

HOW TO USE CHOICES

Organization of *Hepatitis C Choices*

Each person with *hepatitis C* is unique, and each reader of *Hepatitis C Choices* is also unique. Recognizing that your informational needs are personal and may change over time, *Hepatitis C Choices* has been written so that each chapter can be read and understood on its own.

Many people find that reading the entire book provides the most benefit. But for any of a number of reasons, this may be hard to do. If reading the book cover to cover seems overwhelming, we encourage you to read those parts of *Hepatitis C Choices* that are most relevant to your immediate questions and needs. Then come back to other chapters as needed.

You may find medical words in the book that are new to you. These words are italicized. The definitions of these words are in the *Glossary* at the back of the book. Becoming familiar with these words will help you better understand hepatitis C. It might also help you communicate more easily with your healthcare providers. Foreign words also appear in italics. These words are explained in the text but do not appear in the *Glossary*.

Part 1: Information for Everyone with Hepatitis C

These chapters contain information for all people affected by *chronic hepatitis C*. The authors consider this information very important for anyone with chronic hepatitis C regardless of your treatment goals.

Part 2: Hepatitis C Treatment and Management Approaches

These chapters cover treatment options for chronic hepatitis C. Each chapter presents the author's professional view of chronic hepatitis C, and its management and treatment.

Some treatment options have been evaluated in *clinical trials* or other research studies to determine their effectiveness. We have included information about the evidence to support the use of a given treatment if available. This information may come from healthcare providers' personal experience (*anecdotal evidence*), or from formal studies such as *controlled clinical trials*. Overall, evidence from clinical trials is considered to be stronger than anecdotal evidence.

Part 3: Other Topics for People Living with Hepatitis C

These chapters cover topics of concern to specific populations affected by chronic hepatitis C, and other issues of interest to people living with hepatitis C.

Also included in the Appendices are other important documents including:

- matrix showing how chronic hepatitis C is diagnosed
- matrix showing management options for chronic hepatitis C
- additional information about topics covered in the chapters
- a *Resource Directory* for people living with chronic hepatitis C

Purpose of *Hepatitis C Choices*

Hepatitis C Choices was written with several purposes in mind:

- to provide information about chronic hepatitis C to help you make decisions about your treatment and lifestyle
- to provide a balanced view of the currently available treatment options from western medicine and *complementary and alternative medicine (CAM)*
- to help you communicate more effectively with your healthcare providers
- to help you become empowered to be the best *advocate* for your own healthcare

Making Informed Decisions

Potentially life-changing decisions are one aspect of having a serious illness such as chronic hepatitis C. Each of us is unique in how we make decisions. Some people want to know everything they possibly can about their disease. They want to make all their own treatment decisions. Other people prefer to have their healthcare providers make treatment decisions based on their knowledge and expertise. Some prefer having a friend or family member seek out and sort through information. Many use a combination of approaches.

Each person with chronic hepatitis C has his or her own treatment goals. Some consider getting rid of the virus to be their most important goal. Others top priority is enjoying the best possible quality of life. Many have a list of goals with some being more important than others are. Many people make lifestyle changes, while others do not make such choices for personal reasons.

We urge you to identify your personal strengths and limitations. Decide what makes up an acceptable quality of life for you. Knowing these things will help you make healthcare decisions that best suit your personality.

We hope *Hepatitis C Choices* will help you understand your disease and some of the healthcare options available to you. Knowledge empowers you to ask the necessary questions to become your own best advocate. When your questions have been asked and answered, you and your healthcare providers will be in the best possible situation to determine the best treatment approach for you.

Knowing Your Options

You have the right to advocate for yourself to receive the best possible treatment regardless of the source of payment for your healthcare.

In the past, people with chronic hepatitis C often found they had few treatment options and limited opportunity to participate in their own healthcare decisions. Increasingly, healthcare providers and the public are interested in changing this legacy. Being an informed consumer and knowing your rights are particularly important when you are looking for healthcare that is not only of good quality, but also fits your personal needs. This is even more important if you intend to combine or integrate several healing approaches in your hepatitis C treatment plan.

Regaining Control

The day before your hepatitis C diagnosis, you were probably able to say what you hoped to be doing in the near future. The day after your diagnosis, you may have felt that something else had suddenly taken control of your life.

The process of regaining control begins with learning about your disease and your treatment options. Many people newly diagnosed with chronic hepatitis C are relieved to find that it may not be necessary to make an immediate decision about treatment. If your hepatitis C has not progressed significantly and you stop drinking *alcohol*, you may never have to make a decision about aggressive therapy.

Some people with chronic hepatitis C stay healthy by making lifestyle changes in addition to not drinking alcohol. For some, lifestyle changes such as eating a healthier diet, taking vitamins and/or supplements, and exercising regularly

have a profound effect on their health and well-being. Others choose homeopathy, naturopathy, traditional Chinese medicine, and/or other CAM disciplines to maintain their general health and keep the virus in check.

Regardless of your current disease status, drinking and hepatitis C infection are a dangerous mix. You should not drink alcohol in any form.

How you go about maintaining your health, and whomever you decide to consult for your healthcare is up to you. However, we urge you to gather information about the different treatment options you are considering. This will help you make informed decisions about what options are best suited to your treatment goals and personality.

Some Additional Thoughts

The decision to begin any treatment is a big step. Only you know if you are ready to take that step. The purpose in creating *Hepatitis C Choices* was not to advocate for one treatment approach over another, but to encourage you to carefully look at all of your options.

Chronic hepatitis C is often a progressive disease, so your options may change over time. The healthcare provider you choose to see is not nearly as important as having a consistent approach to follow your disease. It is important to realize that unless your blood and liver are examined periodically, you cannot know if your disease is progressing.

We encourage you to decide on your treatment goals and discuss all your options and concerns with your healthcare providers. It is often helpful to get a second opinion, or even a third. Choosing healthcare providers you are comfortable speaking with will help you work together as a team. Making decisions that are right for you will make your choices easier to incorporate into your life.

It is very important to inform each of your healthcare providers about all of the treatment approaches you are using. This is particularly important if you choose an integrative medicine approach that involves healthcare providers or treatments from several different medical disciplines.

Hepatitis C Choices was created to help you become the best possible advocate for your own healthcare. We hope it provides useful information to help you make treatment and lifestyle choices that are right for you. However, this book is only a guide, a collection of reference materials. We strongly encourage you to continue to explore your treatment and lifestyle options, and to gather as much information as you need. Doing so can help you make the best possible decisions for your healthcare and your life.

An Important Note to the Reader

This book was created to provide information about a wide variety of approaches to the treatment and management of chronic hepatitis C. The Caring Ambassadors Hepatitis C Program and the authors of *Hepatitis C Choices* believe access to good information leads to better decisions. However, this book is not a substitute for medical advice. It is critical that you consult your healthcare provider about any matter concerning your health, particularly with regard to new or changing *symptoms* that may require medical attention.

Each chapter and section of the book has been authored independently. Therefore, each chapter reflects the unique approach to the treatment of hepatitis C of its author, based on his or her medical discipline and experience. For this reason, an author is responsible only for the accuracy of the information presented in his or her chapter or section. No

author can confirm the accuracy of the information presented in any other chapter or section.

Most of the contributors to *Hepatitis C Choices* are members of the Caring Ambassadors Hepatitis C Medical Team. Others are guest authors invited by the Caring Ambassadors Hepatitis C Program. The unifying characteristic of the Hepatitis C Medical Team is a willingness to listen and evaluate the diverse viewpoints and treatment options available to people with chronic hepatitis C. *Hepatitis C Choices* evolved from a consensus within the Hepatitis C Medical Team that a single resource describing the various modalities of treatment available would be useful to people with hepatitis C. Cooperation and open discussion are key components of the interaction among members of the Hepatitis C Medical Team, though individual members remain aligned with their own discipline.

Be aware that the only treatment proven through controlled clinical trials to show sustained *clearance* of the hepatitis C virus (as detected by HCV RNA testing of the blood) is *interferon-based antiviral* therapy. Recent studies of pegylated interferon plus *ribavirin* report overall *sustained responses* in 50% to 60% of those treated. In other words, 50% to 60% of people receiving this treatment remain virus-free and are considered *cured*.

We strongly encourage anyone who has significant *fibrosis* on *liver biopsy* to be followed closely for evidence of disease progression. This should include a medical history, physical examination, and laboratory tests. People with *cirrhosis* need to be monitored for *clinical* and biochemical deterioration, and considered for referral to a liver transplant center. If *liver failure* occurs, liver transplantation counseling should be sought immediately. Regular screening for the development of *liver cancer (hepatocellular carcinoma)* should be part of any ongoing hepatitis C management plan.

The choice of treatment for hepatitis C is a personal one. What is right for one person may not be so for another. What is right for you will depend on the status of your disease, the health of your liver, your age, lifestyle, treatment goals, and many other factors. We encourage you to carefully assess the information provided here and elsewhere, and to work with your healthcare providers to choose treatment approaches that meet your individual needs and goals.