"Simply written . . . provides the reader with a wealth of basic information."
David Bernstein, MD, Chief, Division of Gastroenterology and Hepatology, North Shore University Hospital

Living with Hepatitis C FOR DUMMIES®

Nina L. Paul, PhD
Immunology and virology researcher and writer

Foreword by Gina Pollichino, RN

A Reference for the Rest of Us!®

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Wiley Publishing, Inc.

Living with Hepatitis C For Dummies®

Published by
Wiley Publishing, Inc.
111 River St.
Hoboken, NJ 07030-5774
www.wiley.com

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Library of Congress Control Number: 2004116928

ISBN: 0-7645-7620-8

Manufactured in the United States of America

10 9 8 7 6 5 4 3 2 1

1B/RU/QR/QV/IN

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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.

I thank the editorial team, including Natasha Graf, who came up with the idea for this book and brought me to it; Mike Baker, who contributed valuable experience and perspective as project editor; Tina Sims, copyeditor, who has the sharpest eyes; and George Nikias, MD, who heads a hepatitis C clinic in New Jersey and served as technical editor.

An angel brought Gina Pollichino, RN, who has shared her enthusiasm and knowledge about hepatitis C and wrote the foreword to this book.

To the people living with hepatitis C, their family and friends, and their doctors who have shared their stories with me, a huge thank you.

Publisher’s Acknowledgments

We’re proud of this book; please send us your comments through our Dummies online registration form located at www.dummies.com/register/.

Some of the people who helped bring this book to market include the following:

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Senior Copy Editor: Tina Sims

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Cover Photos: ©Ed Pritchard/Getty Images/Stone

Cartoons: Rich Tennant (www.the5thwave.com)

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Special Art: Kathryn Born

Proofreaders: Jessica Kramer, Charles Spencer, TECHBOOKS Production Services

Indexer: TECHBOOKS Production Services

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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

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Hepatitis Neighborhood

Hep C Connection

HIV and Hepatitis

Hepatitis Foundation International

World Health Organization (WHO)

Sources Outside the United States

Drug Companies

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.