

HEPATITIS C: **SUPPORT GROUP MANUAL**

Alan Franciscus, Editor-in-Chief



The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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• *Introduction*

Living with hepatitis C is not easy! In order for people with hepatitis C virus (HCV) infection to successfully manage this condition, it is important that they receive good medical care and support from as many different sources as possible – medical professionals, family and friends, and others living with hepatitis C. Peer support in the form of a support group is one of the critical links in helping HCV positive people face the issues in their everyday lives. The education, support, care, and services available to HCV positive people will help them make the best possible choices to effectively manage their lives.

I was diagnosed in 1996, when relatively little was known about hepatitis C. The information about hepatitis C was scarce, with more misinformation than accurate information available. Shortly after I was diagnosed, I asked my doctor to recommend a support group in my area. To my surprise, he told me that there were no support groups in my area specifically geared toward people living with hepatitis C. I attended a local liver support group that was geared toward people with all types of liver disease, but I did not feel that it addressed my specific needs for information and peer support on the various issues I was struggling with at that time.

A few months after I was diagnosed with hepatitis C, I began interferon monotherapy. It became clear to me early in the course of treatment that I was not prepared to deal with the physical and psychological side effects related to interferon therapy. I became anxious and depressed. Worst of all, I did not recognize subtle changes in my personality. I also realized how much I needed some form of peer support to help me through treatment. It was during this period that I made a promise to myself that I would start a support group after I completed therapy.

Shortly after I completed treatment, I enlisted help from a friend and we started the first hepatitis C specific support group in the area. This was the start of the Hepatitis C Support Project. To prepare for facilitating a support group, I took a three-day course on support group facilitation from a local health agency, which gave me some valuable information and resources. It wasn't particularly difficult to set up and maintain a support group, but a lot of what I needed to know specific to hepatitis C was learned "hit and miss," and it would have been much easier had I been able to learn from others who were experienced with running a hepatitis C support group.

The importance of support groups cannot be overstated. This manual is designed to help others start support groups and to provide some tools to assist in the diffi-

cult job of maintaining an ongoing support group. This is by no means a definitive guide for starting and maintaining a support group, but I hope it will be a helpful tool for current support group leaders, and that it will encourage others to take the big step of starting a new support group. The information in this manual may not be suited for everyone because different approaches may be needed for different populations. Every individual is unique, as is every support group. A support group leader must always consider the members' needs and take every available opportunity to adapt to specific individual and group requirements.

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THE NEED

Why is there a need for support groups? A person living with hepatitis C must make daily decisions about a variety of issues. These issues may include disclosure, stigma, disease management, and treatment issues. Peer support is critical in providing advice and information to help an HCV positive person successfully live with this disease.

Several major reasons why people seek HCV support groups are discussed below.

• *Newly Diagnosed*

When a person is first diagnosed with hepatitis C, it is usually a life-altering event. Being told you have hepatitis C raises many questions:

- What does it mean to have hepatitis C?
- Am I going to die soon?
- How do I tell others I have hepatitis C?
- What should I tell my spouse, family, friends, employer, and coworkers?
- How do I protect others from getting hepatitis C?
- How do I take care of myself?
- How do I take care of loved ones?
- What kinds of treatment are available and how well do they work?
- Do I need to start treatment immediately?

- What about herbs and other supplements?
- Should I avoid alcohol and other drugs?
- How do I cope with a potentially life-threatening disease?

- ***Stigma***

Stigma occurs when we attach negative labels to individuals and make generalizations about certain groups or types of people. Generalizations are endemic in our society because we all sometimes feel the need to categorize people and situations in order to make decisions. Some people find it easier to generalize about certain groups rather than taking the time and energy to understand the differences between individuals. These differences may be due to religious, cultural, physical, racial or even pathological reasons. Negative generalizations on a large scale produce prejudice, in which certain groups or populations in our society become stigmatized.

Stigma has two consistent components: the recognition of different characteristics in groups of people and the devaluation of other human beings. Feeling different is one of the reasons why people seek out support groups – the need to be with like-minded people experiencing similar situations.

Most people who have been diagnosed with hepatitis C face some form of stigma or prejudice in their daily lives. It could be hearing a phrase like “you people,” or a slight pause when you divulge your HCV status. Friends may stop calling, employers and coworkers may act differently, or it could be as subtle as a facial expression. In any event, we all know how it feels to be treated differently based on our being HCV positive. How you handle the stigma associated with hepatitis C is an important issue because it will greatly affect your quality of life, your health (both mental and physical), and just about every other aspect of your life.

Stigma and prejudice affect everyone differently. It may result in denial and could lead to:

- Withholding your HCV diagnosis from family, friends, and coworkers
- Not seeking medical care for fear of being seen by others at a healthcare facility
- Loss of employment and livelihood
- Friends and family “guarding” their children from coming into contact with you

- ***Disease Management***

After the shock of being diagnosed with hepatitis C, a person will have to make a variety of important decisions in order to manage the disease.

Individuals typically will seek information and advice about many issues, including:

- Alcohol and other drugs
- Nutrition and exercise
- Preventing transmission of HCV to others
- Medical management
- Depression and anxiety
- Herbs, vitamins, and other dietary supplements
- Disability issues
- Sexual issues
- Guidance concerning their everyday lives

- ***Treatment***

Dealing with issues surrounding treatment is one of the main reasons why many people seek out HCV support groups. People come to support groups to hear what others have experienced during treatment, as well as to learn about effective strategies to cope with the side effects of therapy.

Peer support is critical for people taking interferon-based therapy. There are a wide variety of physical and psychological side effects that people may experience on a daily basis. The potential for drug-induced psychological problems is frightening for most people to think about. During HCV medical therapy, the side effects can be so subtle that only people in close contact are able to notice any changes. Support group members who have experience with these side effects can help identify them and help others cope with these often distressing issues.

- ***Post-Treatment Issues***

The side effects of treatment may continue even after stopping therapy. It may take even longer to feel completely “back to normal.” The uncertainty of treatment outcome will weigh heavily on most people. Until people receive the news that their treatment was “successful” or “unsuccessful,” they can become quite anxious. In addition, if HCV comes back after enduring a six-month or year-long course of therapy, the outcome is disappointing and can make it difficult for people to decide how to move forward.

These are some of the most important issues that I have seen raised in support groups, but it is by no means a complete list. The variety of different issues raised by HCV positive support group members and the amount of support provided is truly amazing!

• *Support Network for Loved Ones*

One area that is often neglected is the importance of establishing a support network for family, friends, and caregivers of HCV positive persons. In some respects our loved ones need information and emotional support as much as the person living with hepatitis C. Friends and loved ones sometimes feel powerless when they are confronted with the fact that someone they love may get sick, while others may need support as they deal with issues surrounding the death of their loved one; so it becomes important that they are also supported. If an HCV positive person decides to go on HCV treatment, the caregiver may be required to care for the person on treatment. This task can bring emotional issues to the forefront of the relationship and the caregiver will need support and advice on strategies to help the person on treatment.

WHY DO YOU WANT TO START A SUPPORT GROUP?

The majority of people who start HCV support groups have very little prior experience with group facilitation or medical backgrounds that enable them to deal with the questions about hepatitis C and related psychological issues that may be needed to run a successful group. It is important to be aware of these limitations when you start a support group. It is always easier to take on the demands of a support group if help is available from others with an appropriate medical background and from those who have experience running such a group. You do not need to be a medical expert or a person living with hepatitis C, but it is important to surround yourself with people who can help when you face difficult questions or situations.

• *Motive*

If you are developing a plan of action for starting a support group, it is important that you consider your motives first. It can be very difficult to be honest with yourself about the motivation for running a support group, but it is a necessary step. Ask yourself these questions:

- Is it to get your own needs met?
- Is it to help support others?
- Is it to help both yourself and others?

There is nothing wrong with starting a support group to get your own needs met, but if you are not careful, this motivation can sabotage the most important reason for starting such a group – to help others. Another essential purpose of a support group is to help empower other members to make important life choices, which will be difficult if you do

not identify and serve the needs of the entire group, rather than just your own.

• *Are You Open-Minded and Free of Bias?*

Everyone has certain points of view or biases that could potentially affect the level of support that should be available to all support group members. Ask yourself these questions:

- Is it possible that I am biased?
- Would I be open to talking about any issue as it relates to hepatitis C, including:
 - ◆ Interferon-based therapies
 - ◆ Alternative and complementary therapies
 - ◆ Lifestyle issues
 - ◆ Gender
 - ◆ Sexual orientation
 - ◆ Substance use
- Can I accept all members regardless of their ethnic, cultural and racial backgrounds?
- Am I biased concerning the mode of HCV transmission? Will I accept others who believe they contracted hepatitis C from a blood transfusion, injection drug use, or sexual transmission?
- Can I put my ego and my issues aside for the benefit of the entire group?

These are extremely important questions that need to be answered, and your answers will help guide you in the process of starting a support group. More importantly, they will help you fine-tune your goals.

INFORMATION GATHERING

• *Identify Experts*

Members of a support group often look to the facilitator or group leader as an expert on hepatitis C. This can be troublesome unless the facilitator has a medical background and is thoroughly educated about the disease. If you do not have this expertise, it is important to emphasize from the beginning that the role of a facilitator is to assist and direct the support group, not to supply expert medical advice to the members. This should be left to patients' medical providers. It is not even recommended that the facilitator become an "expert," since this could potentially derail the purpose of the group – to support and

guide others. By providing support and guidance to the group members you will help them to become actively involved in the process and take ownership of the group.

Having said this, it is important for support group leaders to learn as much as possible about hepatitis C, as well as to become knowledgeable about running or facilitating a group. Information about hepatitis C is freely available from many sources, such as the Internet, various governmental agencies, HCV non-profits, and published books on the subject. (See Resource section.)

• *Identify Resources*

It is important to develop resources to aid you as you facilitate a support group. You may want to develop a relationship with a local hepatitis C medical provider who can serve as a consultant to the group. It is also useful to have as many experts as possible to consult with on a wide range of issues, and key people who could potentially present information to the group members.

Medical institutions and non-profit agencies may also provide sponsorship and free space to hold support group meetings. This would also help with advertising, since the agency could advertise to their clientele.

• *Do You Need a Co-Facilitator?*

It can be very difficult when you realize that all of the group members' support falls on your shoulders. It will help ease the pressure if you identify a person from the beginning who would be willing to step in or share the responsibility of running the group. The benefits of having a co-facilitator will be discussed in more detail later in this manual.

• *Learn More about Support Groups*

There are many resources to help you learn more about running and facilitating an effective support group:

- Attend other support groups in your area specific to hepatitis C. This will help you learn how others run a group and will help you find out if the needs of the HCV positive population in your area are being served. If the need is being filled by another group, perhaps the best use of your time and energy would be to help an existing group. You may also find that certain people are not being served. The potential for HCV support groups is unlimited, and many more specific groups can be started to help support the HCV community. These may be groups that serve veterans, family members, substance users, or any other group with specific needs.
- Visit and attend other types of support groups. There may be 12-step meetings or other disease-specific support groups that could help you understand the group process

and how to support people with different needs. If you do attend other meetings for research, it is important that you let the members know why you are attending. There is a certain level of trust that needs to be honored at all times.

- Look at publications from other types of support groups that may help guide you through the process of starting your own group.
- Local agencies may offer services or seminars on running a support group.

TYPE OF SUPPORT GROUP

There are many types of support groups ranging from strictly informational to emotional support. In general, all support group meetings have an educational component and provide some emotional support, but how you define and set up your group will set the tone for the type of group you envision. Keep in mind that some people are uncomfortable coming to a “support group,” but feel very comfortable attending an informational meeting or a group that is not labeled as a “support group.”

- *Drop-in Support Meetings*

Drop-in groups are very important for people who need to receive emotional support and education, especially in a time of crisis. People who attend these meetings may also be seeking to learn more about community resources, which may include information about other types of meetings and support groups.

- *Informational Meetings*

Informational meetings are geared mainly towards people who want to learn more about hepatitis C in general, or about a certain related topic. This is the preferred format for people who want to educate themselves and connect with other HCV positive individuals, but who may not feel comfortable talking about very personal issues with others. Even though the main focus is on education, such groups also provide an element of emotional support, since there are others who attend the meetings with similar interests, fears, and questions. In fact, some informational meetings end with people talking in-depth to the expert speaker, facilitator, or other group members about various issues, which may include sharing personal stories or feelings.

- *Emotional Support Group Meetings*

Groups that concentrate on emotional support explore almost every aspect of hepatitis C, and this type of environment helps people really connect with others living with the disease. Since it is more personal in nature than an informational meeting, this support

group format can also be more intense and may bring up many issues and feelings. This manual focuses on providing tools to people who wish to start emotional support groups, but much of the information can be applied to any type of support group.

SUPPORT GROUP LOGISTICS

There are many important decisions that a potential support group leader must make before convening the first group meeting: finding a location, selecting a meeting format, and other issues that, when planned well in advance, will help to make the support group successful.

• *Closed or Open Group?*

Structure is a very important part of the group dynamic. Members of some groups like having newcomers at each meeting, as long as there is a core group they can rely on for ongoing support. It is important to remember that new members will most likely have issues that they think need to be addressed immediately, and they may need basic information that is already familiar to regular members. It is also important to realize that the new members might be exposed to more information than they are ready to handle emotionally. For example, if some members are dealing with issues related to end-stage disease, a new member might become afraid and panicked. It's a fine line between supporting current members and being sensitive to new members who may have been recently diagnosed, or others who are not well-educated about hepatitis C or are not ready to cope with the emotions that may overwhelm a new member.

It is a good idea to interview potential members before they start attending the group. This includes individually interviewing all prospective members when the group is first launched. During the conversation, you can assess whether the person would be a good fit. It is appropriate to be very honest during this process. It is not that you want to exclude someone from the group, but there may be reasons why a particular person might not be a good fit with the other members.

Examples:

- "Our support group is for members who are very sick. Are you able to handle this type of discussion and deal with the emotions that may surface?"
- "Our group is very clear that the mode of transmission is not discussed, and that people are not discriminated against because of past or current behavior. Do you think you could accept this?"

If for some reason this is not practical, a list of support group guidelines for all members should be discussed at the beginning of the session. Examples of group rules will be discussed later in this manual.

• *How Many Members?*

Support groups come in all sizes. Even two people at a meeting can be a very powerful support group. The size of the group will depend on the type of group you want to start. The meeting space or room also dictates the amount of people that can attend. An emotional support group that has many members may become too impersonal for this type of format. Conversely, an informational meeting may benefit by having more people attend, since the members are there to learn more about hepatitis C in general or about specific topics from a speaker rather than from other group members.

As a rule, six to fifteen is a good number of members for an emotional support group. If there are more than 10-15 members, it may be difficult for every person to have time to talk about his or her issues. A group meeting that has eight members in attendance is ideal for everyone getting his or her needs met. In practice, very few emotional support groups have to worry about too many people attending, since most people live busy lives that prevent them from attending every meeting. If you add HCV-related fatigue to the equation, you will find that there will always be some members who cannot attend every meeting. The general rule is that 10 percent of members will not show up at any given meeting for any number of reasons. Even if every member does show up for one meeting, steps can be taken to make sure that every members' needs are served. There are always exceptions, and a lot depends on the support group members' expectations, the meeting space, and the goals of the support group.

• *How Often Should the Group Meet?*

Generally, the nature of the support group will dictate how often it should meet. Monthly meetings generally work best for informational meetings. Support groups that are geared toward providing emotional support usually work best if members meet every week or every other week. These types of groups can meet once monthly, but the close personal connection so important for such groups is difficult to maintain when people only see each other once a month.

• *How Much Time for Each Meeting?*

As expected, the length of the meeting can also vary depending on the format of the group. In general, an hour is probably not long enough for everyone to get his or her emotional needs met. An hour and a half usually works best for most groups, but some may need even more time. It is highly recommended that, if the group meets for longer than an hour, the members take a short break halfway through the meeting to allow for

a stretch or bathroom break. However, it is important that the break(s) be kept short so that any issues brought up before the break can be resumed with little effort. The exception would be if you divided the support group into two parts – one for information or education and one for emotional support. In this case, a longer break is helpful to help the group transition from one format to the other.

It is important to make sure that the length of time agreed upon by the members is strictly followed – always start and finish on time. People have busy schedules, and if a support group starts or ends late, attendance likely will suffer. Starting and ending on time will also help send a message that everyone needs to show up on time out of respect for the other members. However, it is also wise to be prepared to extend the meeting length in certain situations where emotional issues have surfaced during the meeting that require additional time in order to provide support to a member. But the entire group should make the final decision as to whether to stay or leave. The leader or other members can always stay later to talk to a member who needs additional support.

- *What Time Frame – Ongoing or Limited?*

As the name suggests, an ongoing support group can run for an indefinite period of time. A time-limited support group is set up so that the group members know the exact date when the group will begin and end. A group that ends on a specific date works well for people who may not want to commit to coming to a support group over an extended period of time. Time-limited support groups can run for any period of time, but generally run from a few weeks to several months. This is also an excellent format for people who want to see if they are suited to running a group and an opportunity to work out the “bugs” before making a commitment to start a permanent or ongoing group. This is also an excellent way for other members to become more involved in the group. If the group members form personal attachments among themselves, they may decide to meet informally or may even decide to “take over” the existing group and keep it going, or to form another group. This allows for the current facilitator to take a well-deserved break before starting another group.

- *Location*

The support group location is very important in order for people to feel safe and comfortable attending a meeting. Find a meeting space that is convenient to public transportation, offers free or inexpensive parking close to the meeting, and where people will feel safe traveling to and from during the day or in the evening. Look for space at hospitals, community centers, churches, or other public buildings. Another important point is to make sure that the meeting space is easy to find. Some closed support groups meet in members’ homes, which may be preferable for some people since a home environment is more private and comfortable. However, a home environment is

generally not recommended for most types of support groups, because it may be hard to separate the group from the personal, and because most people prefer a “neutral” space.

• *The Meeting Room*

The meeting room sets the tone for a support group meeting – a drab and dreary environment is emotionally depressing and is not very conducive to positive feelings when people are trying to work out problems. However, even a poor environment can be spruced up with posters, flowers, or other items to give people a positive feeling about the meetings.

Check the meeting space for:

- **Privacy** – due to the stigma of hepatitis C, it is important that people feel comfortable attending a meeting without divulging their HCV status. Also, the room should only be used for one support group meeting at a time. If another group occupies the same space at the same time, it will inhibit group members from speaking freely.
- **Size** – it is important that the room be large enough to accommodate all the members and also offer the opportunity to break out into smaller groups if needed, but it should not be too large relative to the size of the group.
- **Furniture** – good comfortable chairs are important for everyone, but especially for people with hepatitis C, since many suffer from muscle and joint pain.
- **Adequate lighting, ventilation, and temperature control** – these types of environmental issues can greatly affect how people feel and how they relate to others in the group.
- **General ambiance** – nothing in the room should offend anyone’s cultural or religious beliefs.

Of course, you may not find all of these characteristics in one space, but it is important to keep them in mind when selecting a space for the meeting.

• *Seating*

Seating and table arrangements are important because they will affect how close (physically and emotionally) the members will feel to one another.

- **Theater or classroom** – this type of set-up is good for an informational meeting, but does not work as well for emotional support groups because the seating arrangement prevents people from seeing each other and may inhibit members from speaking openly and honestly. Another problem is that people in the front have to twist around to see another member speaking behind them. When using a classroom-style set-up,

the door to the room should be at the back, so that if someone enters or leaves the room, the other members will not be disturbed. If you must use this set-up, try to come up with innovative ways for people to communicate more effectively. One example is to arrange the chairs and tables into a “U” shape that would allow all the group members to see each other and communicate openly.

- **Circle format** – the preferred seating arrangement for an emotional support group is to place the chairs in a circle. Leave the middle of the circle empty so that the view of the other members is unobstructed. The only exception to filling the space is putting a box of tissues in the center. This will convey to the members that it is OK to express emotions – even emotions that make us cry. It is also recommended that any vacant chairs be removed from the circle; members will feel more emotionally connected if there are no empty spaces. The circle format allows everyone in the support group to see all the other members. People communicate using their voices, but most people like to see facial expressions and body language to communicate more effectively. The circle format also allows eye-to-eye contact, which is important in establishing a sense of trust among members. The circle format may be difficult for larger groups. If the group is too large to accommodate the circle format, consider splitting the members into two or more circle groups. Multiple circles could potentially be a very powerful experience if you are prepared for it and you have a co-facilitator(s) to help lead the other group(s).

• *Beverages and Food*

Food is always a good way to break the ice and establish bonding within the group. However, it is highly recommended that if food is provided, it should be clear to every member that it should not be eaten during the actual group session so that the members can give their undivided attention to the other group members. Beverages are also important for members, especially if water can be provided. However, food and beverages can be difficult to supply if money is an issue for the group leader or members. There are many strategies to help resolve money issues, including:

- Asking for a donation at the beginning or end of the group to help with the cost of food and beverages.
- Asking for volunteers to be responsible for buying and bringing in food and beverages on a rotating basis.
- Asking local businesses, non-profit agencies, pharmaceutical companies, and/or others to donate snacks and beverages.

You may decide that a better solution is to tell members that food is not allowed during meetings. If the message is clear and concise, there will be no expectation that food or beverages will be provided at the meeting. The exception to this rule is the use of water,

which is highly recommended for HCV positive individuals especially while undergoing HCV medical therapy.

• *Educational Materials*

Information about hepatitis C enables people to make a wide variety of decisions about their health, as well as to become more involved in their healthcare. In these days of managed care and with few resources available for HCV positive people, it is even more important that people learn as much as possible about hepatitis C so they can become their own best advocate. If you do use educational information, be sure it is reliable.

The expense of educational materials is another potential financial hurdle. There are many strategies that can be used to keep the cost of the materials manageable:

- Asking members to copy and bring in educational materials – rotate this responsibility among the members.
- Ordering educational materials from pharmaceutical companies or non-profit agencies that serve the hepatitis C community, such as HCSP. Information from any source should be scrutinized closely to make sure that it is accurate, timely, and appropriate.
- Asking for donations from the support group members.
- Obtaining information from the Internet.

FACILITATION

A peer-led support group is very different from a therapy group led by a therapist who is educated and professionally trained to guide people through complex emotional issues. A peer-led support group is usually led by someone who has not been professionally trained as a therapist. While peer-led support groups should not be intended as a substitute for professional therapy, members may find that they offer emotional support that is therapeutic in nature. It is not overly difficult to learn how to run a support group. Some people are born with the talent to become a good support group leader, but with education, experience, and help from others, almost anyone can become a support group leader if their heart is in the right place.

A support group requires that someone lead or oversee the entire group process. The role can be defined as total or limited, depending on how much time and energy the individual wants to invest. Most people starting a group take on the role of facilitator, but this is not required. Some people prefer to work behind the scenes and leave the

leadership to another member. Others may set up the group (by agreement with other members) to rotate facilitation among the members. There are also groups that have no leader and rely on a true peer-led support concept with equal power and decisions made by consensus of the group members. Alcoholics Anonymous (AA) is an excellent example of a peer-led support group in which specific principles and rules have been developed and applied, but the leadership role is rotated between the members.

• *The Role of the Facilitator*

If you have decided that you would like to facilitate a support group or mentor someone else to become a leader, there are some important steps to take before the first meeting. The first step is to understand the role of the facilitator. Basically, a facilitator's job is to help guide and support the entire group.

There are certain traits that a good facilitator possesses. Many of these traits can be learned from experience or from reading and attending seminars on group facilitation. Some people take naturally to the role, while others may need to practice more to become an effective group leader.

• *Qualities of an Effective Group Leader*

The qualities of an effective HCV support group leader include:

- **Boundaries:** Ability to set clear goals about what steps are needed, set your own emotions aside, and avoid internalizing or taking on the emotional needs of the other members.
- **Communication skills:** Ability to listen and to convey that you understand what is being said.
- **Compassion:** Feeling empathy for people.
- **Conflict:** Ability to deal with conflict and effectively manage potential conflicts between group members.
- **Energetic:** Positive energy for other members to draw upon.
- **Honesty:** To themselves and the other group members.
- **Knowledge of hepatitis C:** A person does not need to be an expert on hepatitis C, but should be knowledgeable about HCV to some extent to help correct inaccurate information.
- **Non-Judgmental:** Ability to be open to members' experiences and not make judgments based on what they have done or what they tell you.
- **Observant:** Awareness of others in the group with regard to verbal and non-verbal language – vocal intonations, facial expressions, and body language.

- **Open mind:** Ability to look at ideas and situations openly and honestly.
- **Optimism:** Ability to look for the positive in people instead of the negative.
- **Positive:** A healthy outlook on life so that the group can draw from your positive energy.
- **Present:** Ability to “be in the moment” and not think about situations outside of the group.
- **Real:** Ability to express your feelings in an honest and open way.

Of course, we are not all saints, but these characteristics are important to have or to strive for or work toward. It may seem like a monumental list of characteristics, but you may be surprised how many you already possess or how easy they are to obtain.

• *Is There a Need for a Co-Facilitator?*

A co-facilitator is highly recommended for groups that have a large membership. In fact, the responsibilities of facilitation can be shared on a rotating basis. A co-facilitator can take some of the pressure off the facilitator and monitor the other group members while the lead facilitator is busy interacting with some members. A co-facilitator can also intervene if there are times when things seem “stuck” or when there are potential problems. If you should decide to seek out a person to co-facilitate, look for the same traits that would make a good facilitator and for someone with whom you feel comfortable working in the support group environment.

• *Membership*

How do you get people to join the support group? Sometimes, it can actually be difficult to recruit members. There are a variety of reasons for this, but probably the most important is that participation in an emotional support group requires a leap of faith to trust that the group will be a safe environment to discuss very private feelings – especially at first, when all the group members are strangers.

Strategies for recruiting members:

- **Develop a flyer** for the support group that will motivate people to want to join the group – proactive, positive, and caring.
- **Post the flyer** in doctors’ offices, medical institutions, community-based organizations, public health departments, or any other agency that may serve and support people with hepatitis C. It would help to personally talk to organizations about the new group, and to get permission to post the flyer.
- **Newspaper advertisements** can be a good way to attract members. Look for community-based or local papers that cater to various communities or to a specific

population that you would like to attract.

- **Develop a press or media kit** and send it to local newspapers, radio, television, or any other media that may be available (a general media kit is available on the HCV Advocate web site).
- **Contact a national or local self-help clearinghouse.** A clearinghouse may be able to list the support group in their directory.

- *Flyers*

Develop a flyer that is upbeat and positive:

- List the objectives or mission of the support group; be clear and concise in your objectives:
 - ◆ “The mission of HepCats is to provide peer support and education for hepatitis C positive people.”
- List affiliations on the flyer, such as medical providers that endorse the group:
 - ◆ “The HepCats support group is endorsed by the Sunnybrook Medical Center.”
- List the location, time, duration, and any other pertinent information:
 - ◆ “Title: HepCats Support Group
 - ◆ Time: Every Wednesday of the month from 6:30–8:00 p.m.
 - ◆ Location: 1225 Market Street, San Francisco, CA 04112
 - ◆ Purpose: To provide peer support to people with hepatitis C
 - ◆ Please call 555-1212 for more information”
- For a drop-in support group, list the exact address:
 - ◆ “Would you like to meet others with hepatitis C and learn how they live positively with HCV? A support group meets every Wednesday from 6:30-8:00 p.m. at 1255 Market St., San Francisco, CA 04127. Check us out!”
- If you decide to name your support group, make it upbeat or specific to the members you would like to attract:
 - ◆ – “The HepCats: For living positively. Being well.”
 - ◆ – “The Positive Partners meet to support partners of people with hepatitis C.”
- List a phone number or another means of contacting you if you want to interview people before they attend a meeting. If you are listing a personal phone number, you may want to consider adding a new telephone line or a new voicemail box to your existing voicemail options. A word of caution – if you list your home phone number, you may want to make sure that you have an option for turning the ringer

off in case you receive calls at odd hours of the day or night. Some people prefer having a voicemail box separate from their personal or home phone.

- Talk with other support groups that are currently serving the needs of the HCV community – you may be offering a particular type of support group that they can support or endorse. For instance, a current patient support group may endorse and send people to a support group for family and friends.

CONFIDENTIALITY

It is important that a support group provide a safe environment in order for the members to speak and give advice freely. Confidentiality is one of the most critical parts of providing a safe environment. A support group leader should always stress confidentiality at the beginning of every meeting and remind the members why this is so important. A discussion of confidentiality among the group members is helpful in setting good boundaries for all the group members.

- *Discussion*

Never talk about what goes on in the group in a way that might reveal the identity of a group member. It is okay to discuss the general content of the group meeting with others, but never disclose any information about a group member which might give a clue about the identity of that person. For example: it is not okay to reveal to someone “there’s this guy in the group who writes for the local newspaper.”

Support group members may be faced with an awkward moment if they run into other support group members in public. Remind the members to be discreet. Discuss this situation with the members.

Questions that might come up include:

- Should I acknowledge the other member?
- Would it embarrass them?
- Should I introduce them to my friends?

Every member will have a different feeling about these questions, so it might be helpful to discuss these situations with all the group members and set some rules that all the members can follow.

• *Ground Rules*

In order for a community to survive, it must enact certain rules or laws to govern everyone in the community. If people in the community ignore the law, the community may falter and be thrown into a state of chaos. In many ways, a support group can be compared to a community, and – like a community – must have certain ground rules. Without them, group meetings could become chaotic and the members may not feel safe enough to talk about personal issues or offer advice to others. Setting the ground rules is one of the most important steps to take before the first meeting. Start by drafting a list of ground rules to be discussed at the first meeting. Discuss the reasons for the ground rules, and ask for comments from all the group members. The members may also have additional rules or changes to the ones that you suggest. After a discussion about the rules, they should be adopted by the entire group membership. It is much easier for people to obey rules if they feel that they have taken part in the approval process. In the future, the ground rules can be changed as long as a majority of the members agree to the changes.

Example of ground rules:

- I will always arrive on time – this is a courtesy to other group members.
- I will attend every meeting if possible – the group is not the same if I am not there.
- I will not inflict physical or verbal violence – it is ok to get angry and to disagree, but it is also important to respect one another's individual differences and points of view.
- I respect the confidentiality of all group members – what is said in the support group stays in the support group.
- I respect that only one person speaks at a time.
- I will not interrupt others – it is disrespectful to the person speaking and to the other group members.
- I will not have side conversations – these are disruptive to the group and disrespectful to the person who is talking.
- I will not monopolize the conversation.
- I am willing to talk, but it is also OK if I decide not to talk if I do not feel like it.
- I will accept other group members without judgment.
- I will accept other members' feelings, whether positive or negative.
- I will keep any discussion in the first person – always use "I."
- I will give advice with care.
- I will listen carefully.

- I will not attend a meeting if under the influence of any non-prescribed drugs or alcohol.

As they say, rules are made to be broken, but some of the rules listed above should be followed to the letter. As a facilitator, you will develop strategies to remind the members about the ground rules that you and they have approved and implemented.

SAMPLE SUPPORT GROUP FORMAT

- *The following is a sample of a support group format:*

The support group meets on the first and third Monday of every month from 7:00-8:30 p.m.

- *Starting the Group (the first 45 minutes)*

The first order of business – each member should check-in with the group. The members usually talk about any important issues that have come up since the last meeting, or just a general “where they are at.” This allows all members to speak and is important for establishing group unity. The check-in for each member is usually 2-3 minutes, but should not last longer than 5 minutes. During the check-in, group members may ask for additional time to talk about topics or problems they would like to discuss with the entire group. The member checking in should not be interrupted with questions or comments.

The facilitator may also introduce a question into the general check-in such as:

- “When you check-in, please describe how you are feeling.” (Discourage members from using “Fine” or other simplistic one-word descriptions.)
- “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 instead of a negative comment. This can also be used for the check-out.)

- *Education or Specific Topic Section (35 minutes)*

The second part of the meeting is ideal for discussing a wide range of topics. It is important to talk about the various topics and to have the group prioritize and set an agenda for topics that should be discussed at each meeting. You may even want to arrange for a speaker to address the group.

• *Ending the Group*

It is important that each member be able to bring closure to the group meeting. Allow about 5-10 minutes at the end of the meeting for the members to check-out. 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.

The ending of the group is an important time for giving the members a positive feeling about group unity and hope for the future. Many groups perform a closing ritual to bring about a sense of group unity and hope. The closing can be a prayer, meditation, poem – or just holding hands with a moment of silence. Ask the group members how they prefer to close the meeting. Ask them to share any prayers or poems that help them.

Examples:

Serenity Prayer:

God grant me the serenity to accept the things I cannot change,
Courage to change the things I can,
And the wisdom to know the difference.

Silent meditation:

All the members form a circle and silently say to themselves:

May I be well (breathe in)

May others be well (breathe out) – Repeat

HARM REDUCTION

When a person is newly diagnosed with hepatitis C there is a lot of information and strategies that are immediately advised. There are many lifestyle changes recommended for people with hepatitis C such as avoiding alcohol, a healthy diet, exercise, avoiding street drugs and many more strategies for people with hepatitis C to use to stay healthy. However, every lifestyle change is a difficult process and changes require help and guidance from loved ones, family, friends, medical providers and peers. One approach that works for most people is a harm reduction approach. For instance it may be too difficult at this time for a person to completely stop drinking, but if they can cut back on the amount of alcohol consumed daily then this is a successful step towards the

ultimate goal of abstinence. The same type of approach should be used for any type of behavioral change. If you advise an individual to make too many changes at once, it will surely result in failure.

STRATEGIES FOR CHALLENGING SITUATIONS

Every support group is unique. Individual support group members bring a wide variety of issues and emotions to every group, based on their personalities and viewpoints.

At times, some members' personalities and viewpoints will clash with those of the facilitator and other group members. The facilitator will need to help resolve any potential problems or conflicts that might arise during the meeting. Try not to worry too much about potential problems – trouble is generally infrequent, and by referring to the ground rules and developing strategies beforehand, you can avoid or handle most of the problems that may surface during a meeting. Since the ground rules have been adopted by the group as a whole, most problems can be resolved by referring to the rules. It is also important to remember that the entire group is responsible for maintaining the harmony of the support group – not just the facilitator.

No one likes to be directly challenged by the facilitator or other group members. If you must interrupt or challenge a member, try using a calm and reassuring voice in a non-threatening manner. Always try to reassure the person with a positive comment when interrupting or when attempting to refocus the group.

• *Common Problems*

Member repeatedly shows up late for support group meetings

Acknowledge that the member is late and remind him or her that members are responsible for showing up on time. Of course, there are always situations that prevent people from arriving on time, so be careful that you are not too rigid.

- "I have noticed that you have been late for the last two meetings – is there anything we can help you with to make sure you show up on time?"

A member is talking too long at check-in

Remind the member of the ground rules – there is a time limit so that everyone can have a chance to talk.

- "It sounds like you may need some time during the group – is there an issue you would like help with from the group after checking-in?"

A member is monopolizing the conversation

A good strategy before this happens is to discuss with the entire group the dangers of one member monopolizing the group, and include it in your group rules. If a member is monopolizing, rambling, or gets side-tracked:

- Bring the member back to the main points by summarizing his or her key points and asking the other group members to comment.
- Interrupt the member: "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 monopolizing – it is harder for people to monopolize the conversation if the leader is not actively engaged.

A group member frequently makes comments or ask questions only to the facilitator

- Look away from the member.
- Pass the questions back to the group.
- After the group, talk with the member about directing comments or questions to the entire group.

Silent moments

Silent moments can be a positive sign that members are feeling comfortable with each other. It can also mean 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.

The silent member

It is OK for members to sit quietly and not participate. If you feel that someone wants to talk but may be shy, you can make direct eye contact with the quiet member. 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 want to share about the discussion?"
- "It's OK if you don't want to comment, but do you have any feelings about what we discussed?"

Incorrect information

Nothing is to be gained by directly or aggressively challenging a member when they state incorrect information. 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 the group."

- “I have heard differently. Let’s talk after group about how we can research this issue and share it with the group at a later time.”

Humor – appropriate and inappropriate

Humor is a wonderful tool for breaking the tension within the group when the conversation becomes too filled with emotions. However, it can also interfere with members coming to terms with emotions and may impede 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 interject inappropriate humor, say: “This is a serious issue and we really need to concentrate on working through it.”

Anger

Anger is a necessary part of the support group process, especially for people with a potentially life-threatening illness. However, it is important that anger be released in a non-threatening way and that it not be directed against anyone in the group. Once anger is verbally expressed, a member should be able to move on. Prolonged anger can sabotage a support group meeting by making people feel that the group is unsafe. If anger continues to dominate a meeting, try these approaches:

- Acknowledge the feelings being expressed by the member. “You have expressed some powerful emotions. What does this bring up for the other members?”
- 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 before we continue with the discussion.”
- Acknowledge the feeling of the member and reassure the member that everyone wants to help.
- If the member becomes too angry, ask the member to step outside for a minute and try to calm the member down.
- Try moving on to another topic, but make sure you come back to the member and check in when the emotions have calmed down a bit.

Crying

Crying is an essential part of the grieving process. If someone starts to cry, reassure him or her that the feelings are normal. If the person is unable to continue to talk, move on to another topic or ask the other members to check-in. Be sure to always come back to the member after he or she has stopped crying to check in and ask if the member would like to continue talking about the issue.

Side talk

Side talking is very disruptive to the group and leaves other members feeling like they are being left out of a personal conversation, instead of creating an atmosphere of sharing information and feelings. The best advice is to remind the members of the ground rules at the beginning of the meeting, and enforce the rules when appropriate. A facilitator may have to stop the group for a moment to make the point or interrupt the members and ask them if they want to share.

FUNDING

In general, a support group leader does not need very much money to run a meeting, especially if other agencies are able to provide free meeting space or donate materials and other services. However, if a support group decides to expand its mission to provide more groups or other services to the community, a fundraising strategy should be well thought out and in place before the first group meeting takes place. Regardless of whether you decide to go large or small, a budget of possible expenses is recommended at the beginning of the planning stage.

- *Budget*

The first step to managing money is to develop a budget. Try to estimate all the possible expenses you might incur for the first year of operation – such as postage, copying, snacks, beverages, telephone bills, or any other charges – well before the first meeting. Once the expenses are estimated, you will have a better idea of the amount of fundraising you will need to keep the group running for one year. Many times, the expenses you budgeted can be covered by volunteers and/or in-kind donations, but it is important to have a realistic picture of support group expenses.

- *Cash*

Raising cash for support group operations is one of the easiest ways to run a group if your expenses are minimal. There are many ways to generate cash to help with any support group costs.

- **Cash Donations** – At the beginning or end of each support group meeting, pass around a jar or can for donations. Don't be afraid to tell the members that certain items cost money and that there is an expectation that all the members should help offset the expenses. Also, try asking members to bring in food and beverages on a rotating basis or to be responsible for copying educational materials for the meetings.
- **Garage or Sidewalk Sales** – One of the easiest ways to raise cash is to have a garage

or sidewalk sale. Enlist the help of the support group members and their families and friends to help organize and staff the sale, and ask them to donate items to sell. Ask the group members if they live in an area that is highly trafficked and see if they could host the sale. You might be surprised by how much money a sidewalk sale can bring in to help offset support group expenses.

- *Donations from Agencies*

As the saying goes – it never hurts to ask! Approach agencies or companies and ask them to donate services or food for support group meetings. This may include bakeries, coffee houses, local physicians' offices, or anyone else you think might be willing to support the group.

- *Donations from Pharmaceutical Companies*

Pharmaceutical companies that sell hepatitis C drugs may be willing to help defray some of the expenses of a support group. Contact your local pharmaceutical representatives and ask if they would be willing to donate food, beverages, educational materials, or even speakers for your group. If you do not know the local representative, contact the national office for a referral to the local representative. A word of caution: it is very important to make sure that information presented or given at the meeting is free of bias. Pharmaceutical representatives should always disclose their affiliations.

- *Non-Profit Status*

In order to receive tax-deductible grants, an organization must apply for commercial or non-profit status with both the federal and the state government. A support group or advocacy organization will usually apply for non-profit status since they do not intend to make money from their activities. Applying for non-profit status is not too difficult, but the application process can be time-consuming and the day-to-day business operation must be carefully managed. In addition, all of the revenue and expenses must be recorded and tax returns must be filed with both the state and the federal government. If you decide to apply for non-profit status, check with your local, state, or federal government to learn more about the application process.

Another option would be to find a non-profit agency that would be willing to act as your fiscal agent. Some agencies will act as your fiscal agent for free, but usually the umbrella agency will charge you a small percentage of the money you generate to provide this service. This is a very good option for many smaller advocacy groups so that they will not have to devote precious time to the business of a non-profit, and can therefore spend more time running and maintaining the support group.

NEXT STEPS

Now that you have the information you need to start a support group or maintain an existing group, the next steps are up to you. HCV support groups can have a tremendous positive influence in people's lives. Almost every support group leader I have ever talked with has commented that leading a support group has been one of the most rewarding experiences of their lives. As well, the vast majority of people with hepatitis C who attend support group meetings have commented that the experience of attending a support group and being supported by their peers is the one event in their lives that transformed them from a state of ignorance, fear and anger to one of acceptance. This process also helps people develop strategies to move forward in their lives and to become better self-advocates.

I hope this manual has helped you to become a more effective support group leader. I look forward to working with many of you to improve the manual and bring more support and care to people affected by hepatitis C. Any suggestions to improve this manual or our services would be greatly appreciated. Please send comments to alanfranciscus@hcvadvocate.org

RESOURCES

Hepatitis C Information

- Hepatitis Foundation International:
1-800-891-0707
www.hepfi.org
- American Liver Foundation:
1-800-223-0179
www.liverfoundation.org
- Hep C Connection:
1-800-522-4372
www.hepc-connection.org
- HepCBC:
www.hepcbc.ca
- Centers for Disease Control:
800-CDC-INFO/232-4636 (general number)
<http://www.cdc.gov/hepatitis/ChooseC.htm>

- Americans for Disability:
1-800-949-4232
- Social Security:
1-800-772-1213
<http://www.ssa.gov>

Suggested Reading

- *The Hepatitis C Help Book*, by Misha Cohen, OMD, LAc, and Robert Gish, MD. St. Martin's Press (2007).
- *Living with Hepatitis C: A Survivor's Guide*, by Gregory T. Everson, MD. Hatherleigh Press (Fifth edition 2006). 800-367-2550.
- *Healing Hepatitis C*, by Christopher Kennedy Lawford and Diana Sylvestre MD, Harper Paperbacks, 2009.

Pharmaceutical Resources

- Partnership for Prescription Coverage
1-888-477-2669
www.pparx.org
- Genentech (Member of the Roche Group):
1-877-PEGASYS (1-877-734-2797)
www.genentechaccesssolutions.com/portal/site/AS/
- Merck (includes Schering-Plough subsidiary):
1-866-939-HEPC (4372)
www.merck-cares.com
- Kadmon Pharmaceuticals:
1-800-405-8506
www.3riverspharma.com
- Vertex:
1-888-552-2494
Patient Assistance: www.vrtx.com/patients.html

Help us to keep our Support Group information current!

In order to provide the most timely and accurate information for our Web site visitors who are seeking emotional support and information we need your help.

If you facilitate, attend or have information about a group, please let us know.

If your group is already listed, please go to our website www.hcvadvocate.org and verify that the information is up to date.

If not, please email this form to: supportgroupinfo@hcvadvocate.org

OR return this form by FAX to 1-877-203-3580 (toll free)

The more information we can give people, the better chance they have of finding the groups.

Name of group: _____

Address of meeting: _____

City & State: _____

Days & times: _____

Contact Name: _____

Contact Phone #: _____

Contact Email: _____

Website: _____

HEPATITIS C: **SUPPORT GROUP MANUAL**

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The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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