

HEPATITIS C SUPPORT GROUP **Handbook**

A note from Alan Franciscus, friend and advocate of people who have hepatitis C. He is also the Founder and Editor-in-Chief of the website, www.hcvadvocate.org:

For many people, living with hepatitis C is not easy. Every day, we are faced with making many important decisions that can affect almost every area of our lives. The best way to live well with hepatitis C is to learn as much about it as we can, so we can seek and receive the best possible medical care. An equally important part of staying healthy is to get support from healthcare providers, family, loved ones, friends, and peers. This means learning directly from others who have hepatitis C and who are willing to share their life experiences. One of the best places to find and receive peer support is in a support group.

I found out I had hepatitis C in 1996. At that time, there was very little information or support for people with hepatitis C. The information that was available then was hard to find, and much of it was just plain wrong. Shortly after I found out I had hepatitis C, I asked my healthcare provider to recommend a support group in San Francisco. To my surprise, he told me that there were no support groups in San Francisco for people with hepatitis C!

About 4 months after I found out I had hepatitis C, I began treatment with interferon monotherapy. I soon realized that I was not prepared to deal with the many physical and mental side effects of interferon. The physical side effects included terrible headaches, as well as muscle and joint pain. I also became anxious and depressed. Worst of all, I did not recognize the signs of the depression and anxiety that I was having. After a couple of months (and at a friend's urging), I talked with my healthcare provider and received advice about the mental and emotional side effects of anxiety and depression, as well as the medicine I could take for these issues. It was at this point that I fully realized how important peer support is for someone going through hepatitis C treatment. I also realized that I didn't want anyone else with hepatitis C to go through the same issues without getting the support that I needed to stay on therapy and help make the journey easier. So, I made a pledge to myself that once I finished treatment, I would start a hepatitis C support group.

True to my word, I worked with a friend of mine to open the first hepatitis C support group in San Francisco in 1997. I'm happy to report that after all these years, that support group is still running and thriving.

It wasn't really difficult to set up and maintain a support group, but a lot of what I needed to know I gained from taking a workshop and by "hit or miss." It would have been much easier for me if I had had some sort of material and advice that was geared towards starting and running a hepatitis C support group.

The need for this type of information became clear when people from all over the country started contacting me for advice about starting a support group in their community. I began to gather information pulled from my own experience, along with advice from others that I had collected, into a document. The result of my years of trial and error and, more importantly, the advice from others, is what is included in this handbook.

I hope that the handbook will give you the necessary tools for starting a support group. Support group leaders don't necessarily need a lot of knowledge or skills to run a group. The most important qualities of a support group leader are dedication, putting the members' needs first, and being a person who cares about others. I am continuously amazed by the people who run support groups. They are a special kind of person who touches the lives of so many others affected by hepatitis C. I am assuming that since you are reading this handbook, you are taking the challenge to be that very special person for your community. I hope so, because we really need you!

Alan Franciscus

Table of Contents

Introduction	4
1. Why Do People Need Support Groups?	6
2. Do You Have What It Takes to Lead a Support Group?	9
3. Gathering Information	11
4. Types of Support Groups	13
5. It's All in the Details	15
6. Leading a Group	21
7. Getting the Word Out	23
8. Confidentiality: Respecting People's Privacy	28
9. Sample Support Group Format	30
10. Even the Smallest Steps Are Steps in the Right Direction	32
11. Ways to Work Through Tough Problems	34
12. How to Get Funding	38
13. What Comes Next?	40
14. Resources and Glossary	41

The information in this handbook is designed to help you understand hepatitis C. It is not intended as medical advice. If you have hepatitis C, you should consult a healthcare provider.

Introduction

Every day, men and women learn that they have hepatitis C. They may think they are the only ones struggling to cope with the disease. Good thing there are caring people like you who prove them wrong by bringing together people with hepatitis C.

When people first learn they have hepatitis C, they often feel alone. But the truth is, there are millions of people with hepatitis C. Studies show that people born from 1945 through 1965 have been hit the hardest by the hepatitis C virus.

While this news may be a bit overwhelming, it should also bring a little comfort to everyone living with hepatitis C. They should know that getting help, support, and understanding isn't limited to caregivers. There are also a lot of people who have—or are going through—the same thing, so they can relate firsthand.

This handbook is designed to help you take this “people power” and turn it into a support group for those affected with hepatitis C in your community. We've put into this handbook everything we think is needed to start and run a successful group.

The only thing missing is you.

This handbook is designed to:

- *Help you start and lead a support group*
- *Give you tools to help your existing support group*

Throughout this handbook, we refer to the person who organizes or leads the support group—you—as the *leader*.

Who needs a hepatitis C support group?

- *People who have just been told they have hepatitis C*
- *People who are being monitored, but not treated, for hepatitis C (some people have symptoms and some do not)*
- *People thinking about treatment or are currently in treatment for hepatitis C*
- *Family members and close friends of someone who has hepatitis C*

No two support groups are alike.

Just as every person is different, so is every support group. Not everything in this handbook may be ideal for every support group to use. As the leader, you may feel you need to make changes to better fit your group.

The accompanying ***Hepatitis C Support Group Lessons*** has 12 lessons to help you get your group up and running. Each lesson has 1 to 4 pages of text, plus a 1- to 2-page handout. We hope you find them interesting and helpful.

1: Why Do People Need Support Groups?

Support groups may help people make better decisions.

People with hepatitis C need support groups to help work through different issues.

At a group, members can:

- *Give each other help and advice*
- *Give each other emotional support*
- *Help each other make better choices in their lives*
- *Help each other feel safe and secure*
- *Help each other feel better and understand themselves better*
- *Learn how to teach others about the basics of hepatitis C, such as:*
 - *How the virus spreads*
 - *What is safe to do (kissing, hugging, and playing with their children, etc)*
 - *What is not safe to do (sharing toothbrushes, razors, etc)*

Support groups are very helpful for people who live alone or who need a bit of extra support close by. They also help people learn how to talk about hepatitis C with friends, family, and coworkers. And healthcare providers are often happy when their patients have the aid of a support group.

Support groups may help people make good choices.

People with hepatitis C are often confused and stressed out. Support groups can help them feel both more calm and more hopeful. Below are some of the things people may want to discuss at their support groups.

Did you just learn you have hepatitis C?

Learning you have hepatitis C can be upsetting, and you may find yourself with a lot of questions, such as:

- **What is hepatitis C?**
 - *How do I deal with such a serious disease?*
 - *Can I get rid of this virus?*

1: Why Do People Need Support Groups?

- **How do I tell others I have hepatitis C?**

- My wife, husband, girlfriend, or boyfriend?
- My friends and family?
- Should I tell my coworkers?

- **How do I protect others from getting hepatitis C?**

- **How can I talk about treatment choices with my healthcare provider?**

- Should I start treatment now?
- What about herbs and other supplements?
- Should I avoid alcohol, smoking, and street or illegal drugs?

What is a social stigma, and how do you deal with it?

Social stigma is when someone disapproves of someone else's association with a group that some people may look down upon. They might look different, be of another race, follow another religion, or even have a disease.

Some people may judge you because you have hepatitis C. They may:

- Judge you for what you did in your past
- Think that they should stay away from you so they won't get sick too

When people feel negatively about others based on what they think is a fact, they are *generalizing*, or having a *bias*. Unfortunately, these attitudes are common in every society, and they are simply caused by ignorance. Some people just don't like what they don't understand.

How you handle the stigma that often comes with hepatitis C is important. How other people act because you have the virus can affect almost every area of your life.

Social stigma affects everyone differently. Some people may respond by going into *denial* (not admitting the truth to themselves or others). This could lead to:

- Spreading the virus because the person is too embarrassed to tell their family or friends about the risks
- Not seeking medical care because the person is afraid that people they know may find out

How does your life change with hepatitis C?

Once your healthcare provider tells you that you have hepatitis C, you have to make some very important decisions about many things, including:

- Stopping all alcohol, smoking, and drug use
- Living a healthier lifestyle by eating better and exercising
- Learning how not to spread the virus to others

Do you know what your treatment choices are?

Many people join hepatitis C support groups to learn about getting treated for the virus. They come to hear what others have gone through during treatment, and to learn ways to handle the side effects of the medicines.

Peer support (getting and giving help to others like you) is very helpful for people taking medicines for hepatitis C. This therapy can cause many side effects. People who have been through the treatment before can give you tips and advice on how to cope.

What do I need during treatment?

Talk with your healthcare provider before starting treatment. You need to ask what you may expect, because everyone reacts differently to medicine. Your healthcare provider can help you understand:

- *Treatment results from clinical studies*
- *What are common side effects and how they would be managed*
- *How long your treatment may take*
- *What you may need to do to prepare for treatment*

What happens after treatment?

The end of treatment can be a tough time too:

- *It's common to have side effects, even after the regimen is over. It can take months to feel back to normal*
- *It can be very hard waiting to hear if you are cured or not.*
 - *Cure means that the virus is no longer in your blood 6 months after you finish all treatment. Another name for this is Sustained Virologic Response (SVR)*
- *Unfortunately, not everyone is cured or clears the virus*

Learning that the virus has come back after you've finished your treatment, or that treatment does not work for you, can be heartbreaking. It may be difficult deciding what to do next and how to move forward after the shock wears off.

Support groups can welcome friends and family.

Sometimes, friends and family members need as much information and emotional support as the person living with hepatitis C. They may feel powerless when someone they love is ill.

These caregivers might find support groups very helpful for themselves, too.

2: Do You Have What It Takes to Lead a Support Group?

The purpose of a hepatitis C support group is to give its members the power to help each other.

Many people who start or lead a hepatitis C group have never done it before. A lot of support group leaders aren't medical experts. Many do not have a medical background. But you don't need to be a person living with hepatitis C to run a support group. You simply need a kind heart, a little patience, and a strong desire to help others. Then, you need to commit to lead and be there for others.

Of course, it doesn't hurt to have the help of experts when you have questions. It's vital to build good relationships with:

- *Healthcare providers (doctors, nurses, physician assistants, etc)*
- *People who have run support groups before*

What do you want to get out of leading a support group?

Ask yourself these questions:

- *Is it to help myself?*
- *Is it to help others?*
- *Is it to help both myself and others?*

There is nothing wrong with starting a support group for your own good. But it is equally important that you want to help other people too.

How open-minded are you?

Everyone has some biases or *prejudices* (disliking someone for no specific reason). Will the way you feel about other people get in the way of you helping all the members of the group the same way? Ask yourself:

- *Can I accept all members, regardless of their race, religion, or sexual preference?*
- *Will I feel differently about someone who got the virus from a blood transfusion than someone who got it from injecting drugs or having sex?*
- *Can I put my own issues aside for the sake of the entire group?*

2: Do You Have What It Takes to Lead a Support Group?

- *Will I be comfortable talking to other people about their:*
 - *Sex lives?*
 - *Drug and alcohol use and abuse?*
 - *Family issues?*

How you answer these questions will help you decide if you are open-minded enough to lead a support group.

How organized and dedicated are you?

As the support group leader, you need to be determined to lead the people in your group on a regular basis. They count on you to be there to guide the meetings. Can you make a full commitment?

3: Gathering Information

Learning more about hepatitis C is helpful to you and the people in your group.

Identify experts.

The people in your group can usually get expert advice from their healthcare providers and you should suggest they go there first. So don't feel that you have to be an expert to lead your group. You just have to make sure that everyone gets a chance to share their story, and that everyone understands the ground rules of the group. Let the healthcare advice come from healthcare professionals.

The only difference between you and the other people in your group is that your focus and interest are in helping others as well.

Even though you don't have to be an expert, you should still try to learn as much as you can about hepatitis C. Free information is available from many sources:

- *The Internet (but get your information from credible sources)*
- *Various governmental agencies*
- *Nonprofit hepatitis C groups*
- *Companies that make hepatitis C medicines*

The information contained in this handbook will also give you some basic information about hepatitis C.

The most reputable websites will list the dates of their research, so you can be sure that you are getting the latest information. You'll find a list of useful sites at the end of this handbook.

Another way to educate yourself is by talking with local hepatitis C healthcare providers, who can also serve as guest speakers or advisors to the group.

Medical institutions and nonprofit organizations may offer sponsorships and free space for your meetings. They may also help you with advertising to invite potential members. It wouldn't hurt to give them a call to find out.

Do you need a co-leader?

Running a support group can be a big job. One way to make it easier for you is to share the responsibility. Once your group starts, you might want to choose someone who is willing to help you run the group. We will explore the benefits of having a co-leader later in this handbook.

Finding out more from other groups.

There are a lot of ways to learn how to run a successful group:

- *Sit in on other hepatitis C support groups in your area. This can help you:*
 - *Learn how others run their groups*
 - *Find out if the area you live in needs a group. You may choose to start a group for veterans, family members, substance abusers, or people of a certain age group*
 - *See if the best use of your time and energy is in helping an existing group, rather than starting a new one*
- *Visit other types of support groups:*
 - *Meetings for groups of people with other disorders or diseases can give you ideas on how to run your group*
 - *Be sure to tell the members of the group you visit that you are there to learn ways to help your own group. Honesty is very important in support groups*

Organizations that run support groups print leaflets and other materials that contain helpful hints on starting a group. Also, some local agencies may offer services or seminars on running a group.

4: Types of Support Groups

Support groups can be driven by information or experience. What do you want your group's focus to be?

There are basically 3 kinds of support groups:

- *Educational (often in a lecture format with guest speakers)*
- *Thoughtful (in which people with hepatitis C share experiences and advice with each other)*
- *A blend of educational and thoughtful (many groups are a little bit of each)*

You may want to divide the group meetings into 2 parts. The first part can be educational (perhaps featuring a guest speaker), followed by a short break. The second part of the meeting could then give members the chance to talk about their own experiences and feelings.

What's in a name?

Some people are uncomfortable coming to something called a "support group." They may feel more at ease attending an "informational meeting," a "discussion group," or a "get-together." It's something to think about when deciding what to call your group.

Drop-in groups.

Drop-in groups help people who need emotional or educational help at the spur of the moment. They may be in the middle of a crisis and need understanding and compassion.

Educational group meetings.

These can help people who want to learn more about hepatitis C in general, or about a certain related topic.

These meetings are a good way for people to learn about living with hepatitis C. These groups are more about listening than talking. This is the right group for people who aren't ready to talk about personal issues.

Even though the main focus is about learning, these groups can also give people emotional support. People can feel more comfortable being with others like them, who have the same interests, fears, and questions as them.

Sometimes, informational meetings end with group members discussing issues. And sometimes, these discussions get personal.

Thoughtful group meetings.

These are the right groups for people who want an emotional connection with others going through the same things as them. At these groups, members may share with each other their most private thoughts, fears, and struggles. They can give each other tips for dealing with side effects, staying healthy, and finding good, reliable information. They also sometimes lend each other a shoulder to cry on.

The important thing to remember is that you get to choose the kind of support group you want to lead. You are the one who will maintain the focus of the group, centering either on educational facts or on life experiences, and probably, including a little of both.

5: It's All in the Details

Plan all the details in advance. It will save you from needless worry, and it will make your group much more successful.

Before your first meeting, you have a few important decisions to make, such as:

- *Finding a location*
- *Choosing a format*
- *Picking experts*

Planning ahead can make things easier for you and help you create exactly the kind of group you want.

Do you want a closed or open group?

Some longtime group members like having newcomers join in. Newcomers can bring a different outlook. They can:

- *Renew the group's commitment*
- *Invigorate the discussion with new ideas*

But a newcomer's fresh perspective can also come with some concerns:

- *Longtime members may not be comfortable with newcomers*
- *New members may have different emotional needs*
- *Newcomers may not know what is already familiar to longtime members*
- *Newcomers may not be prepared to see the disease or the treatment's side effects on longtime members*

As the leader, you will need to be supportive of the longtime group attendees, as well as be sensitive to the needs of new members (if your group is open to them). It's important to strike a balance.

Getting to know your members.

To understand your members better, it helps to meet each of them in the days or weeks before the first meeting (if you can). As you talk with them, ask yourself, "Would this person be a good fit for the group?" Be honest during this process. This is not because you want to keep anyone out, but because not everyone will be a perfect fit with your other members.

Here are some questions you may want to ask at each interview:

- *"Our support group includes people who are currently being treated for hepatitis C. Can you handle discussions about that and deal with the emotions that may surface?"*
- *"In our group, we don't talk about how each of us got hepatitis C. We don't judge members because of things they may have done in the past. Do you think you can accept these conditions?"*
- *"Can you keep the things we talk about in meetings confidential?"*

Sometimes it is not practical to meet each group member. So before each meeting, go over the ground rules. You'll see some examples of ground rules later in this handbook.

How many members should your group have?

Support groups can be any size. Even 2 people at a meeting can be a very powerful support group. The size of the group will depend on what type of group you want. For example:

- *A thoughtful support group should be on the smaller side. Too many people can make the setting feel impersonal, making it hard for people to open up and share freely. As a rule, 6 to 15 people are best for this kind of group*
- *An educational meeting can have many people attend. The members are there to learn more about hepatitis C from a speaker, not from each other. They are basically an audience*

Keep in mind that the meeting room may limit how many people can attend.

How often should your group meet?

The kind of group you have helps dictate how often to meet:

- *For thoughtful support groups, members meet weekly or every other week. Because close bonds may develop at these meetings, the members will look forward to seeing each other and sharing with each other more often*
- *For educational groups, monthly meetings usually work best*

How long should each meeting last?

The length of the meeting also depends on the format of the group:

- *For a thoughtful support group, 90 minutes usually works best; some people may even prefer more time*
- *For an educational group, the time frame may be decided by the amount of time the speaker has to dedicate, or by how much information there is to discuss*

Once the group decides, make sure you always start and finish on time. People are busy, and if you start or end late, attendance can suffer. If you let certain members come late too often, it could hurt the group as a whole. Group members likely have enough uncertainty in their lives. Your meetings and meeting times should be one thing they can always count on.

If the group meets for longer than an hour, it's a good idea to take a short break in the middle of the meeting. This gives everyone a chance to stretch and use the facilities. It also makes it easier to change the group format.

Should your group meet just for the short term or forever?

Some groups meet for as long as the members are interested in keeping the group going. This can mean months, years, or even decades.

Other groups are designed to meet for only a few weeks to several months. How long you want your group to meet is up to you.

If your group is designed to get together only for a certain number of meetings, be sure to tell the members the exact dates when the program will begin and end.

A group that ends on a specific date works well for people who may not want to commit for a long time.

Sometimes, group members form personal attachments with each other, so they may decide to continue meeting on their own. They may also decide to take over the group to keep it going. If this is the case, you may want to help teach them what you know about running a group.

Location.

Support groups need to meet where members feel safe and comfortable.

Preferably, the meeting location should:

- *Offer easy access to public transportation and free or affordable well-lit parking*
- *Let people travel safely there and back in the day or evening*
- *Be easy to find*

Look for space at hospitals, community centers, churches, or other public buildings. They will often provide free space for nonprofit groups.

A home is not a good idea for most types of support groups. It can be hard to separate the group from the host's personal space. Most people prefer a neutral location.

The meeting room.

The meeting room helps set the tone for a support group:

- *A drab and dreary room is depressing. It should be a cheerful, encouraging place that makes people feel comfortable and at home*
- *A group that doesn't have a lot of funds can also spruce up their space using posters, flowers, or other items that will lift the group members' spirits*

Check the meeting space for:

- *Privacy. It is important that people feel comfortable attending meetings without advertising that they have hepatitis C*
- *Size. The room needs to be large enough to fit everyone, even if you break into 2 smaller groups. But it shouldn't be so large that the group doesn't feel some degree of intimacy (feeling of closeness)*
- *Furniture. Comfortable chairs are important for people with hepatitis C, since many suffer from muscle and joint pain*
- *Lighting, air, and temperature control. Each one affects how people feel and how they relate to each other*
- *General atmosphere. Nothing in the room should offend anyone's cultural or religious beliefs*

Seating.

Think about how you want to set up the chairs. How you do it can affect how close people feel (physically and emotionally).

Here are some thoughts to consider for theater or classroom-style seating:

- *This works for educational meetings, but not as well for thoughtful groups:*
 - *The people in the front will have to twist around to see those speaking behind them*
 - *If they can't see each other, it can be harder for some people to speak openly*
- *If you have a thoughtful group but are stuck with classroom-style seating, come up with new ways for people to talk comfortably. For example, have people sit in a "U" shape. That way, people can speak to each other "face to face"*
- *It's good to have the door at the back of the room, so that if someone comes in or leaves, people will not be disturbed*

Here are some thoughts to consider for circle seating:

- *This is the best arrangement for a thoughtful support group:*
 - *Leave the middle of the circle empty so members can see each other. People talk with their voices, but being able to see facial expressions and body language creates trust*
 - *Remove all empty chairs from the circle to help everyone feel connected*
 - *Put a box of tissues in the center. This tells everyone that it is okay to express emotions—even if it means shedding tears*
- *The circle format may be difficult for larger groups. Consider splitting the group into 2 smaller circles. This can work well if you have a co-leader to head the other circle*

Should you have beverages and food?

Food brings people together; however, if you decide to have food at your meetings, request that members not eat during the actual session. (You may want to make an exception for people who need to eat for a medical reason.) You want them to be able to give each other their complete attention. Beverages are also nice to have on hand; water is especially good for people going through treatment. Of course, food and beverages can be difficult to supply if money is an issue.

Here are some ways to deal with money issues:

- *Ask for volunteers to bring in food and beverages on a rotating basis*
- *Request a donation at the beginning or end of each group*
- *Invite local businesses, nonprofit groups, and other organizations to donate money for snacks*

You may prefer not to allow food during meetings. If so, make this clear to members so you can manage their expectations.

Educational materials.

Giving people information about hepatitis C helps them make decisions about their health and take charge of their own care. Remember, when you give out information to the group, they may think that you endorse or recommend the information. That's why it is important that you always know who created the materials you share. You need to be sure that the information is from a reliable source. Some good places to find information are:

- *The Internet (a list of reliable sites is at the back of this booklet)*
- *Government agencies (such as the Centers for Disease Control and Prevention and the US Department of Veterans Affairs)*
- *Nonprofit hepatitis C groups*
- *Drug companies, which often have websites and brochures about specific diseases and treatments that they make. (If you decide to go this route, you should make sure to handle it delicately. It is important to keep the group's trust in you as a leader. You don't want to appear as though you are pushing a product.)*
- *Hospitals or healthcare provider offices*

See the information and handout material included in the accompanying **Hepatitis C Support Group Lessons**. The manual also provides some basic information about hepatitis C and many topics for group discussions.

5: It's All in the Details

The cost of educational materials may prove to be an obstacle. Here are 3 ways to help with that cost:

- *Ask people to print out or make copies of educational materials that they can bring to the meetings. Have everyone in the group share the responsibility of doing this*
- *Order information from drug companies, advocacy groups, and nonprofit agencies, such as the Hepatitis C Support Project (see the Resources section). You need to read the information closely to make sure that it is accurate, true, and appropriate*
- *Ask for donations from the support group members*

6: Leading a Group

You've already shown initiative by taking the first step and picking up this handbook. This is an important trait of a leader.

What makes a good support group leader?

As the leader, you have many responsibilities, including:

- *Finding a place to meet*
- *Keeping the meeting on track*
- *Making sure your meetings have helpful information for members*

You may be a natural-born support group leader. Or, you may have to learn as you go. The point is, you already have what it takes, because your heart is in the right place.

How much time and energy you want to spend on being the support group leader is up to you.

Most people who start a group take on the role of the leader. But some people prefer to have someone else direct the group once everything is set up.

Some groups have more than 1 leader. Others have a rotating leadership policy among their members. One example is Narcotics Anonymous®* (NA). NA groups follow strict rules that never change, but the leadership role rotates from member to member.

What is the leader's role?

Since you have decided that you would like to lead a support group, you have a few important steps to follow before your first meeting:

- *Understand your role. Basically, a leader's job is to help guide and support the entire group*
- *Realize your talents. Honesty and the willingness to listen will help you to earn the trust and respect of your fellow group members*
- *Be patient with yourself. Some people take naturally to the role, while others may get there with practice*

What makes a good support leader?

A strong support leader has these 7 qualities:

1. *Focus: The ability to set clear goals and keep focused until the end. This person can put his or her ego and personal feelings aside*
2. *Communication skills: Listens well and has the ability to express him or herself clearly and effectively*
3. *Compassion: Cares deeply about people's feelings and well-being*
4. *Trust: Approachable, truthful, and keeps things private*
5. *Knowledge about hepatitis C: Not necessarily a medical expert but knows the facts enough to help correct misinformation*
6. *Unbiased and nonjudgmental: Accepts everyone equally, regardless of race, religion, sexual preference, or how they became infected*
7. *Optimistic: Looks for the positive in people and in life instead of the negative*

This may seem like a long list of qualities, but you may be surprised by how many you already have.

Will you need a co-leader?

If you have a large group, you may want to have a co-leader to:

- *Split the group into 2, where each of you runs one half of the group*
- *Jump in if the discussion seems stuck, or when there are unexpected issues*
- *Step in for you if you have to miss a meeting*

If you are looking for a co-leader, choose someone you're comfortable working with.

7: Getting the Word Out

It's important to make sure that anyone who is looking for a support group is able to find one. That's why publicizing your group is so important.

Be clear about the goals of the group.

When you're looking for people to join the group, remember that different people have different needs. Some may want an informational meeting on hepatitis C. Others may be seeking an emotional support group.

People need to feel safe to discuss very private feelings. This is important to keep in mind as new members get to know each other. Some people simply can't ever have this kind of trust. For them, an informational meeting may be better. As you develop your strategy as the group leader, it's important to remember that you can't please all of the people all of the time.

What are some ways to invite members?

First, you need to get the word out that you are starting a hepatitis C support group. Here are some suggested strategies:

- **Develop a flyer that encourages people to join your group**

- o *Flyers give people a good sense of what the group will be: nonjudgmental, positive, and caring. You also want to explain the purpose of the group, where it meets, and how to sign up*
- o *Plan to distribute or post the flyer in healthcare providers' offices, public health departments, hospitals, community health clinics, community-based organizations, bulletin boards, and any other office that may serve and support people with hepatitis C. First, request permission from these offices and organizations to post the flyer*

- **Make a flyer that is upbeat and positive**

- o *Stress the purpose of the support group; be clear and to the point. For example, "The mission of our support group is to give people with hepatitis C peer support and education in an open, comfortable, and nonjudgmental environment"*
- o *List any healthcare providers and organizations that endorse or provide funding to the group. For example, "This support group is endorsed by the X Medical Center"*

7: Getting the Word Out

- **State the location, time, duration, and any other important information. For example:**

- o Title: Hepatitis C Support Group

- o Time: Every Wednesday from 6:30 pm to 8:00 pm

- o Location: 191 Main Street, Any Town, Zip Code (provide a map)

- o Purpose: To provide community discussion and support for people living with hepatitis C

- o Please call 1 (XXX) XXX-XXXX for more information or e-mail Name@mail.com

- **For a drop-in support group**, list the exact address in the description. For example: "Would you like to meet others who have hepatitis C and learn how they live with their condition or handle treatment? Our support group meets every Wednesday from 6:30 pm to 8:00 pm at 191 Main Street, Room 337, Any Town, Any State, Zip Code. You are welcome to drop in and check us out!"

- **For a closed group**, include your phone number or e-mail address. That way, you can meet face to face or interview potential members over the phone. Either way can help ensure they are right for your group. Consider getting a new, non-home phone number for safety and privacy. If you put your phone number on the flyer, turn off your ringer when you don't want to be disturbed. Some people prefer having a voicemail box separate from their personal or home phone

NOTE: A general media kit is available at the HCV Advocate website (www.hcvadvocate.org), and a sample flyer is on the next page.

Have Hepatitis C? You're Invited to Join Our NEW Support Group

Come meet other people who have hepatitis C. Learn how they live with their condition and handle treatment.

Our group's mission is to give people with hepatitis C peer-to-peer support and education in a nonjudgmental, caring environment.

To sign up: Call 1 (XXX) XXX-XXXX or
E-mail: Name@mail.com

Where: Community Center
191 Main Street, Room 337
Any Town, Any State, Zip Code

When: Wednesdays, 6:30 pm to 8 pm

This support group is endorsed by the Any Town Community Hospital.

Reach out to help promote your group.

Talk with other support groups that serve the needs of the hepatitis C community. Your group could offer a special type of support that no other group does.

After your group begins having meetings, post a new flyer listing upcoming speakers and topics. It may encourage others to join when they see who will be speaking. Other ideas are:

- **E-mailing www.hcvadvocate.org:** They maintain and publish a national database of hepatitis C support groups. Contact them to see about listing your group
- **Creating a press or media kit:** This is a package of materials you send to the press. It may include a press release, which is a brief news article announcing your group and explaining how people can sign up. Typically, you mail or e-mail it to local radio stations and newspapers. You may also want to include your flyer. After you send it, follow up with a phone call to show it is important
- **Contacting local newspapers:** Look for newspapers that cover your community or the specific audience that your group wants to attract. It helps to call the newspaper and develop a relationship with the local editor, since they are always looking for news. Ask if they will run a free announcement. If not, consider taking out an advertisement
- **Checking with community websites:** Many of these websites list local events for free and run articles about nonprofit groups
- **Speaking with clearinghouses:** These are online links to nonprofit, self-help, and advocacy groups. Ask the clearinghouse to list your new group on its website. Here is one example of a clearinghouse: www.health.gov/nhic/pubs/2011clearinghouses/clearinghouses1.htm
- **Reaching out with social networking:** This is another easy way to advertise and keep group members informed of any changes. The 2 most popular social networking sites are Facebook and Twitter
- **Writing a blog:** Do a Web search for the leading hepatitis C blogs, and ask if any of them will write about your new group. Also, consider starting your own blog. Members of your group can contribute to it, and it may prove to be a great way to attract new members
- **Creating a Yahoo- or Google-type group list:** These electronic programs let you e-mail many people at once
- **Posting information to online bulletin boards:** Online, locally based websites may be helpful places to invite people to join
- **Creating a new e-mail** so that you can keep your personal life separate from the support group

Mailing lists.

Establish a mailing list—preferably one with e-mail addresses. This will save on postage and it is quicker than regular mail. Some good things to include in your e-mails are:

- *Lists of future speakers and topics*
- *Requests that people RSVP (let you know if they'll be coming) for each meeting, so you know how many people to expect*
- *Flyers for people to share or post*

Do not send group e-mails to people unless you have their permission.

Meeting signs.

Make laminated signs that can be reused for each meeting. Place them in elevators and hallways so people can find their way to the meeting. You can buy them at an office supply store.

8: Confidentiality: Respecting People's Privacy

Trust is vital for a support group to be successful. Here's how you can help people in your group feel safe and secure.

To borrow from a popular ad campaign: "What happens in the group stays in the group."

The most important thing that your group can provide its members is a safe environment. People need to feel free to share their experiences and know it will stay within the group. They should never have to worry that anything said will be repeated outside the group.

At the start of each meeting, remind the group that privacy is important:

- *Building trust makes the group comfortable*
- *When they feel secure, people often open up*
- *Sharing experiences and feelings helps everyone in the group*

Talk to your group about the rules for privacy:

- *No one should talk outside of the group about what people said in the group, especially in a way that might reveal the identity of a group member. You may want to tell everyone in the group to only use first names*
- *It is okay to discuss the general subject of the group meeting with others. But do not disclose any personal information about group members. For example, it is not okay to say, "There's this guy in the group who writes for the local newspaper." It would be okay to say, "There's someone in the group who wore a blue shirt"*

Maintaining privacy outside of the group is important. If people see someone else from the group in public, it can be awkward. Remind the members to be discreet.

Discuss what members should do if they see someone from the group in public. For example:

- *Should they acknowledge the other member?*
- *Would it embarrass them?*
- *If they introduce the member to their friends, what is the best way?*

Everyone in the group may have a different feeling about these issues. It might be helpful to talk about these situations and figure out some rules. Then, you can all agree to follow those guidelines.

What are the ground rules?

A support group should have some ground rules. Without them, group meetings could become unruly and chaotic. Members need to feel safe enough to talk about personal issues and offer advice to others. Rules can help give everyone a chance to be heard.

So before your first meeting starts, think of some ground rules. Write them down, so that the group can then add to and improve on them during the meeting. Also:

- *Talk about the reasons for the ground rules and ask for comments from all the group members*
- *Feel free to add or make changes as people make suggestions*
- *Discuss the rules, then have the group vote on and adopt them*

It is much easier for people to follow guidelines when they have had a role in creating them. Ground rules can be changed as long as the majority of members agree. Here are 8 suggested ground rules:

- 1. I will try my best to arrive on time and attend every meeting*
- 2. I will respect the confidentiality of all group members*
- 3. I will be honest*
- 4. I am willing to talk, but it is also okay if I decide not to talk*
- 5. I will not interrupt others or disrupt the meeting with side conversations. I respect that only one person talks at a time. I will not take over the conversation. I will listen carefully*
- 6. I will accept all other group members without judgment. I will not give feedback or advice without the other person's permission*
- 7. I will respect other members' feelings, whether positive or negative, and I will express my feelings in a nonjudgmental way. I will make "I" statements, such as, "I feel sad," rather than "You" statements, such as, "You make me feel sad"*
- 8. I will not attend a meeting if I am under the influence of any non-prescribed drugs or alcohol*

Have each member sign the rules. This shows that the whole group adopts these guidelines. As the leader, remind everyone that these are the rules everyone agreed to.

9: Sample Support Group Format

Create a format for your group to follow.

Below is a sample of a support group format, where the support group meets on the first and third Monday of every month, from 7:00 pm to 8:30 pm.

Starting the group (the first 35 minutes, 7:00 pm–7:35 pm).

- After arriving, the members take a few minutes to check in with each other. For the first few weeks, they may need to reintroduce themselves
 - The members discuss any important issues that have come up since the last meeting. Everyone gets to speak at this time
 - The check-in for each person is usually 2 to 3 minutes, but not longer than 5 minutes. During the check-in, some group members may ask for additional time to talk about topics or problems they would like to discuss with the entire group. No one should interrupt the person who is checking in
- The group leader may introduce a theme into the check-in, such as:
 - “When you check in, please describe how you are feeling.” (Discourage members from using “fine” or other 1-word answers)
 - “When you check in, please tell us one thing that you feel good about or grateful for.” (It helps group members to start out with a positive comment instead of a negative one. This can also be used for the check-out at the end of the meeting)

Education or specific topic section (35 minutes, 7:35 pm–8:10 pm).

The second part of the meeting is for discussing a wide range of topics. Come to the meeting with an order in mind for these topics. At some meetings, you can arrange for a speaker to address the group.

Within the Lessons Manual, there is a series of 12 modules or lessons for you to use as discussion guides. Each one gives you a framework around which to build a meeting.

Short break (5 minutes).

Allow members to take a 5-minute break. This allows participants some time to collect themselves. It also helps keep people focused and it may help encourage participation in the rest of group.

Ending the group (15 minutes, 8:10 pm–8:25 pm).

It is important that each member finds *closure* during the check-out part of the meeting. This means that they can go home feeling that they've been able to express everything they needed to.

- *This is the time for members to have a final word or thought*
- *This could be a simple goodnight or a comment about the meeting*
- *The person checking out should be allowed to talk without interruption*

Some groups perform a closing ritual. Your group could close with prayer, meditation, a poem, or just holding hands for a moment of silence. Ask your members how they would like to close each week's meeting. They may choose to share a prayer or poem that helped them find inspiration and hope.

Here are some end-of-meeting examples:

- *Serenity prayer: "God, grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference"*
- *Silent meditation: All the members form a circle and silently say to themselves (2 times), "May I be well," (breathe in), "May others be well," (breathe out)*
- *"Thank you for coming. Be safe"*

Typical Support Group Meeting Format
Starting the group (35 minutes)
• Introduction and review of the rules
• Check-in: Each member talks for 2 to 3 minutes
Short break (5 minutes)
Education or specific topic (35 minutes)
• See lessons for ideas
Ending (15 minutes)
• Check-out: Each member shares a final word or thought
• Closing ritual (poem, prayer, or meditation)

To learn more about support groups, see Lesson 11: "Ways to Work Through Tough Problems."

10: Even the Smallest Steps Are Steps in the Right Direction

Your group can help improve members' quality of life, even if it is a little at a time.

When people are newly diagnosed with hepatitis C, their healthcare providers may recommend many lifestyle changes. Among these changes are:

- *Avoiding alcohol*
- *Eating a healthy diet*
- *Exercising*
- *Not taking street or illegal drugs*
- *Quitting smoking*

For more lifestyle changes, see Lesson 6: "Living With Hepatitis C," in the accompanying **Hepatitis C Support Group Lessons**.

For many newly diagnosed people, making these changes to their lifestyles can be difficult. Too many of these changes at once often results in failure.

Group members can help people stay on track. Family, friends, and healthcare providers can also make these lifestyle changes easier to accept.

One way to help people adjust to these changes is through *harm reduction*. It's an approach where even the smallest steps in the right direction are celebrated, because even the smallest steps get you closer to your goal.

- *For example, it may be too difficult at this time for someone to stop smoking completely. So if he or she can cut back on the number of cigarettes each day, then it is a small step forward. Each time the person cuts back a few more, it's another successful step until he or she finally reaches the goal of completely stopping*
- *This approach can be used for any type of behavioral or lifestyle change, where the person can't go all the way at once*

Members of the group can encourage success using harm reduction. People in the group should openly share their own experiences about how they took small steps until being able to stop completely. They can also add how good they feel about themselves for sticking with their plans.

Others can talk about the small steps they are currently taking, and how they are looking forward to reaching their final goals.

10: Even the Smallest Steps Are Steps in the Right Direction

Small steps do add up. Consider having a weekly celebration of small personal wins, such as making it to the halfway point for treatment, or not having a beer for a week. Ask your group members to make suggestions.

Setbacks are part of the process. Encourage people who are trying to keep trying. Ask the group members to make suggestions to the person who needs to get back on track.

11: Ways to Work Through Tough Problems

Dealing with people in support groups can be challenging. But it doesn't have to be a problem.

Every support group is unique. Each member brings his or her own issues and emotions to each meeting.

Sometimes, the different personalities and viewpoints of people in the group will clash. This is your chance to help members work out their differences.

It's not impossible. For starters, try not to worry about potential conflicts. They don't happen very often, if at all. Besides, you have the ground rules to help you avoid or handle such situations. Remember, the whole group voted on the ground rules, so you have the whole group on your side.

Keep in mind that no one likes to be directly challenged by the leader or anyone else. If you must interrupt or challenge someone, be gentle, but firm. Use a calm and reassuring voice in a non-threatening manner. Start off by making a positive comment to the person.

COMMON PROBLEMS

A member repeatedly shows up late for support group meetings:

- *Mention that the person is late and remind him or her that we are all responsible for showing up on time. Things happen that make people late. So be careful that you are not too rigid with him or her*
- *One good way to handle this is to say, "I have noticed that you have been late for the last 2 meetings. Is there anything we can do to help you join us on time?"*

A member is dominating the conversation:

This issue needs to be a part of your ground rules. One member dominating the group may frustrate others, which is unfair. If a member is dominating, rambling, or gets sidetracked, you can:

- *Summarize the main point and ask the other group members for their point of view. For example: "Thank you, Steve, for sharing how you were able to deal with the chills during treatment. How do you think you will be using that strategy if you need it, Peter?"*
- *If the speaker makes a number of good points, say so. Then, choose the most helpful one. Suggest that the group focus on it. You may have to interrupt the person. One way to do it is to say, "You bring up some interesting points. Do any others have any comments, or would others like to share how this relates to them?"*
- *Avoid direct eye contact with the person dominating. It is harder for people to dominate the conversation if the leader is not actively engaged*

A member keeps interrupting the guest speaker:

If you have an invited speaker giving a lecture, explain to the member that there is a lot of material to cover. Ask your group to hold questions until the end.

A member frequently makes comments only to, or asks questions of, the leader:

- *Look away from the member*
- *Repeat the questions back to the entire group*
- *After the meeting is over, talk with the person about directing comments or questions to the entire group*

There are silent moments:

Silent moments can be a positive sign. It can mean:

- *That the members are feeling comfortable with each other*
- *That people are digesting information, or may be trying to process some feelings*

If the silence runs on for too long, ask the members, "Does anyone have any other thoughts about what was just discussed?" Or, you can simply move along to the next topic.

A member never speaks up:

Some people may want to sit quietly and not participate. That's okay. If you feel that people want to talk but may be shy, you can make direct eye contact with them. Check out their body language for hints that they may want to jump into the discussion. You can also ask them:

- *"Do you have anything you would like to share about the discussion?"*
- *"Do you have any feelings about what we discussed?"*

There is incorrect information:

It is not a good idea to challenge members aggressively if they say something you know is false. Instead, try to speak in a calm and soothing voice:

- *"Hmm...that's not what I have heard or read. Maybe we can talk about it after group"*
- *"I have heard differently. Let's talk after group about how we can research this issue. Then, we can share with the group what we learned at a later time"*

Don't directly challenge the information as false, but if there is no scientific evidence to support the information, say so. Invite the participant to discuss the issue with you later: "I have another explanation I'd like to share with you after group."

Humor: What's appropriate and inappropriate?

Humor is a wonderful tool for breaking the tension within the group when the conversation becomes upsetting. However, it can also interfere with members coming to terms with their emotions. It may even get in the way of an important discussion. Try these strategies:

- *Ignore the humor and move on*
- *Make a comment, such as, "That was really funny, but I think we need to stick to our discussion"*
- *If a person continues to make inappropriate jokes, say, "This is a serious issue, and we really need to concentrate on working through it"*

There is anger in the group:

Anger is a necessary part of the support group process. This is especially true for people with a potentially life-threatening disease. People need to be able to release their anger in a safe way. Make sure no one directs their anger toward anyone in the group. Once the member voices his or her anger, the group should be able to move on.

If the anger continues, it can harm a support group meeting. It can make people feel that the group is unsafe. If anger continues to dominate a meeting, try one of these 5 approaches:

1. *Acknowledge the person's anger: "You have expressed some powerful emotions. How do you think these affect the other members?"*
2. *Ask for a time-out, so that you and the other members can deal with the anger: "I can see that you are really upset. Let's take a couple of minutes to cool down before we continue with this discussion"*
3. *Reassure the member that everyone in the group wants to help*
4. *If someone becomes too angry, ask the member to step outside for a minute to try to calm down*
5. *Try moving on to another topic, but make sure you come back to the member and check in when his or her emotions have calmed down*

There is arguing in the group:

People in groups will argue. If it gets out of hand, show that you respect the person's feelings. Then, encourage him or her to use the group to get additional information, or to give his or her perspective on the issue.

There is crying in the group:

Crying is an important and natural part of the grieving process. If someone starts to cry, reassure him or her that these feelings are normal. Acknowledge his or her feelings, and provide comfort (and tissues). Gently shift to talking to another group member, but come back to check in with the member when he or she has stopped crying.

If the person is upset to the point of concern, you could step out of the room with him or her until the person has settled down.

If the member is unable to continue to talk, move on to another topic, or ask the other members to check in.

There are side conversations in the group:

Side conversations are disruptive and disrespectful. They show that the member is not interested in the group discussion, and they can make other members feel like they are being left out. Some ways to deal with side conversations include:

- *Reminding the members about the ground rules at the beginning of the meeting. If need be, enforce the rules*
- *Walking over to the people having the sidebar. Sometimes, just by standing near, they will drop their conversations*
- *Calling for a time-out and stopping the group for a moment. This will help you make the point that a ground rule has been broken. You could also interrupt the offenders and ask if they have something to share with the group*
- *You can say, "Hold on for a minute," and wait for the people to stop talking*

12: How to Get Funding

Finding sources of cash to run your meetings can be a challenge. Here are simple tips that have been helpful for other groups.

You don't need a lot of money to run a meeting. You should not have to pay out of your own pocket to cover the costs—after all, you are donating your valuable time. It is even easier if other agencies are able to provide free space or donate materials and other services.

Your support group could decide to expand its mission to provide additional meeting times or offer other services. If that happens, you will need a fundraising strategy. Whether you plan to have a large or small group, it is a good idea to develop a budget.

Develop a budget.

Your first step to managing money for the group is developing a budget. You will need to do this before your first meeting. Start by thinking about all the possible expenses you might have for the first year of operation, such as:

- *Postage*
- *Copying*
- *Snacks/beverages*
- *Telephone bills*
- *Other charges*

Once you estimate the expenses, you will have a better idea of how much money you will need to raise for each year. Often, you can cover your group's expenses by raising money from volunteers and donations.

Ways to get funds.

Raising cash for your support group is easier if you keep the cost of running the group low. Here are some ways to cover the costs:

- *Cash donations: At the beginning or end of each support group meeting, pass around a jar or coffee can for donations. Don't be afraid to tell people that there are costs associated with running the group. Also, ask people to:*
 - *Help fund the group, since they are participating in the group. Make sure members understand that they should only donate what they can afford. But if they don't have anything to give, they are still valued members of the group*
 - *Bring in food and beverages on a rotating basis*
 - *Volunteer to photocopy educational materials for the meetings*

- *Garage or sidewalk sales: One of the easiest ways to raise cash is by having a garage or sidewalk sale. You can:*
 - o *Get members and their families and friends to help organize and staff the sale*
 - o *Encourage members to donate items to sell*
 - o *Ask a group member who lives in an area where many people walk by if they can host the sale*

You might be surprised by how much money a sidewalk sale can bring in. Be sure to check with your town about any rules for these sales.

Can you get donations?

It never hurts to ask. For your support group meetings, ask local government healthcare organizations and companies to donate:

- *Services*
- *Space*
- *Food*

You could also ask bakeries, coffee houses, local healthcare provider offices, and anyone else you think might be willing to support the group.

If you want to seek grant funding.

If you want to seek grant funding, you will have to apply for commercial or nonprofit status with both the federal and the state government. Support groups usually apply for nonprofit status, since they do not intend to make money. You should know that:

- *It is not hard to apply for nonprofit status, but filling out the application can take time. You also need to manage the day-to-day business operations carefully*
- *All of your revenue and expenses must be recorded. You also must fill out a state and federal tax return*

Check with your local, state, and federal governments to learn more about the application process.

Another option is to focus on running the group instead of raising money for the group. If you choose this approach, you can use a nonprofit local government healthcare agency to act as a *fiscal agent* (an organization that will legally hold money and do all the accounting for your group). Some agencies will handle your money for free, but others will charge you a small percentage of the money you raise.

13: What Comes Next?

The first step was reading this handbook. The next steps are up to you.

Now that you have the information on how to start a support group, give the group some serious thought.

Many people have said that leading a support group has been one of the most rewarding experiences of their lives.

The majority of people who attend hepatitis C support group meetings say they enjoy the group experience. Being supported by their peers helped them to transform their lives from a state of ignorance, fear, and anger to one of more acceptance and greater self-esteem.

This process can also help you. Other group leaders have said it helped them develop strategies to move forward in their own lives and become better self-advocates (people who can speak up for themselves).

Good luck and much success to you and all of your future group members.

14: Resources and Glossary

Spend time with these resources to continue to learn more and share what you've learned.

Hepatitis C Resources

American Liver Foundation

1-800-GO-LIVER (1-800-465-4837)

www.liverfoundation.org

Information on liver disease, including hepatitis C

Caring Ambassadors Hepatitis C Program

www.hepcchallenge.org

Hepatitis C Choices book (free PDF); information and awareness

Centers for Disease Control and Prevention (CDC)

1-800-CDC-INFO (1-800-232-4636)

www.cdc.gov/hepatitis/index.htm

Fact sheets and answers to frequently asked questions about hepatitis

Hepatitis Education Project

www.hepeducation.org

A website for people with hepatitis C and their friends, family members, and healthcare providers.

Information, advocacy, support, and other resources

Hep C Connection

1-800-522-HEPC (1-800-522-4372)

www.hepc-connection.org

Resources, education, and support for people affected by the hepatitis C virus

Hepatitis C Support Project

www.hcvadvocate.org

Provides resources and information on hepatitis C, from clinical trials to alternative treatments. Also includes complementary therapies and information about living well with hepatitis C

Hepatitis Foundation International

1-800-891-0707

www.hepfi.org

Information on viral hepatitis and liver disease

Mayo Clinic

www.mayoclinic.com

Up-to-date information and tools that reflect the expertise and standards of the Mayo Clinic

MedicineNet (owned by WebMD)

www.medicinenet.com/hepatitis_C

Medical information on hepatitis C

MedlinePlus Health Information

www.nlm.nih.gov/medlineplus/hepatitisc.html

An extensive health information website that includes a medical dictionary, information on prescription and nonprescription drugs, and an overview of hepatitis C

National AIDS Treatment Advocacy Project (NATAP)

www.natap.org

Educates people about HIV and hepatitis treatments, and advocates for those with these conditions. Provides hepatitis C news and conference coverage

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

www.niddk.nih.gov

Contains a database of educational materials and a discussion of hepatitis C

National Institutes of Health (NIH)

www.nih.gov

Comprehensive health website with links to health publications and current research

United States Department of Veterans Affairs (VA)

www.hepatitis.va.gov

Information, brochures, and handbooks on hepatitis C

Drug Manufacturers and Other Resources

Better To Know C Program

Vertex Pharmaceuticals

1-888-552-2494

www.BetterToKnowC.com

Partnership for Prescription Assistance

1-888-4PPA-NOW (1-888-477-2669)

www.pparx.org

All About Hep C

Schering/Merck

www.AllAboutHepC.com

Tune In To Hep C

Schering/Merck

www.TuneInToHepC.com

Other Resources

Rules and regulations regarding medical conditions and the workplace can be obtained from:

Americans with Disabilities Act (ADA)

www.ada.gov

Federal Equal Employment Opportunity Commission (EEOC)

www.eeoc.gov/facts/qanda.html

Federal Family and Medical Leave Act of 1993 (FMLA)

www.afm.ars.usda.gov/hrd/payleave/family/FMLAentitlements.htm

New privacy laws about medical information and records can be found at:

US Department of Health and Human Services (HHS)

Health Insurance Portability and Accountability Act (HIPAA)

www.hhs.gov/ocr/privacy

GLOSSARY

Acetaminophen: The generic name for over-the-counter pain and fever relievers, such as Tylenol®. Large doses can cause liver failure. Ask your healthcare provider if you can take acetaminophen. It should never be taken with alcohol.

Acute: A term used to describe disease symptoms of a short period of time.

Acute hepatitis C: A short-term illness that usually occurs within the first 6 months after someone is exposed to the hepatitis C virus. About 75% to 85% of people who become infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

Adverse event: An unwanted reaction you get from taking a medicine.

Alanine aminotransferase (ALT): A liver enzyme that plays a role in building up and breaking down protein. Healthcare providers check the serum level as part of a liver function test. If your liver cells are damaged, the serum levels of ALT may be high. Hepatitis C can cause your ALT level to go up.

Anemia: A condition in which your blood has a lower-than-normal number of red blood cells. Symptoms include feeling tired, having a shortness of breath, having a headache, and having your heart beat too fast or too slow for no reason.

Antiviral drug: A medicine that fights a virus.

Aspartate aminotransferase (AST): An enzyme normally present in liver, heart muscle, and red blood cells. It is released into the blood when you've been injured (including getting infected with the hepatitis C virus). Higher levels of AST in your blood may mean you have the hepatitis C virus.

Blood transfusion: The transfer of blood from one person into the bloodstream of another person. Before July 1992, people were at risk of getting infected with the hepatitis C virus through blood transfusions. Since then, blood is screened more carefully.

Blood-borne virus: A virus in your blood that can infect someone else through blood-to-blood contact (through shared needles when blood is exchanged, for example).

Body mass index (BMI): A measurement of body fat. It is calculated by the weight of your body and your height. Your healthcare provider can use it to help find out if you are overweight.

Chronic: A permanent or reoccurring disease or condition.

Chronic hepatitis C (CHC): A serious condition that inflames and damages the liver. It can lead to potentially fatal liver diseases, such as cirrhosis, liver failure, and liver cancer. About 75% to 85% of the people who are infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

Cirrhosis: The late stage of liver disease. It's when the liver has scar tissue that has replaced normal liver tissue. As a result, the liver does not have enough blood flowing through it.

The liver has fibrosis (scar tissue that has replaced normal liver tissue), and has a bumpy surface from new growth. There are 2 types of cirrhosis—compensated and decompensated:

- *Compensated cirrhosis means that the liver is very scarred but can still do what it is supposed to do. People who have compensated cirrhosis can be treated with hepatitis C medicines*

- *Decompensated cirrhosis (also known as end-stage liver disease) means that the liver is so scarred that it can't work properly. The liver can no longer keep the person healthy. Decompensated cirrhosis is a life-threatening condition*

Clearing the virus (or being cured of the virus): Describes the best result after treating hepatitis C. You are cleared of the virus, or cured of the virus, when no virus is detected in your blood 6 months after you finish all treatment. This is also called a *Sustained Virologic Response (SVR)*.

Combination therapy: 2 or more drugs used at the same time to treat a disease or condition.

Direct-acting antiviral (DAA): A type of medicine used in combination with other medicines to treat hepatitis C. It is a class of medicine that you swallow as a pill. DAAs directly target the hepatitis C virus as it multiplies.

Depression: A state of being when you may have problems concentrating, lose interest in things you once enjoyed, feel guilty or hopeless, or have thoughts about death or suicide.

End-stage liver disease: The last stage of liver disease. It happens when the liver is not getting enough blood flowing through it, when the liver has *fibrosis* (scar tissue that has replaced normal liver tissue), and when it has a bumpy surface from new growth. This disease is also known as *decompensated cirrhosis*, and it can cause death.

Fatty liver: Too much fat in the liver cells. It is the most common type of liver disease in the United States. Having diabetes, being overweight, and eating a diet with too much *cholesterol* (fat in food), all increase chances for getting fatty liver disease.

Fibrosis: Scar tissue that replaces healthy liver tissue. It can lead to cirrhosis, liver cancer, and even death.

Gastroenterologist: A medical doctor who is an expert on the digestive system, which includes the stomach, intestines, and liver.

Genotype: A virus type that has a special genetic makeup. There are at least 6 genotypes for hepatitis C. In the United States, genotype 1 is the most common: genotypes 2 and 3 are found in a smaller number of people with hepatitis C. Genotypes 4, 5, and 6 are not common in the United States.

Genotype 1: The most common type of the hepatitis C virus in the United States.

Hepatic portal vein: The main vein that carries nutrients from the digestive tract to the liver where the nutrients are processed. Liver disease, such as cirrhosis, increases blood pressure in the portal vein, which can lead to complications and even death.

Hepatitis: Inflammation (swelling) of the liver.

Hepatitis C disease: A liver disease caused by the hepatitis C virus. The hepatitis C virus lives in a person's blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact. Hepatitis C is a major public health problem and the leading cause of chronic liver disease in the United States. It is also called *hep C* or *HCV*.

Hepatitis C virus: A virus that lives in a person's blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact.

Hepatitis C is a major public health problem and the leading cause of chronic liver disease. It is also called *hep C* or *HCV*.

Hepatologist: A gastroenterologist who is an expert in treating people with liver diseases, such as hepatitis C.

Interferons: Proteins that our immune system makes to fight viruses and other inflammatory diseases. Interferon can also be a *synthetic* (man-made) medicine. It is an injection and is part of the treatment for hepatitis.

One type of interferon is called peginterferon alfa that is often combined with the drug ribavirin. They are both used together to treat hepatitis C, genotypes 2 and 3. Those 2 medicines are also used with another medicine, a DAA (direct-acting antiviral), to treat people who have genotype 1.

Jaundice: A yellow coloring of the skin and eyes. Jaundice can appear when the liver is not working normally. It is also one of the signs of end-stage liver disease.

Liver biopsy: A procedure where a small piece of liver tissue is taken out of the body by a long needle. Healthcare providers then study the tissue under a microscope to see if it is diseased.

Liver cancer: Develops when a cell or group of cells becomes damaged and begins growing in an unusual way. It often causes *liver tumors* (lumps of tissue). People with hepatitis C are at a higher risk of getting liver cancer. Between 1 and 5 people out of every 100 get liver cancer after having cirrhosis. Liver cancer is also called *hepatocellular carcinoma* (HCC).

Liver enzymes: These are proteins that the liver makes to help do some important tasks. We all have some enzymes in our blood, but too many enzymes may be a sign that the liver is damaged or sick.

Pegylated interferon alfa: A type of synthetic interferon that is given as a weekly injection. Pegylated means the interferon stays in the body longer.

Polymerase inhibitor: A class of compounds that work to inhibit (stop) the polymerase enzyme from working, in order to prevent a virus from multiplying.

Protease inhibitor: A class of compounds that work to inhibit (stop) the protease enzyme from working, in order to prevent a virus from multiplying.

Prothrombin time (PT): A test that measures blood clotting.

Rapid virological response (RVR): A term used for blood test results after 4 weeks of treatment that shows that the hepatitis C virus can no longer be detected.

Relapse: An instance in which illness symptoms of a disease return after showing improvement. A relapse of hepatitis C can happen after reducing the virus or after stopping therapy.

Ribavirin (RBV): A medicine used in combination with peginterferon alfa to treat hepatitis C. When used alone, it is not effective in the treatment of hepatitis C.

Ribonucleic acid (RNA): Genetic material. Hepatitis C virus RNA can be detected in the blood within 2 to 3 weeks after a person is infected. After treatment, if a blood test shows no hepatitis C virus RNA, the person is considered clear of the virus.

Support group: Small meetings of people who have hepatitis C. The people share information and help each other deal with the challenges of life and having hepatitis C.

Sustained virologic response (SVR): A term used when the hepatitis C virus does not show up in blood tests taken 24 weeks after treatment has stopped. SVR is also called “a cure,” or “clearing the virus.”

Undetectable: The virus can’t be detected or found in viral blood tests.

Viral load: A measure of the amount of hepatitis C virus in the blood. Test results are usually written in international units per milliliter (IU/mL).

Virus: A tiny infectious “agent” or “germ” that causes diseases.