuse my fears. And please, keep it simple."*

I've also hung my hat on the fact that every individual facing hepatitis C is just that — *an individual.* You may be young or old, male or female. You're of a different race, ethnic group, or nationality than others. You have different responses to different medications, as well as different personal preferences on the types of medications you'll take. You have different levels of healthcare due to different finances and locations. In this book, I present various options and choices so that you can find the ones that work best for you.

Throughout this book, I emphasize the value of a positive attitude, because it helps you deal with the healthcare system, reduces stress, and just plain makes you feel better (as well as everyone around you).

I believe that it's important to dispel myths about hepatitis C and eliminate prejudices and stigmas against people with the virus. The best offense against closed-mindedness is information. So I help clear up any misconceptions and questions you may have about the disease, and I give you information, tips, and resources for dealing with negativity that you may face because of your illness.

Conventions Used in This Book

Throughout the book, I use certain words interchangeably:

- In some places, the doctor is a *he,* and in other places, a *she.*
- When I write *healthcare providers* or *healthcare practitioners,* I usually mean your doctor (physician). But this term includes professional nurse practitioners, physician assistants, nutritionists, and naturopaths.
- Hepatitis C is also called hep C, hep C virus, and sometimes HCV (hepatitis C virus)
- When I refer to medications, I usually present the generic name first, followed by the brand name in parentheses.

To help you navigate through this book, I use the following typographical conventions:

- *Italic* is used for emphasis and to highlight new words or terms that are defined in the text.
- **Boldfaced** text is used to indicate keywords in bulleted lists or the action parts of numbered steps.
- `Monofont` is used for Web addresses.
- Sidebars are shaded gray boxes that contain text that's interesting to know but not necessarily critical to your understanding of the chapter or section topic.

Finally, I aim to provide the most accurate statistics on hepatitis C. But numbers change, depending on a large number of factors, such as the specific medications, the different types of people a study looked at, and so on. So consider the numbers I give you as approximations.

What You're Not to Read

Each of you has different needs and interests, so read the chapters that apply to you. If you don't know a child with hepatitis C, for example, skip the chapter on children. The same thing applies to sidebars that are asides to the main topic and information marked with the Technical Stuff icon. On the other hand, you're free to read all of the text, if you want. I happen to think it's all great information (but I could be a little biased on that matter).

Foolish Assumptions

All writers have to make assumptions about their audience, and I'm no different. While writing this book, I've assumed the following:

- ✓ You're not really a dummy, or else you wouldn't have picked up this book.
- ✓ You have come to this book to find reliable, up-to-date information on hepatitis C in a clear and readable format.
- ✓ You want some background on the virus and your liver so you can get a handle on what's going on in your body.
- ✓ You want to learn about alternative treatments, whether you actually use them or not.
- ✓ You want to know the pros and cons of interferon treatment.
- ✓ You will at least think about dropping some of those bad habits, if doing so will help you stay healthy.

How This Book Is Organized

To help you navigate through the different aspects of hepatitis C, I've separated the information into parts: basic background information; medical information; lifestyle and living issues; and specific chapters for children, women, minorities, and family and friends.

Part I: Understanding and Exposing Hepatitis C

You may be wondering what the heck is going on inside your body when you have hepatitis C. In this part, I present the basic science about hepatitis C. You can read about the hepatitis C virus and other hepatitis viruses, how these viruses are transmitted, and how to protect others. I also explain how hepatitis C infects and harms your hard-working liver, and describe the symptoms and how the disease progresses.

Part II: Diagnosing and Treating the Disease

In this part, I explain the different types of doctors who can treat hepatitis C and offer advice on how you can find and work with a doctor. I discuss the different laboratory tests that you undergo before a diagnosis is made, and give you information on conventional and alternative hepatitis C therapies, which you can use to help you decide on treatment. This part is where you also can find a discussion of liver transplants.

Part III: Living a Good Life with Hep C

This part offers advice on choosing healthy foods, exercising regularly, reducing stress, and avoiding substances and lifestyle choices that will further harm your liver. I also explain how to get the support you need, discuss your hep C with others, manage your work life, and handle financial issues related to dealing with this chronic illness.

Part IV: Considering Different Groups with Hepatitis C

Anyone can get hepatitis C, and in this part, I look at specific issues related to children, women, men, different ethnic groups, and other special groups with hepatitis C. Another important group is the family and friends of people with hepatitis C, and I devote a whole chapter to helping these folks.

Part V: The Part of Tens

In this classic part of the *For Dummies* books, you can find tips about traveling when you have hepatitis C and getting a good night's sleep. I also list resources that you can turn to for more information about hepatitis C.

Icons Used in This Book

Throughout the book, you'll see small illustrations to the left of some text. These are called icons, and they alert you to the type of information presented.

TIP

This fine piece of art alerts you to practical information and insight that you can put to use.

REMEMBER

The Remember icon marks information that's so important, you don't ever want to forget it.

WARNING!

When I discuss something that could be dangerous to your health, I use the Warning icon.

TECHNICAL STUFF

This icon indicates you're entering a jargon zone that you may wish to skip or where you may want to tread carefully. It's great information, don't get me wrong, but not reading it won't affect your grasp on the matter at hand.

SEE YOUR DOCTOR

When you see this icon, you need to consult your physician about a particular matter.

HEP C NOTEBOOK

I use this icon to let you know when you should obtain and file away copies of important medical information.

Where to Go from Here

You're ready to delve into the meat of the book now. Like all *For Dummies* books, this book is designed to let you get in and get out — you can start reading anywhere. Each chapter is a self-contained bundle of information, so using the table of contents, you can head straight to the chapter that best meets your needs. Or you can start with Chapter 1 and read straight through.

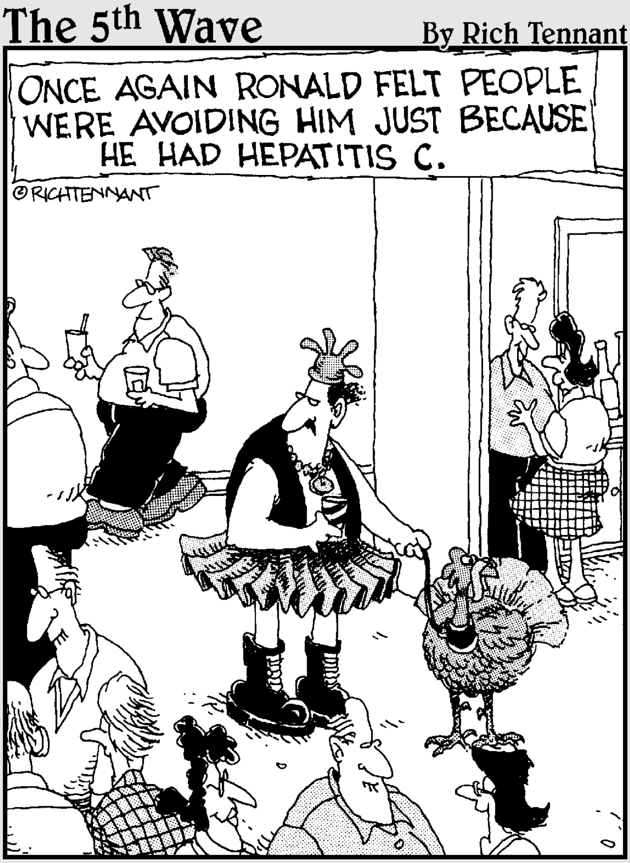
Here are my suggestions to enhance your use of this book:

- Have your test results and other medical information handy as you go through the book.
- Start a healthcare notebook or binder of the information.
- Write down any questions that come up to ask your doctor, support group, or spouse.

Remember, many other people with hepatitis C are walking the same steps, and you can find them, if you like, in support groups (see Chapter 14). Good luck in your journey to live well with hepatitis C!

Part I

Understanding and Exposing Hepatitis C



In this part . . .

When you have hep C, you're not alone. Millions of people around the world have been exposed to infected blood, causing an epidemic of hepatitis C. Like other hepatitis viruses, hepatitis C infects the liver. In many people, hepatitis C has the unfortunate feature of staying in the body for decades and becoming a long-term chronic illness. Hep C has a long list of symptoms, depending on the damage to your liver. In this part, I describe the basic biology of the hepatitis C virus, your immune system, and the workings of your wonderful liver. I also explain the symptoms and disease progression of hepatitis C.

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.

REMEMBER

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.