

# **Initiating and Maintaining a Hepatitis C Support Group:** A How-To Program Guide

*The VA Hepatitis C Resource Center Program  
and National Hepatitis C Program Office  
Veterans Health Administration  
U.S. Department of Veterans Affairs*





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**[www.va.gov/hepatitisc](http://www.va.gov/hepatitisc)**





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# I. Objectives and Format of This Program Guide

This document is intended to provide the clinician with a how-to guide for initiating and maintaining support groups for veterans with hepatitis C. Essentially it serves as a primer for conceptualizing the structure and purpose of the group and as a practical guide for organizing and executing the logistics associated with starting a support group. It is based on the collected experience with support groups by members of the HCRC Support Group Guide Planning Committee, commissioned by the National Hepatitis C Program of VA Central Office to develop this manual.

After discussing the benefit of support groups for patients with hepatitis C, this manual will list and elaborate on the suggested steps for starting a support group. These steps range from assessing the needs of your patient population to implementing and modifying your group based on members' feedback. The appendixes at the end of the manual include sample forms for use with your support group, as well as additional sources of information regarding hepatitis C. Future versions of this manual will include educational modules and materials for use in the didactic component of a support group.

The full text of this document can be found and downloaded at [www.va.gov/hepatitisc](http://www.va.gov/hepatitisc). This document is not copyrighted, and users are encouraged to print and distribute as many copies as they need.

## II. The Veteran's Perspective – A Letter from Gene Mask

*May 18, 2003*

I was asked to write a short summary of why I feel our hepatitis C support group works and how, as well as why I believe support groups are important. I was diagnosed with hepatitis C in 1996. I had no idea what the disease was or what its treatment was all about. At the time, there were no support groups and very little in the way of education for veterans; I didn't really know how to take care of myself (or my liver). After a long battle to get help failed, I ended up with liver failure and had to get a transplant. With better education and access to treatment and resources, I might not have needed a transplant. I feel fortunate that help is more readily available now for myself and other veterans with hepatitis C. I continue to learn new things about the disease and how to live with it, especially at the support group. I feel more empowered than ever; I am an advocate for education on hepatitis C and am a member of the National Hepatitis C Advisory Board and the Northwest Regional Board.

The Hepatitis C Resource Center staff at the Portland VA Medical Center has put forth every effort to help us start our group. Our first challenge was to set up a format for the group. I stress the necessity of having a veteran with hepatitis C participate in forming and facilitating the group. I feel that by doing this we help the veterans open up more and look at the group leaders as credible. In addition, having a staff member who can ensure that the individual needs of group members are addressed is essential. I also feel that feedback from the veterans is important. The group is for them, so we sought to tailor the group to match their expressed needs. Their feedback establishes the basis of the group and tells us the questions that the veterans want answers to. We feel that these considerations help us offer the best education and support.

Even though the group is still young and changes are being made, I believe the format we have used so far (having speakers on subjects chosen by the vets at some meetings and open discussions at others) has worked. We have been able to provide education on topics such as treatments, diet, and exercise, as well as a safe place to discuss personal experiences and fears. I also feel that by including the spouse or caregiver of the veteran, we give these individuals a chance to understand the problems the veteran is having and offer a place to voice their concerns and feel supported. Finally, having our meeting in the evenings makes it more available to the veteran and caregiver.

My thanks to those responsible for putting hepatitis C education and support high on the priority list. I feel that our efforts will result in faster and better treatments for veterans and a reduction in long-term critical care.

Sincerely,



Gene P. Mask

### III. Rationale for Support Groups

Veterans with hepatitis C are an important population served by the Veterans Health Administration. The VA is exploring and evaluating new practices to ensure that hepatitis C–infected veterans receive the best possible health care. These patients have their own unique set of needs stemming from such problems as deficits in disease-related knowledge, stress due to social stigma, and medical and psychiatric comorbidity. Antiviral treatment for hepatitis C causes unpleasant side effects for many, and the course of treatment could be better tolerated if patients relied on each other for mutual support. Support groups offer an effective treatment modality that can be beneficial for veterans living with hepatitis C.

#### *What does a support group provide?*

**Group cohesion** – Feelings of trust and safety are primary benefits of group affiliation, as is the recognition of the universality of one’s problems, which decreases feelings of personal isolation.

**Education** – Interpersonal learning is exchanged in group settings, and increased knowledge about hepatitis C infection is the first step toward successful self-care and evaluation of treatment options. Many patients have misconceptions and misinformation about their disease, which can be remedied by group participation.

**Discussion** – Veterans learn as much from each other as they do from providers and staff. Creating an opportunity for dialogue facilitates this exchange of information.

**A venue for expression of needs** – Providers can learn what veterans feel they need to help them manage and cope with hepatitis C infection.

**Prevention** – Alerting veterans and caregivers to behavioral risk factors can help limit transmission of hepatitis C, while at the same time assure them about what kind of contact is safe (e.g., kissing, hugging, playing with their child).

**Opportunity for followup** – Weekly or even monthly participation in a group allows providers to continue monitoring patients informally and reinforce important messages for effective self-care.

## IV. Steps in Support Group Development

Here is a general outline of the steps involved in developing a support group. Each of these steps is expanded and elaborated on in subsequent pages:

1. Conduct a needs assessment
2. Identify target population
3. Select group format
4. Identify resources
5. Attend to logistics
6. Establish your group
7. Implement a feedback function

### *1. CONDUCT A NEEDS ASSESSMENT*

A formal or informal needs assessment is essential to help with decisions you will have to make about group format, meeting time, group size, and so on. This needs assessment may range from a written survey of your hepatitis C patients to simply engaging several individuals in a discussion about what they would find helpful. As a start, you might use a variation of the support group feedback forms contained in Appendixes E and F to find out about patients' interests. Conducting focus groups with patients is another way to assess the needs of your population. Focus groups can be very technical and challenging without professional help, so if you do bring patients together to find out their opinions, you may want to consult someone who has done this in the past.

Asking patients what they need is important; do not assume that you already know what they want. Collect information about both the content of the group meetings (e.g., topic interests) and logistics (e.g., when and how often to meet). Veterans will have differing opinions as well (retain previous phrase with change), so you will have to go with what appears to meet the greatest need for the greatest number of patients.

**NOTE:** It is important to give yourself enough time to set up your new group. Try to allow for a 3-month lead time. It takes time to contact patients, and you will want to allow an adequate time frame to get the word out and attend to the details of establishing a new group.

### *2. IDENTIFY TARGET POPULATION*

Who are the intended participants of the group? This is the first and probably the most important decision to make. Keep in mind that patients are at varying stages of their liver disease and have varying knowledge about hepatitis C virus (HCV). On the basis of your needs assessment, you will have to decide who would benefit most from group participation:



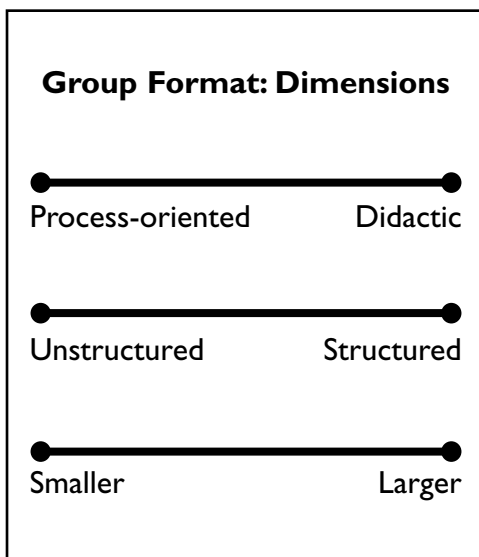
- Patients on antiviral treatment?
- Patients not eligible for antiviral treatment or who have failed treatment?
- End-stage liver disease patients?
- Any and all patients with hepatitis C and their family members?
- Veterans only, or veterans and nonveteran patients?

Also, how many patients do you plan to invite? Your target population and selected group format largely will determine this.

Don't worry if you feel that you can't address every patient's needs immediately. You may decide to start with a very specific target population for your first support group, then use that experience to either expand your group or start other groups.

### 3. SELECT GROUP FORMAT

There are a variety of group formats to consider. Groups can differ from each other on several different dimensions. The most relevant dimensions for support groups are *structure*, *size*, and *focus* (i.e., process-oriented vs. didactic in focus). A process-oriented group is one in which attention is focused more on individual members' concerns, thoughts, and feelings rather than on topical information provided by an "expert." The three dimensions mentioned are illustrated in the following figure:



Keep in mind that these dimensions are largely independent of each other. One could have a monthly, lecture-format type of group that is highly didactic, structured, and large. However, one also could hold a smaller group that is process-oriented but very structured in order to achieve specific goals to enhance patient coping and mastery. A skills-building group for patients on interferon is an example of this type of format.

The group format you select for your patients will depend largely on their needs and your available resources. Below are several general categories of groups. Your hepatitis C group may be a hybrid or modification of these types.

## Support Group

- Objective: At a minimum, these groups provide opportunity for social interaction.
- May be loosely defined, although participants usually share some characteristics.
- Benefits: Vicarious learning, sharing of resources.
- Patient-led vs. provider-led?
  - See considerations under “Co-facilitation” below.
- Process-oriented vs. topic-oriented?
  - Topic could be predefined or ad hoc, based on the needs of the members.
  - Process groups are less structured, but no less challenging to ensure effectiveness (see information under “Therapy Group” below).
- Size of group: 8–12 members optimal for process-oriented group.
- May be open to family members.

*Example: Group for patients undergoing interferon treatment*

## Education-Oriented Group

- Objective: Learning more than mutual support.
- Organized around a topical objective.
- Often a series of meetings of defined duration.
- Topics established in advance.
- Topical expert leads the presentation, although a facilitator usually is also present.
- Social support is a byproduct rather than a primary goal.
- Usually open to family members.

*Example: Guest lectures for hepatitis C patients and their family members*

## Therapy Group

- Objective: Mental health intervention.
- Led and facilitated by a mental health professional.
- Size limited depending on nature of group.
- May be either ongoing or time-limited.
- Usually organized around common diagnosis or diagnoses among patients.
- Usually closed to family members or others.

*Example: Psychotherapy group for patients with both post-traumatic stress disorder and hepatitis C*

## Recovery Group

- Objective: To promote and maintain abstinence from substance use.
- Focused topic and/or mutual support—e.g., Alcoholics Anonymous, CODA (Co-Dependents Anonymous).
- Usually ongoing.
- Drop-in approach common.

*Example: Group for HCV patients recovering from intravenous drug use*

## Hybrid/Combination Groups

- May involve a dual population.
  - HIV/HCV co-infection
  - HCV and addictions treatment
- May be a dual-purpose group or involve splitting the session to address multiple goals.
  - Education plus support
  - Support plus therapy

## 4. IDENTIFY RESOURCES

It may be helpful to have two facilitators for a group, with one being a VA staff person or a professional and the other, if possible, a peer facilitator.

### Co-facilitation

Using two facilitators in any group has several advantages:

- While one facilitator is taking a more active role by speaking to or facilitating the group, the other facilitator can attend to the process or system issues of the group, making note of followup issues for after the group meeting and offering a crucial second point-of-view.
- Having two facilitators offers a chance to model positive interpersonal skills: facilitators can openly disagree on subjects and demonstrate constructive resolution.
- Practically, having two facilitators means the group can continue even on days when one facilitator is absent.

### Choosing a Second Facilitator

We strongly encourage having at least one peer facilitator for the group. Many veterans may prefer leadership from another veteran who also has HCV: such a peer facilitator models successful coping skills and offers personal knowledge and experience with HCV and treatment. Some veterans see a peer as a more credible source of information than a professional. Ideal peer facilitators are often patients who have already assumed some type of advocacy role regarding their health care or the care of other veterans. Peer facilitators can be recruited by providers, at educational events, through local veterans service organizations, and at other community venues.

Having a professional facilitator ensures that the interpersonal aspects of the group are therapeutic, regardless of the group's type (e.g., educational vs. process). The professional facilitator should train and mentor the peer facilitator in developing basic group skills just as the peer facilitator should train and mentor the professional facilitator in the personal experience of having HCV. This training can be formal or informal, but the most important learning occurs with continuous feedback and discussion with debriefing after group sessions. We recommend training peer facilitators in at least the following areas:

- Communication skills: e.g., “I” statements, empathy, active listening
- Motivational interviewing: e.g., developing discrepancy, rolling with resistance
- Basic group and system principles and interventions: e.g., group roles, group developmental stages, fostering cohesion
- Facilitation strategies and techniques: e.g., redirecting, rewarding group behavior, handling disruptive behavior, tolerating awkward silences

Please consult Appendix D for elaboration on these topics.

### **Flexibility**

All that being said, groups can be successfully run by one or two facilitators, peer or professional. In areas with limited VA resources, a group organizer may have to find creative ways to start a group using community resources. Although VA professional facilitators may be unavailable to lead an HCV group, they still may have the time to mentor peer facilitators, individually or as a team, in group skills. Having a well-run therapeutic group that addresses patients' needs is more important than adhering to a predetermined format for which there are no local resources.

### **Security**

Peer facilitators should be approved VA volunteers who have gone through appropriate orientations and safety checks to ensure patients' safety, confidentiality, and well-being.

### **Roles**

It is *crucial* that *before* the group begins, the facilitators agree on their roles and how they will manage the group together. Facilitators may decide to be completely equal in leadership and division of labor or to divide their responsibilities differently: one facilitator may be the leader while the other plays a more secondary role, or one may be in charge of the group's process (e.g., the professional facilitator) while the other is in charge of the content (e.g., the peer facilitator). How the responsibilities are divided is not as important as having the division clear and agreed upon by the facilitators. When a volunteer or peer facilitates, the professional facilitator or other VA employee should make clear to members the boundaries on the volunteer's participation.

### **Guest Speakers**

Early on, start building a list of contacts to use as potential speakers at your meetings. Keep in mind that many speakers need several months' lead time to commit to a specific date or time.

Speakers should be familiar with hepatitis C patients and possess a thorough knowledge of the topic or their specific content area. Speakers whose presentations you have attended and enjoyed and those who are adept at drawing people into discussions are best to invite. See Appendix G for potential content areas you may want to address.

You may also want to consider having physicians, nurses, social workers, or psychologists attend the group sessions from time to time (or as guest speakers) to act as further resources for the group. Ideally, these individuals should have experience in the area of liver disease or in treating serious illness.

Many hepatitis C patients have indicated particular interest in certain topics. You can find a list of these topics in Appendix G. Support group planners may seek out guest speakers with specialized knowledge or expertise in these areas. (The Support Group Guide Planning Committee plans to develop the suggested topics listed in Appendix G as educational modules and include supplemental materials, such as lecture notes and PowerPoint slide presentations, in future versions of this Guide.)

### **The American Liver Foundation**

The American Liver Foundation (ALF) is another resource for starting support groups, particularly if your group is to be based in the community rather than at a VA medical facility. ALF has an expert speakers' bureau and provides many helpful suggestions for structuring and conducting your support group. You may wish to contact ALF and work together once you have an idea as to the purpose and target population of your group. ALF is also able to list your support group on its local Web site. You may find out how to speak with the ALF representative for your area by contacting ALF via the resource information provided in Appendix H.

### **Industry Support**

Corporations that develop health care products and services sometimes offer resources that can benefit your group, such as informational materials on hepatitis C and patient care consultants who can serve as speakers. VA rules prohibit soliciting support from industry representatives, but donated support, such as unrestricted educational grants, may often be used to augment the resources available from your facility. Many VA medical centers have specific policies or procedures pertaining to acceptance of support from outside sources, and you should make sure that you understand and abide by these. *Representatives of outside organizations that provide support should not be permitted to attend patient support groups.*

### **Community Resources**

One mission of this manual is to help group facilitators empower veterans with knowledge and resources that promote optimal self care. To increase information access, we suggest you provide veterans with a resource list addressing their varied concerns. This list could include the following:

- Contact information on agencies and Web sites that promote liver health, education, and advocacy
- Relevant case management and social service resources (e.g., legal aid, Social Security, housing, Americans with Disabilities Act, and disability rights contacts)
- Recommended readings on liver health, hepatitis C, and related issues
- Information on current liver research
- Public health clinics and other locations that test for hepatitis (especially for significant others)
- Advocacy organizations
- Other hepatitis C support groups in the community
- Contact information on alcohol and drug recovery resources (such as treatment centers, local 12-step and Self Management and Recovery Training (SMART) recovery meetings, directories and/or contact numbers or Web sites)

This manual provides a directory of national resources (see Appendix H). You are encouraged to add any local resources to this listing, which should be updated periodically. Hard copies of the resource list could be made available at each group meeting along with educational brochures about the liver and hepatitis C.

## **5. ATTEND TO LOGISTICS**

### **Planning**

The following planning points are important to address early on:

- When are most participants available?
- When is the facility available?
- How frequently will people be able to meet (weekly, monthly)?
- Is there adequate parking?
- Is there access to audiovisual equipment?
- Is the room arrangement and number of chairs sufficient for the group?
- Who will be responsible for opening and closing the facility?

### **Location**

Once you have an idea of when and how often your group will meet (at least for the first couple of meetings) you need to secure a location for the group. Ideally, you will have meeting space at your VA facility. The space should be large enough to seat everyone comfortably, but if the space is too large it may feel cold and impersonal for the purpose of the support group.

If you have to hold your support group *offsite*:

- Some locations may require payment for use of the facility.
- Contact community resources (e.g., library, town hall) or community organizations (American Red Cross, Rotary Club, Lions Club, YMCA/YWCA, Salvation Army).
- Most organizations have community relations offices as a contact point.
- Also consider local hospitals, health centers, a doctor's office, or the local Visiting Nurses Association.
- Have an idea of the total number of meetings and/or the number of months you plan to meet prior to making the initial contact call (most meetings last approximately 1½ hours, plus time for questions).
- Don't forget time for setup (refreshments, video, etc.) and cleanup.
- Let your point of contact know projected dates and times, that the meetings are free of charge, and that the group is voluntary and nonprofit.

Wherever you hold your group, be sure to consider safety issues (adequate lighting, in a safe area), especially for night groups, to minimize the possibility of harm to or harassment of participants. Also consider confidentiality issues when creating your signs for the support group. For example, "Liver Support Group" would likely be preferable to "Hepatitis C Support Group" when posting signage.

### **Establishing a Clinic in CPRS for the Hepatitis C Group**

One important step in developing your hepatitis C group is to set up one or more clinics in the **Computerized Patient Record System (CPRS)**, in order to capture accurately the workload data associated with the group. This should be done before the groups begin but near the end of the planning process.

To set up a clinic in CPRS you will need the following information:

1. The length of each group session
2. The primary provider(s) associated with the group sessions
3. Other providers who will be routinely speaking to the group

You will need to work with your station's Decision Support Service (DSS) program manager or analyst, or other staff responsible for creating clinics in CPRS. Find appropriate staff to help you identify and set up the primary and secondary stop codes within that clinic as well as local codes to capture every element of the workload associated with the group. You may need only one clinic to capture the workload or you may need several, depending on the providers associated with the group. Please advise the person assisting with the clinic setup that veterans attending these clinics must not be charged for the visit.

There may be other considerations for setting up a clinic at your facility. Some facilities may require a review of patient education materials. Others may have a system for reimbursement of travel costs for attending the meeting. Any requirements for individual facilities should be addressed ahead of time, and the process should be in place prior to the first meeting.

**Referral Process**

How you select and bring people into the support group will vary depending on its format and objectives. Each method has advantages and disadvantages, as indicated below.

Referral Strategy	Most Appropriate Uses	Advantages	Disadvantages
Invitation in person or by phone	For small or process-oriented groups (e.g., patients on treatment)	Provides a personal connection; encourages participation	May be time-consuming or labor-intensive, especially for larger groups
Mass mailing	For large groups (e.g., all hepatitis C patients)	Reaches a wide audience	Not very personal; provides little feedback on who or how many will attend; moderately time-consuming and labor intensive
Provider-referred	When group participation is recommended as part of a patient’s treatment plan	Encourages participation and compliance	Variability among providers in willingness to refer to group
Flyer	Large groups open to all comers	Requires least amount of effort	No feedback or control over who will attend
Newspapers, community bulletin boards	When the goal is to reach veterans not attending clinic on a regular basis	Increases access to underserved veterans	May increase clinical workload

Providers can be the best referral source for potential group participants. They often know the patients’ needs as well as their current health status. Discuss who might benefit from group participation with physicians (especially gastroenterologists, hepatologists, and infectious disease specialists), nurses (especially those who treat liver disease), social workers, psychologists, and other mental health professionals (especially those who work with patients with a history of substance abuse and/or chronic disease).



If you send invitations to patients by mail, our early experience with this method resulted in a 10 to 20 percent attendance rate among those we invited. If you call selected patients by phone, your response rate likely will be higher, and you will also have a greater sense of who will attend by what they tell you.

Many newspapers have a community bulletin board you can access without charge. Some States have monthly newsletters that list dates, times, and activities for public service groups in the State. Take advantage of bulletin boards and public service announcements from local media, making sure to clear information in accordance with local policy.

Some institutions may require a group to be registered or approved by a patient education coordinator or hospital education committee. Be sure to check your local policies to see if this is the case at your site.

A flyer, either to post or to mail to potential participants, is a good visual aid to promote your group.

### **Meeting Logistics**

A meeting planning tool is enclosed (see Appendix B) to help keep track of what has been done and what needs to be done for each meeting, once your meetings are under way. Here are some considerations for your first group and beyond:

- **Audiovisual** – Do you have the equipment that you or your guest speaker needs for a presentation (e.g., VCR, PowerPoint, overhead projector)?
- **Food/Refreshments** – Food helps to attract and maintain group participation. If possible, provide food that is healthy for patients with liver disease (i.e., avoid high-sugar sodas and caffeinated beverages). If you serve food, remember the little things everyone needs (napkins, utensils, serving spoons).
- **Directions/Signs** – Patients will easily get frustrated if they have to walk the length of the hospital to find the meeting room.
- **Announcements** – Groups are great forums for disseminating information, especially information about upcoming meetings and speakers.
- **Handouts** – Do you have enough copies?
- **Brochures/Flyers** – See “Community Resources” section above.
- **Room Environment** – Check temperature, lighting, and seat arrangement in advance. You may need to obtain a key beforehand to gain access to the room.
- **Name Tags** – Do you want people to wear them or not?

*General Practice Note: START AND END ON TIME!*



## 6. ESTABLISH YOUR GROUP

### **Guidelines**

Having some general guidelines and expectations regarding group conduct established from the beginning can make the group more comfortable for the members. This will help to resolve difficult situations without appearing dictatorial. Appendix C is a list of patient rights and responsibilities you may wish to incorporate.

### **Confidentiality**

At the first meeting it is a good idea to establish and emphasize that every member should respect the confidentiality and anonymity of individual group members. Your group may also decide if it is to be open or closed to spouses, family members, or friends. Group members should feel free to express themselves without fear that their private lives will become a matter of public knowledge outside the group.

### **Mission Statement**

To begin, prepare a mission statement for the first meeting (see sample in Appendix A). Ask members to suggest changes or additions. With their input and feedback, you will be able to ensure that the interests and needs of the group will be met. You should review this mission statement periodically to help the group stay focused on its purpose and goals.

### **Potential Problem Areas**

Facilitating a group, large or small, can be tricky. The table on the next page lists common problem areas that often arise in groups, along with some suggested remedies.

Problem	Solution
Monopolizing the conversation	Invite others to share: “Let’s hear if some other people have had a similar experience.”
Argumentativeness	Reflect/validate the speaker’s feelings; encourage him or her to use the group to get additional information or others’ perspective on the issue.
Emotionality	Acknowledge their feelings; provide comfort (and tissues). Gently shift to another group member, but come back to “check in” with the emotional member when he or she has stopped crying. If the person is very upset, perhaps a facilitator could leave the group with him or her temporarily until he or she feels better.
Incorrect information	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.”
Lack of participation	Invite the member to share: “I notice you have been quiet through all of this; what are your feelings about (or your experience with) the issue?”
Rambling	Reflect that the speaker makes a number of good points; suggest the group focus on the most relevant point.
Interruption of the speaker with questions	If you have an invited speaker giving a lecture, point out that there is a lot of material to cover and suggest the group hold their questions until the end.

We suggest you read Appendix D to learn more about group facilitation. Many of these tools may come in handy once the group starts.

### **Question-and-Answer Period**

Even if you have decided to go with an educational or lecture-style format for your group, it is important to allow ample time for members to ask questions or share their comments on an issue. Some educational presentations are informal and allow for questions during the lecture, but often it's best to hold questions until after the speaker has presented all of his or her planned material.

### **The Social Aspect of Support Groups**

Much of the strength of support groups is found in the patient-to-patient interactions that occur before, during, and after the “official” meeting. This is when veterans share information, compare notes, and even exchange phone numbers for informal contact outside of the group. While starting and ending groups on time is a good suggestion from a group management perspective, encouraging this peer-to-peer networking is important to promote patient self-help and to let the group thrive. Perhaps you can identify a safe, accessible place where patients can continue to talk even if your meeting room has to be locked up or released to the next scheduled user. If this is a possibility, announce to group members at the beginning of the meeting when the group officially ends and when and where informal discussions may continue.

### **Special Considerations for Hepatitis C Groups in Mixed Outpatient and Domiciliary Settings**

1. **Confidentiality.** Try to choose a space that allows for persons to enter unnoticed by the general population. Remember that hepatitis C is a disease that often carries a stigma. Domiciliary patients may choose not to attend rather than reveal their hepatitis C positive status.
2. **Frustration.** Many veterans in a substance-use domiciliary will be frustrated if they are attempting to establish some sober time or to decrease their alcohol intake before starting treatment. Encourage veterans to use the time to prepare their bodies and minds for the treatment.
3. **Familiarity and Group Dynamics.** Domiciliary patients often spend the majority of their time in each other's company. They may know each other well and have patterned ways of interacting throughout the many groups within the domiciliary program. This can affect the group dynamic in several ways you may not anticipate, especially if you are not domiciliary staff. You will need to establish the hepatitis C group as its own group, not just one of a number of domiciliary groups. Holding the group outside of the domiciliary (e.g., in an outpatient clinic) and including nondomiciliary patients can help establish this fact. Discourage participation of those who do not have hepatitis C by offering limited hepatitis C information in the other domiciliary health classes.
4. **Origin of Hepatitis C.** Those who are newly diagnosed often question the origin of the virus or the source of their infection. Be cautious not to let this discussion get too far

within the support group. It can lead to divisiveness within the group between those who obtained the virus from high-risk behaviors (e.g., IV drug use) and those who did not (e.g., a blood transfusion). Mixed populations are particularly susceptible to this dynamic as persons in the domiciliary often are early in recovery from drug or alcohol abuse and readily disclose high-risk behaviors.

### **Starting a Hepatitis C Support Group: Two Perspectives From the Field**

I am a social worker at the Anchorage VA Outpatient Clinic who was tasked with developing a hepatitis C group, although the goals and purpose of such a group initially were not well defined. First, I set out to learn what veterans and providers hoped to achieve from this group. I found that we have two groups of patients, each with very different needs. In addition to hundreds of outpatients with the disease, we also have a domiciliary unit where many veterans have hepatitis C, often newly diagnosed.

I began by learning everything I could on the topic of hepatitis C. The resources I found most helpful were the VA hepatitis C brochures and video series and the VA Web site. I also talked with the domiciliary providers and hepatitis C specialists, as well as hepatitis C+ veterans, about what they wanted in a hepatitis C group. While veterans wanted more information about the disease and support, providers wanted better-educated and more compliant patients. After more than a year of research, we put together a 6-week education series, followed by a separate ongoing support group. We offer the education series quarterly, which enables us to have guest speakers for the 6-week series, including a patient care consultant from industry, our hepatitis C treatment provider, a dietician, psychiatric nurse practitioner, and myself as the social worker. The support group is offered monthly and well attended by those on treatment and those nearing the start of treatment. Veterans share their struggles with the disease as well as their successes. I have been fortunate to have co-facilitators who have been tremendous resources in the continual refinement and development of these groups.

*—Michele Richardson, MSW*

I am a registered nurse working for the VA Southern Oregon Rehabilitation Center in White City, OR, the largest freestanding domiciliary in the VA system. Most of the residents are here for substance abuse treatment. Approximately 25 percent of this clientele are also infected with hepatitis C. In 1999, I (among others) saw a need for some type of education/support group directed toward hepatitis C. There did not seem to be many resources for veterans who were trying to come to grips with recent diagnoses of hepatitis C. Also, many veterans were confused, as there are several types of viral hepatitis.

I began by inviting the few veterans I knew were infected with hepatitis C to the first few groups and modifying my format to meet the needs of the group. The group grew by word of mouth in the first year. After some time the group became consistent enough to qualify as a clinic. I now get referrals from other providers at my facility. I continually refine the education part of the group as new data are published. The process part of the group also evolves as different needs are identified. Although I have changed job positions and am now in more of a supervisory role, I still facilitate the group. I feel it is very important for the veterans here to understand what is confronting them and to be able to have a forum to voice their concerns. Both peers and veterans have commented to me that this group fills these needs.

—John Penkert, BSN, CARN

## 7. IMPLEMENT A FEEDBACK FUNCTION

### **When the Session Is Over**

Although a group session ends for its members, facilitators still have many important tasks to continue the group's work.

### **Debriefing Between Facilitators**

Facilitators should meet immediately after the group, even if only for 10 minutes, to discuss what happened and develop plans for followup. Here are some topics you may want to cover during your debriefing:

- Clinical issues requiring followup (e.g., a participant discussed severe depression or suicidal ideation, seemed agitated, is likely to drop out prematurely)
- Process issues in the group (e.g., a participant who dominates the group or one who does not participate, scapegoating, deflection from emotional issues)

- Case formulations and intervention plans: developing therapeutic plans for individual participants and the group as a whole
- Followup list of unanswered participant questions or requests for more information (e.g., referrals)
- Process issues between facilitators: mutual feedback, examining countertransference (i.e., personal reactions to group members), reaching agreements on practices, handling particular situations, responding to particular requests

## **Evaluating the Session**

### ***Feedback form***

Using a standardized feedback form (see examples in Appendixes E and F) at the close of every group offers continuous feedback from participants to shape the group to their needs. Ideally, feedback should address three key aspects:

- Structure – length, meeting times, formats
- Process – facilitation style, issues between participants
- Content – topics for guest speakers or focused discussions

### ***Data analysis***

Once you solicit a group's feedback, it is extremely important to use that information. Let the group know at the outset that their feedback shapes the group, and then show them their feedback matters by altering the group accordingly. Members feel empowered when their efforts create real change. To ask the group's opinions and then not act on them risks alienating members and divesting them from their very own group. The group fundamentally belongs to the members to address their concerns and needs: the process within the group should empower members, encouraging their roles as active participants in their own health both within and outside of the group. The group fosters a norm of active collaboration in their health care.

## **Planning the Next Group**

The first meeting will generally be organizational in nature. Each member should have the opportunity to express what he or she would like to experience from the group. It's important to ask, not assume, what patients will want. Not all members will want to listen to a guest speaker every month. Some might prefer to just vent their emotions and learn to deal with side effects of treatment. Collect information about both topic interests and logistics (when, how often to meet).

## **Flexibility and Creativity**

Groups are not set in stone and should change with the changing composition and needs of their members. Groups may change in purpose, focus, content, or structure. If one group seems to have outlived its usefulness, don't be afraid to end it and start a different type of group that might address patients' needs in a new way.

**Attending to Members' Feedback**

Facilitators may decide to make changes directly based on member feedback, bring feedback to the group for discussion, or engage the group in a more collaborative planning of changes.

**Reminder Calls and Letters**

Reminders can work in a number of ways. One useful strategy is for facilitators to make the initial invitation to join the group face-to-face or by phone, then send members reminder letters before every group meeting. No-shows and drop-outs are common occurrences in groups, so facilitators should agree on a followup plan for handling them. It is especially important to follow up with members who have expressed some important concerns or are having a particularly difficult time with their illness. If volunteer or peer facilitators are to contact members, the VA facilitator should ask members' permission first, guarantee their confidentiality, and clarify the limits on volunteers' access to the members' medical information.

**Multidisciplinary Collaboration**

Group leaders should collaborate with other providers, such as medical, mental health, and substance abuse staff. When facilitators obtain a patient's informed consent to join the group, they should make this collaboration and information sharing clear. A multidisciplinary staffing of participants' treatment is usually the most efficient way to optimize care, but even a one-to-one collaboration between providers of different professions, whether face-to-face or over the phone, can considerably augment care. Group facilitators may see patients more frequently and for longer periods than physicians, so they might offer information on members' quality of life, support systems, coping skills, daily challenges, and recent changes. Facilitators may wish to ask other providers to follow up on issues raised in group; similarly, other providers may ask the facilitator to follow up with issues in the group.

**Longstanding Groups**

Just as your group may run its course and end naturally after fulfilling its usefulness, it may also become a mainstay of your health care facility. Don't be surprised if the group takes on a life of its own, with members developing their own rituals and traditions. Allow for the group to have alternative functions, such as holiday parties, participation in community events (e.g., local Liver Walks), or even reunions for very long-standing groups.

As one longtime support group member advises, stick with a generic name for the group. Your group may evolve over time and eventually look very different than it did when you held the first meeting.



## V. Final Thoughts

Running support groups can be extremely rewarding, as well as frustrating. Here are some parting tips on how to take care of yourself and avoid burnout:

- Network with other providers. Process and debrief challenges. Coordinate care with other providers and use a team approach. If some of your own issues emerge as a result of your helping others, seek counseling.
- Keep yourself abreast of new information by participating in ongoing education.
- Follow the advice that you teach to clients about physical, mental, emotional, social, and spiritual self-care. Self-care is the opposite of burnout.
- Recharge yourself! Pay attention to your personal time away from work and schedule activities that make you feel better. Set time aside for yourself. The more you enjoy your time away from work, the more you have to share at work.
- Recognize resentments against clients, colleagues, and work as signs that you are giving too much and not attending to your own needs.
- Set realistic goals for yourself at work. Keep reminding yourself, “It’s not my job to save the world.” Instead, focus on the smaller ways you can make it a better place today, if only for one person at a time.
- Know you are making a difference. Keep a file of all the thank you cards and commendations that remind you of the many people who appreciate what you do.



# Acknowledgments

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## Appendixes

- A. Hepatitis C Support Group Mission Statement (Sample)*
- B. Support Group Meeting Planning Grid*
- C. Hepatitis C Support Group Participant Rights and Responsibilities*
- D. Theories and Techniques for Support Group Facilitators*
- E. Initial Hepatitis C Support Group Feedback Form*
- F. Ongoing Support Group Evaluation Form*
- G. Suggested Hepatitis C Educational Topics*
- H. Hepatitis C Resources*

*Appendix A*

## Hepatitis C Support Group Mission Statement (Sample)

A support group serves to empower the patient through increased knowledge gained from speakers and other members as well as through the assurance that he/she is not going through his/her problem alone.

**Appendix B**

<b>Support Group Meeting Planning Grid</b>	
Program Title	
Meeting Date	
Location of Meeting	
Room Reserved	
Expected Attendance	
Speaker	
Facilitator(s)	
Agenda for Meeting	
Handouts	
Audiovisual Equipment	
Food/Refreshments	
Publicity/Plans	
Flyers/Newsletter	
Directions Posted	
Contact Person	



*Appendix C*

# Hepatitis C Support Group Participant Rights and Responsibilities

1. *We agree to participate in this program in a group setting with other hepatitis C patients and their families.*
2. *We understand the need for complete confidentiality and trust within the group.*
3. *We accept an individual's choice to actively participate or simply listen.*
4. *We will begin and end meetings on time.*
5. *We encourage "I" statements to keep discussions in the first person.*
6. *We let one person speak at a time.*
7. *We don't let one person monopolize the discussion.*
8. *We recognize the importance of actively listening to the person who is speaking.*
9. *We emphasize each individual's role in the group's success.*
10. *We will not be judgmental toward other members; we are here to support, not criticize.*
11. *We accept all feelings, whether they are positive or negative.*
12. *We agree that each of us is responsible for our own comments and that we need to consider the group setting prior to disclosing personal information. We should keep in mind that some questions and comments may need to be presented in an individual session.*
13. *We recognize and authorize that a participant's personal medical information may be disclosed in the group setting in order to respond appropriately to that participant's questions.*

By my signature below, I show that I understand the purpose of this document.

Patient Signature \_\_\_\_\_ Date \_\_\_\_\_

Facilitator Signature \_\_\_\_\_ Date \_\_\_\_\_

## Appendix D

# Theories and Techniques for Support Group Facilitators

### Systems Theories

Whenever people come together, they tend to form a system of complex interactions that can be understood as an organic whole. Focusing exclusively on one individual's behavior in a group ignores the context affecting that behavior: the complicated interplay of give and take in human relationships, forming intertwined feedback loops of actions and reactions. Systems follow certain principles:

- **Homeostasis** – Systems tend to maintain their status quo. Attempts to change the system are often met with opposite, counterbalancing forces to keep the system as it was.
- **Feedback** – The system has feedback loops of information that help it gauge itself and maintain homeostasis.
- **Development** – Like all organisms, systems begin, grow, change, decay, and end.
- **Norms** – Each group develops characteristic ways of behaving and of defining “normal” behavior.
- **Roles** – Individuals in a closed group tend to take on more static functions within the group, such as “leader,” “devil’s advocate,” “scapegoat,” and “identified patient.”

### Stages of Group Development

Groups typically follow certain broad and overlapping stages of formation, growth, and decay (Corey & Corey, 1997; Yalom, 1995):

- **Beginning** – Trust is a central issue. Participants begin to learn what it means to be a member of the group, take tentative steps toward participating in the group, and observe and test others' reactions to them. The facilitator works to establish an emotionally supportive environment, fosters functional group norms, and validates feelings of fear, ambivalence, and alienation. Early facilitator interventions focus on acknowledging all participants' contributions and highlighting commonalities among participants.
- **Transition** – Conflicts arise as participants see beyond their common goals to differences in styles of participating. Every group has conflict, but a group becomes therapeutic by bringing this conflict to the surface and resolving it directly and constructively. Conflict is a natural pathway of development and is necessary for the group to progress to cohesion. Participants become aware that to make progress in the group, they'll need to risk becoming vulnerable and to attempt new behaviors. Participants find their respective roles and places in the group. Facilitators' authority is often challenged. Facilitators must be keenly attuned to transference and countertransference and respond with process more than content in mind.

- **Working** – By working through the conflicts of the transition stage, the group reaches a functional cohesiveness and trust through which it achieves its central goal. Participants feel a common bond, disclose more, participate more, mutually support each other, and actively facilitate the group’s process. This stage is devoted to process, so educational/informational, open-enrollment, and nonprocess-focused groups may never reach this stage, and may not need to, in achieving their aims.
- **Ending** – Participants acknowledge that the group will end and struggle with finding meaning and value in having participated even though it is ending. Participants identify and consolidate gains, as well as plan how to generalize their new behaviors in group to the rest of their lives. Participants may feel both happy about “graduating” and unhappy about losing the group. This is a time when old dysfunctional behaviors may reemerge. Participants may deny or minimize feelings of loss by saying they will keep in touch with other group members, but facilitators must help participants discuss the loss honestly.

### **Curative Factors in Group Therapy**

Irving Yalom (1995) identified 12 factors in groups that may facilitate positive change:

1. Interpersonal Learning, Input – Learning how others perceive and experience you
2. Catharsis – Learning how to express and tolerate feelings
3. Cohesiveness – Feeling accepted, belonging
4. Self-Understanding – Discovering and accepting parts of yourself (good and bad)
5. Interpersonal Learning, Output – Learning how you typically distort the way you perceive and experience others
6. Existential Factors – Facing issues of injustice, isolation, and death, and that you are ultimately responsible for your life
7. Universality – Knowing that you are as well off (and sometimes as bad off) as others
8. Instillation of Hope – Gaining a sense that a solution is possible
9. Altruism – Helping others makes you feel better about yourself
10. Family Reenactment – A chance to have a more positive interaction with the group than you did with your family
11. Guidance – Getting specific advice and recommendations from others
12. Identification (Imitative Behavior) – Learning from others’ experience and trying their behaviors

### **Facilitation Techniques**

Certain basic techniques are easily learned and quite useful in facilitating groups:

- **3 Rs of Listening** – Focusing on listening rather than preparing to respond to what is being said: preparing to listen (Readying), encouraging the speaker to say more (Reaching), and paraphrasing what the speaker has said (Reflecting).



- **Immediacy** – Showing you’re interested by making eye contact; nodding; reacting with other appropriate face, body, and vocal expressions; gesturing; and maintaining an appropriately close distance from the other person.
- **Addressing by Name** – Calling people by their names establishes a personal connection and can help calm an agitated participant or focus one who is moving off task.
- **“I” Statement** – A communication format focusing on the speaker’s experience of the person being addressed: “I feel [emotion] when you [behavior]; I would prefer [alternate behavior] and/or [positive/negative consequences].”
- **Giving Feedback** – Sharing how a participant’s behavior personally affects you. The speaker should focus only on his or her personal reaction, focus on behavior over character or some attribute that is more difficult to change, be very specific by giving a concrete example, and use very recent examples.
- **Confrontation** – Pointing out how a participant’s behavior affects you (or others in group) and highlighting the possible consequences.
- **Soliciting Feedback** – Asking others for their reaction to your behavior or that of a group participant.
- **Paraphrasing (Reflecting)** – Restating a participant’s words in a concise way. This shows people that you are listening and often helps them observe their own experience.
- **Supporting** – Acknowledging people’s experience and their right to feel however they do. This helps calm or soothe negative feelings.
- **Labeling** – Helping a participant name a feeling he or she is experiencing.
- **Perception Checking** – A three-part method for verifying the accuracy of interpretations, including a description of the observed behavior, at least one possible interpretation, and a request for confirmation of the interpretation. “I notice that you [sensory data/behavior]; to me that means [interpretation]; is that right (request for clarification)?”
- **Self-Disclosure** – Revealing personal information about yourself to the participants. When a facilitator self-discloses, he or she should consider the goal in disclosing and plan on how much to disclose. Self-disclosure is a powerful tool in the early stages of group to help model such behavior and establish a group norm; however, the facilitator should be careful of disclosing too much, monopolizing the group, or using the group for personal reasons.
- **Praising (Stroking)** – Calling attention to a specific positive behavior of a participant and how it affects others.
- **Deflecting** – Rather than responding to a communication made directly to you (the facilitator), you open the discussion up to the group as a whole or to another specific participant. This is a way of encouraging cross-talk between participants rather than having each one interacting only with the facilitator. It is also a useful way of ending one participant’s monopoly of group time and inviting others into the conversation. For example, “Has anyone else had a similar experience?”
- **Punctuating** – Summarizing or making an observation as a way of stressing the importance of what has just happened or as a means of ending one train of discussion or speaker’s time and starting a new one.

- **Broken Record** – Repeating your statement calmly to get your point across.
- **Using Silence** – Tolerating or fostering awkward pauses and silences in the group. This is one of the most useful group process techniques and one of the easiest ones to overlook for beginning facilitators. People naturally tend to be uncomfortable with silences and try to rush to fill the void with a new topic; however, the silences are often times when people are becoming aware of strong or anxiety-evoking feelings or are provoked into deep thought. Allowing a prolonged silence may deepen participants’ experience of their feelings. By not “rescuing” the group from this discomfort, the facilitator may allow another participant to come forward and deepen or add to the conversation. If no participant comes forward after a long enough pause or if one attempts to move off the topic entirely, the facilitator can deepen the conversation by saying something like, “Although nobody spoke in the past few minutes, I know that everybody was thinking or feeling something that they didn’t say. Would you please share what you were just feeling or thinking about?” You can build your tolerance for such silences by sitting with a group of friends or coworkers and agreeing to be silent for the next 1, then 2, then 3 minutes. You will observe a natural tendency to end the awkward silence by talking or laughing.

### **Motivational Interviewing**

Miller and Rollnick (1991) articulated a nonconfrontational therapeutic approach to foster behavior change. Many have applied their approach to work with substance use disorders, but motivational interviewing is now proving effective with other health behavior change as well. They recommended five therapeutic principles or activities for assisting people to move toward behavioral change. These principles can be used in groups as well as individually.

- **Express Empathy**
  - Listen to understand.
  - Accept participants as they are.
  - Ambivalence is a normal human experience.
  - Reluctance to give up something that causes problems is normal.
  - Joining (empathically siding) with the participant can foster change.
- **Develop Discrepancy**
  - Becoming aware of a behavior’s consequence is an important step toward changing it.
  - Everything has good and bad consequences.
  - Look for consequences in participants’ adaptive coping, legal, health, work, and social contexts.
  - Discrepancy between a behavior and important personal goals can foster change.
  - Explore participants’ personal goals.
  - Participants develop the reasons for change themselves, rather than being told by the facilitator.

■ **Avoid Argumentation**

- Arguments are counterproductive.
- Direct argumentation calls for a reaction from the participant.
- Saying “You can’t” makes people want to assert their freedom by proving they can.
- Resistance signals a need to change your (the therapist’s) strategy.

■ **Roll With Resistance**

- “Psychological judo” – Use the participant’s inertia; sidestep an issue the participant is “dug in” on rather than butting heads with him or her.
- Perspectives can be shifted.
- The participant is an ally in solving the problem.
- Invite participants to try other perspectives, but don’t impose them.
- The participant generates solutions: Ask, “What would you like to do about this?”

■ **Support Self-Efficacy**

- Believing that someone can change motivates him or her (hope).
- Participants are actively making decisions about their lives (even when they decide not to change things).
- Participants (not the therapist) are responsible for choosing and making changes.

**References**

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- Rollnick, S., P. Mason, and C. Butler. *Health Behavior Change: A Guide for Practitioners 11th Ed.* Edinburgh: Churchill Livingstone, 1999.
- Yalom, I. *The Theory and Practice of Group Psychotherapy, 4th Ed.* New York: Basic Books, 1995.



Appendix E

# Initial Hepatitis C Support Group Feedback Form

Today's date: \_\_\_\_\_

I am (circle one)...  a veteran  a significant other

For significant others:

I am...  HCV+  HCV-  don't know

When did you learn you had hepatitis C? \_\_\_\_\_

Have you been on treatment for hepatitis C before?  Yes  No

If yes, what was the result of treatment?

- a. Cleared the virus
- b. Did not clear the virus (treatment did not work)
- c. Still on treatment

Has any provider ever told you treatment would not be a good idea for you?

- a. Yes
- b. No
- c. Have not talked about treatment with a provider
- d. Already tried treatment

Please rate the following topics as to how much they interest you:

(1 = not interested at all, 7 = very interested):

Basic info about hepatitis C	1	2	3	4	5	6	7
Exercise approaches	1	2	3	4	5	6	7
Diet/nutrition	1	2	3	4	5	6	7
Alternative meds/herbal medicine	1	2	3	4	5	6	7
Understanding your lab results	1	2	3	4	5	6	7
Treatments for hepatitis C	1	2	3	4	5	6	7
Side effects of treatments	1	2	3	4	5	6	7

Preventing the spread of hepatitis C	1	2	3	4	5	6	7
Managing mood changes	1	2	3	4	5	6	7
Managing fatigue	1	2	3	4	5	6	7
Relationships	1	2	3	4	5	6	7
Liver biopsy	1	2	3	4	5	6	7
Liver transplant	1	2	3	4	5	6	7
Benefits (VA, SSA, etc.)	1	2	3	4	5	6	7
People's reactions to my hepatitis C	1	2	3	4	5	6	7
Other: _____	1	2	3	4	5	6	7

**Which of the following formats do you prefer for this group?**

- Speakers
- Videos/slide shows
- Group discussions
- Time to talk/process/vent
- Other: \_\_\_\_\_

**Would you like to attend this group (circle one):**       weekly       monthly

**The best day of the week to attend would be (circle one):**     M     T     W     Th     F

**The best time of day would be:**       Morning       Afternoon       Evening

**If you have a question or concern that was not answered today, please write that question or concern here for us to address at a future meeting:** \_\_\_\_\_  
\_\_\_\_\_

**What did you find helpful or interesting about this group today?** \_\_\_\_\_  
\_\_\_\_\_

**What wasn't helpful about this group today? What did you *not* like?** \_\_\_\_\_  
\_\_\_\_\_

**Other suggestions?** \_\_\_\_\_  
\_\_\_\_\_



*Appendix F*

# Ongoing Support Group Evaluation Form

Today's date: \_\_\_\_\_

I am (circle one)...       a veteran                       a significant other

**For significant others:**

I am...       HCV+                       HCV-                       don't know

**What information provided in this group was most helpful to you in understanding hepatitis C?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What was least helpful?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What topics would you like to see covered more or less extensively?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What topics would you like to be added to the program?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**How did these group sessions help you in understanding and coping with a diagnosis of hepatitis C?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**What other changes, comments, or suggestions do you recommend?** \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Thank you for your participation. Your answers will be used in further developing the hepatitis C group program.

## ***Appendix G***

# **Suggested Hepatitis C Educational Topics**

Many hepatitis C patients have indicated the following topics as being of particular interest to them. Support group planners may seek out guest speakers with specialized knowledge or expertise in these areas.

1. Your Liver & Hepatitis C
2. Understanding Lab & Biopsy Results
3. Risk of Transmission & Intimate Relationships
4. Diet & Nutrition
5. Managing Sleep, Fatigue, and Exercise
6. Interferon-based Treatment for Hepatitis C
7. Alternative & Complimentary Therapies for Hepatitis C
8. Symptom & Side-effect Management
9. Liver Transplant Issues
10. Emotional Self-Care
11. Anger Management
12. Benefits & Service Connection

The Support Group Guide Planning Committee plans to develop these 12 topics as educational modules and include educational materials (i.e., lecture notes, PowerPoint slide presentations) in future versions of this Guide.

*Appendix H*

## Hepatitis C Resources

### Web Sites

*Veterans and Providers*

Veterans with Hepatitis C

[www.va.gov/hepatitisc](http://www.va.gov/hepatitisc)*Patient Support*

Adverse Event Reporting Program

[www.fda.gov/medwatch/index.html](http://www.fda.gov/medwatch/index.html)

HCV Advocate

[www.hcvadvocate.org](http://www.hcvadvocate.org)

Health Talk Hepatitis C Education Network

[www.healthtalk.com/hepc](http://www.healthtalk.com/hepc)

Hep C Vets

[www.hepcvets.com](http://www.hepcvets.com)

Hep Net (Canadian Hepatitis Network)

[www.hepnet.com](http://www.hepnet.com)

Hepatitis Central

[www.hepatitis-central.com](http://www.hepatitis-central.com)

HIV and Hepatitis

[www.hivandhepatitis.com](http://www.hivandhepatitis.com)

Medscape Resource Center

[www.medscape.com](http://www.medscape.com)

Melissa Palmer, MD (Liver disease &amp; Hepatitis)

[www.liverdisease.com](http://www.liverdisease.com)

Rx List

[www.rxlist.com](http://www.rxlist.com)*Health Organization Links*American Association for the Study of  
Liver Disease[www.aasld.org](http://www.aasld.org)American Autoimmune Related  
Diseases Association[www.aarda.org](http://www.aarda.org)

American Gastroenterology Association

[www.gastro.org](http://www.gastro.org)

American Liver Foundation

[www.liverfoundation.org](http://www.liverfoundation.org)Centers for Disease Control and Prevention  
Hepatitis Branch[www.cdc.gov](http://www.cdc.gov)[www.cdc.gov/ncidod/diseases/hepatitis/index.htm](http://www.cdc.gov/ncidod/diseases/hepatitis/index.htm)

Food and Drug Administration

[www.fda.gov](http://www.fda.gov)

Hepatitis C Society of Canada

[www.hepatitiscsociety.com/home.htm](http://www.hepatitiscsociety.com/home.htm)

Hepatitis Foundation International

[www.hepfi.org](http://www.hepfi.org)

Italian Liver Foundation

[www.dfc.unifi.it/ilf/eng-home.htm](http://www.dfc.unifi.it/ilf/eng-home.htm)

National Business Coalition on Health

[www.nbch.org](http://www.nbch.org)National Council on Patient Information  
& Education[www.talkaboutrx.org/select.html](http://www.talkaboutrx.org/select.html)

National Foundation for Depressive Illness

[www.depression.org](http://www.depression.org)

National Institutes of Health

[www.nih.gov](http://www.nih.gov)National Center for Complementary and  
Alternative Medicine<http://nccam.nih.gov>National Institute of Diabetes and Digestive  
and Kidney Diseases[www.niddk.nih.gov/index.htm](http://www.niddk.nih.gov/index.htm)

National Library of Medicine

[www.nlm.nih.gov](http://www.nlm.nih.gov)

National Network for Immunization Information

[www.immunizationinfo.org](http://www.immunizationinfo.org)

United European Gastroenterology Federation

[www.uegf.org](http://www.uegf.org)

Viral Hepatitis Prevention Board

[www.vhpb.org](http://www.vhpb.org)

World Health Organization

[www.who.int/health\\_topics/hepatitis/en](http://www.who.int/health_topics/hepatitis/en)



**General Health Information**

Dr. C. Everett Koop's Web Site	<a href="http://www.drkoop.com">www.drkoop.com</a>
Healing Well	<a href="http://www.healingwell.com">www.healingwell.com</a>
Health Finder	<a href="http://www.healthfinder.gov">www.healthfinder.gov</a>
Health Touch Online for Better Health	<a href="http://www.healthtouch.com/level1/menu.htm">www.healthtouch.com/level1/menu.htm</a>
Life Saving Alternatives to Blood Transfusions	<a href="http://www.noblood.org">www.noblood.org</a>
United Network for Organ Sharing (UNOS)	<a href="http://www.unos.org">www.unos.org</a>

**Clinical Trials**

Center Watch	<a href="http://www.centerwatch.com">www.centerwatch.com</a>
Clinical Trials Registry	<a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a>
Veritas Medicine	<a href="http://www.veritasmedicine.com">www.veritasmedicine.com</a>

**Travel Information**

CDC Healthy Travel Information	<a href="http://www.cdc.gov/travel/index.htm">www.cdc.gov/travel/index.htm</a>
WORLD Traveler Hepatitis Information	<a href="http://www.travelsafely.com">www.travelsafely.com</a>

**Pharmaceutical/Pharmacy**

Chiron Corporation	<a href="http://www.chiron.com">www.chiron.com</a>
Fujisawa Healthcare, Inc.	<a href="http://www.fujisawa.com">www.fujisawa.com</a>
Glaxo Smith Kline	<a href="http://www.gsk.com">www.gsk.com</a>
Home Access Health (home test kit for Hep C)	<a href="http://www.homeaccess.com">www.homeaccess.com</a>
Idenix Pharmaceutical	<a href="http://www.novirio.com">www.novirio.com</a>
Intermune	<a href="http://www.intermune.com">www.intermune.com</a>
Merck	<a href="http://www.merck.com">www.merck.com</a>
Priority Healthcare	<a href="http://www.hepatitisneighborhood.com">www.hepatitisneighborhood.com</a>
Priority Healthcare Corporation	<a href="http://www.priorityhealthcare.com">www.priorityhealthcare.com</a>
Rebetron Combination Therapy	<a href="http://www.rebetron.com">www.rebetron.com</a>
Roche	<a href="http://www.rocheusa.com">www.rocheusa.com</a>
Roche-HIV	<a href="http://www.roche-hiv.com/front.cfm">www.roche-hiv.com/front.cfm</a>
Schering	<a href="http://www.beincharge.com">www.beincharge.com</a>
Walgreens Specialty Care	<a href="http://www.walgreens.com">www.walgreens.com</a>

**Mental Health**

Center for Mental Health Services	<a href="http://www.mentalhealth.org">www.mentalhealth.org</a>
Mental Help Net	<a href="http://www.mentalhelp.net">www.mentalhelp.net</a>

**Exercise and Fitness**

Health and Fitness Tips	<a href="http://www.health-fitness-tips.com">www.health-fitness-tips.com</a>
Hepatitis Neighborhood	<a href="http://www.hepatitisneighborhood.com">www.hepatitisneighborhood.com</a>
Centers for Disease Control and Prevention	<a href="http://www.cdc.gov">www.cdc.gov</a>
Hep C Connection 1-800-522-4372	<a href="http://www.hepc-connection.org">www.hepc-connection.org</a>
American Liver Foundation	<a href="http://www.liverfoundation.org">www.liverfoundation.org</a>
Nursing Center	<a href="http://www.nursingcenter.com">www.nursingcenter.com</a>
Hepatitis Foundation International 1-800-891-0707	<a href="http://www.hepfi.org">www.hepfi.org</a>



## Organizations

### ***Alcoholics Anonymous***

#### ***World Services***

475 Riverside Drive, 11th Floor  
New York, NY 10115  
Tel 212-870-3400

Contact to find a support group for alcoholics in your area.

### ***American Digestive Health Foundation***

7910 Woodmont Ave., Suite 700  
Bethesda, MD 20814  
Tel 301-654-2635  
Fax 301-654-1140

### ***American Gastroenterological Association***

4930 Del Ray Ave.  
Bethesda, MD 20814  
Tel 301-654-2055  
Fax 301-652-3890

### ***American Liver Foundation***

75 Maiden Lane  
Suite #603  
New York, NY 10038  
1-800-GO-LIVER (465-4837); Jackie Spencer  
is the VA contact at ext. 134  
1-888-4HEP-USA (443-7872)  
Tel 212-668-1000  
Fax 212-483-8179  
info@liverfoundation.org

### ***Hep C Connection***

1714 Poplar St.  
Denver, CO 80220  
Tel 303-393-9395  
Fax 303-393-9358

### ***HEP C Foundation***

1502 Russett Drive  
Warminster, PA 18974  
Tel 215-672-2606  
Fax 215-672-1518

### ***Hepatitis Education Project***

4603 Aurora Ave N.  
Seattle, WA 98103  
Tel 206-732-0311  
www.hepeducation.org

### ***Hepatitis Foundation International***

30 Sunrise Terrace  
Cedar Grove, NJ 07009  
Tel 1-800-891-0707  
Fax 973-857-5044

### ***Society of Gastroenterology Nurses and Associates***

401 North Michigan Ave.  
Chicago, IL 60611-4267  
Tel 1-800-245-7462  
Fax 312-527-6658

### ***Local Support Groups***

[Insert your local support groups here]

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## Suggested Reading

Dolan, Matthew. *The Hepatitis C Handbook*. Catalyst Press, 1997.

Everson, G. and H. Weinberg. *Living with Hepatitis C: A Survivors' Guide*. Hatherleigh Press, 1998.

*Hepatitis Management and Treatment, A Practical Guide for Patients, Family and Friends* (magazine).

Maddrey, Willis C., M.D., and Eugene R. Schiff, M.D. eds. *The Hepatitis Workbook. A Guide to Living with Chronic Hepatitis B and C*. Schering Corporation, 2001.

National Family Caregivers Association, *The Resourceful Caregiver*. Mosby Lifeline, 1996.

Pollin, Irene. *Taking Charge: Overcoming the Challenges of Long-Term Illness*. MSW, and Susan K. Golant, Times Books, 1994.

Stolman, Marc D. *A Guide to Legal Rights for People with Disabilities*. Demos Publications, 1994.

White, Barbara J. and Edward J. Madara. *The Self-Help Source Book*. Northwest Covenant Medical Center, 1995.



## About VA Programs in Hepatitis C

The Department of Veterans Affairs (VA) leads the country in hepatitis C screening, testing, treatment, research, and prevention. VA is the largest single provider of medical care to people with hepatitis C infection in the United States.

The National Hepatitis C Program works to ensure that veterans with or at risk for hepatitis C receive the highest quality health care services from the VA system. Led by the VA's Public Health Strategic Health Care Group (PHSHG) and carried out by VA medical facilities across the country, the hepatitis C program has a comprehensive approach to hepatitis C prevention and treatment that includes screening, testing and counseling, patient and provider education, optimal clinical care, and management of data to continuously improve program quality.

The Hepatitis C Resource Centers (HCRCs), a part of the National Hepatitis C Program, develop best practices in clinical care delivery, patient education, provider education, prevention, and program evaluation that can be used by the entire VA health care system and other medical care systems. They function as field-based clinical laboratories for the development, testing, evaluation, and dissemination of new and innovative products and services for improving the quality of hepatitis C clinical care and education in every VA medical facility.

VA provides extensive information on hepatitis C for health care providers, veterans and their families, and the public at [www.va.gov/hepatitisc](http://www.va.gov/hepatitisc).

## User Feedback Form

The Hepatitis C Resource Center would like to hear from you about this edition of *Initiating and Maintaining a Hepatitis C Support Group: A "How-To" Program Guide*. To share your opinions, please complete this tear-out tri-fold page, fold it, and drop it in the mail. Your answers will be used to inform development of future editions of this guide. Thank you!

**1. Overall, how useful did you find this guide?**

- Very useful                       Somewhat useful                       Not at all useful

**2. Did you find this guide to be:**

- a. Well organized?                       Yes                       No

If No, why not? \_\_\_\_\_  
\_\_\_\_\_

- b. Easy to read?                       Yes                       No

If No, why not? \_\_\_\_\_  
\_\_\_\_\_

- c. Up-to-date?                       Yes                       No

If No, why not? \_\_\_\_\_  
\_\_\_\_\_

**3. Would you recommend this guide to other health care providers?**                       Yes                       No

**4. Which sections did you find most useful? Why?** \_\_\_\_\_  
\_\_\_\_\_

**5. What additional information would you like to have included in the guide?** \_\_\_\_\_  
\_\_\_\_\_

**6. What sections do you think should be left out of the guide?** \_\_\_\_\_  
\_\_\_\_\_

**7. Were there parts you thought were inaccurate? If so, please suggest changes:** \_\_\_\_\_  
\_\_\_\_\_

**8. How could this guide be improved?** \_\_\_\_\_  
\_\_\_\_\_

**9. What is your occupation?** \_\_\_\_\_

**10. Is there someone at your VA who would use this guide to start an HCV support group?**

- Yes, me                       Yes, someone else                       No, nobody



You may keep your responses anonymous, but if you would not mind possibly being contacted by the HCRC for followup, would you please provide the following? Name: \_\_\_\_\_ Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

**11. After reading the guide, how prepared do you feel to start your own HCV support group?**

- Very prepared       Somewhat prepared       Not at all prepared

**12. What are the barriers to starting an HCV support group in your facility?**

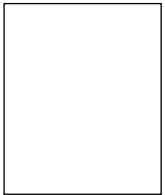
- No staff       No time       Hard to identify patients/get referrals  
 Other: \_\_\_\_\_

**13. If there were someone at the HCRC to consult with on starting or running an HCV support group, would you contact him/her?**

- Yes       No

Thank you for your time!

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\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



*Northwest Hepatitis C Resource Center  
VA Puget Sound Health Care System  
1660 S. Columbian Way (S-152-HCRC)  
Seattle, WA 98018*

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[www.va.gov/hepatitisc](http://www.va.gov/hepatitisc)



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