

HEPATITIS C

PEER SUPPORT GROUP MANUAL

For people living with hepatitis C
or hepatitis C- HIV co-infection,
family and friends affected by HCV,
and staff of AIDS service organizations
and community health centres



Knowing helps.

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Adapted from a longer Hepatitis C support group manual available for download at www.hcvadvocate.org.

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Why do a peer support group?

Peer support can play an important role for people living with hepatitis C (HCV) infection, including those with HIV-HCV co-infection. People need a lot of support during HCV treatment for example, because the side effects of the interferon-based medications can change the way we think, feel and behave. In addition to the necessary support from a doctor or hepatitis C nurse, peer support can really help someone coping with the physical, mental and mood changes that result from treatment.

Peer support can help reduce depression and fear. It can help you understand what is happening to your body and to develop positive ways to deal with emotions and changes. Peer members of the group who have already been through treatment can be good advisors. They “have been there too” and can empathize and relate. Peer support breaks down isolation and helps to link people to needed resources.

Currently, there is a critical shortage of peer support groups for people living with HCV and HCV/HIV co-infection in Canada. As more people get tested and diagnosed and begin to think about and start treatment, the need for support will grow. A person living with HCV must make daily decisions about a lot of different issues. A peer support group is one way to get advice and information to help you successfully live with the disease.

How does a peer group differ from a therapy group?

A peer group is not a substitute for a therapy group. A therapy group is led by a professional therapist who is trained to guide people through difficult emotional issues. A peer-led group is usually led by someone who is not professionally trained, but who has knowledge of the issues at hand, and some skills in leading the group. People can often find emotional support that is therapeutic and helpful in a peer support group.

The goals of a peer support group

A peer support group is a safe place to discuss:

- treatment options, treatment side effects
- stigma and discrimination
- harm reduction
- feelings of isolation
- depression
- physical, mental health and addictions issues
- coping mechanisms
- disclosure
- the capacity to heal mentally, physically and spiritually
- educational and prevention information and support service referrals

Why do *you* want to start a support group?

It is important to understand why you want to start a support group. Is it to get your own needs met, or is it to help yourself as well as others? You want to make sure your own needs do get met, but you can't let them get in the way of keeping the group going. You have to be able to put your issues to one side for the benefit of the entire group.

You need to ask yourself:

- Am I biased in any way, about how HCV is transmitted for instance?
- Am I open to talk about any topic?
- Can I accept all members regardless of their background?

Choosing a facilitator: What qualities does the effective peer support group facilitator have?

The effective facilitator:

- Must be a good listener and be able to reflect back to the group to make sure there is clarity and understanding of the issue at hand in order to promote discussion, insight, possible solutions and referrals.
- Looks for similarities and patterns of thoughts and behaviors, individually and collectively.
- Exhibits a non-judgmental attitude and unconditional acceptance, while recognizing individual strengths.

- Makes sure that everyone gets the chance to express themselves, that they are heard, and are supported.
- Demonstrates it is not important how we got hepatitis C (HCV) or HCV/HIV co-infection, we are all unique yet we share more in common than differences. It is important that the peer group facilitator encourages group members agree to this, so people are not judged and factions don't develop within the group (i.e., "IDU" versus "tainted blood").
- Must be honest and open to sharing his or her own knowledge and experience as appropriate, which helps to develop trust and group free-flow.
- Is able to help the group set some boundaries, then maintain them and control emotional involvement and responses.
- Maintains clear rules for confidentiality, stressing that group is a safe place for dealing with emotional issues and that what is said in group, stays in group; breaches of confidentiality or trust will not be tolerated.
- Should be aware of his or her own strengths and weaknesses and be resourceful.
- Encourages members to try new ways of feeling, thinking and behaving that are positive.
- Must be able to deal with potential conflicts and manage them. Must be present in the moment, open-minded, compassionate, energetic and positive. An important skill is to be observant to verbal and non-verbal language (vocal intonations, facial expressions and body language).
- Doesn't try to be an expert on hepatitis C but rather serves as a resource so the group as a whole gains a basic understanding of the disease and how it affects us. Knows when to refer group members to medical or health-care professionals.
- Knows when to tap into resources such as service providers, AIDS service organizations and community health centres to help with specific issues. Group members themselves may be very knowledgeable about resources (e.g., food banks, location and hours of operation of addiction centres, drop-ins, clothing and meal programs, and self-help programs at community health centres.)

Do you need a co-facilitator?

It can seem daunting for one person to take on the responsibility for facilitating a support group, especially if it's a large one. Finding a co-facilitator makes the job easier. Make sure the two of you are a good fit, with skills that suit each other's strengths and weaknesses. Co-facilitators:

- Can share responsibilities
- Provide support for each other
- Can intervene if things seem “stuck” or assist when potential conflict arises
- Allow for team work for breakout exercises.
- Can provide mutual feedback and review

Types of peer support groups

Almost all peer 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. Here are some different types of support groups.

Drop-in Meetings:

- Important for people who need to receive emotional support and education especially during a time of crisis.
- People who attend these meetings may also be seeking to learn more about community resources and information about other types of meetings and support groups.

Informational (Educational) Meetings:

- For people who want to learn more about Hepatitis C in general or a specific topic.
- This format suits people who want to educate themselves and meet other people living with hepatitis C but who may not be comfortable talking about very personal issues with others.
- Even though the main focus is educational, such groups also provide an element of emotional support as there are others attending the meeting with similar interests, fears and questions who may share personal experiences or feelings.

Emotional Support Group Meetings:

- Explores all aspects of hepatitis C and this type of group helps people to really connect with other people living with hepatitis C.
- It is more personal and intense in nature and brings up many issues and feelings. Facilitators must be able to manage emotional intensity, assist personally, and know when to refer people to another resource.

Who, what, where: Next steps

Location

Deciding where your meetings will take place is a very important decision. People must feel safe and comfortable. Try to find a meeting space close to public transit with parking if possible. Space can be found at hospitals, community health centres, churches, schools or other public buildings. Community health centres are a good choice as group members may have access to other services such as mental health and/or addictions help, prior to or after the group.

The meeting room

The room for regular meetings should be private, appropriate in size for the group, and have good lighting and ventilation. Comfortable chairs are important as people living with hepatitis C and HCV/HIV can have fatigue, and muscle and joint pain. Seating can be theatre/classroom for informational groups (you can also use a U format), or in a circle format for emotional support groups.

Beverages and food

Sharing food is a good way to help members feel more comfortable and can help people with food issues (hard time cooking or eating, poor appetite). Having water available to drink is very important to those with HCV, HCV/HIV and for those on treatment. Group fundraising activities, asking for donations, potlucks, asking for support from non-profit agencies, churches or pharmaceutical companies are possible funding options for food and beverages.

Membership in the group

Now you know where your group will meet, how will you determine who will join?

- **Group size:** The size of the group will depend on the type of group you want to start, the size of the meeting room, support group members expectations and the goal of the support group. For an emotional support group, you may want to limit the size to six to 10. Having too many members will make the experience impersonal and it will be hard to meet member's expectations to have the time to talk about their issues and having their needs met.

For an informational meeting it may be beneficial to have a larger size since members are there to learn more about hepatitis C in general or specific topics from a speaker rather than from other group members.

- **Recruitment:** Create an ad or flyer that clearly and concisely explains what the group is about and its format. State whether the group will be open or closed, time-limited or on-going.

Encourage and engage interest in the support group by stating what will be covered and the benefits of support. Clearly state times, date and location of the meetings. Distribute to doctor's offices, treatment nurses, community health centres, hepatitis C organizations, local public health, ASOs and local media.

- *Interview potential members:* The facilitator may need to see if a member is a good fit for the group and that he or she can emotionally handle information, issues and feelings of others. It is up to the facilitator what type of group it is — for the newly diagnosed group, dealing with end-stage, a group that is on treatment, or a blend — but members need to be sensitive to differing levels of knowledge, emotional and cultural responses in all groups.

The first meeting

The purpose of the first meeting is for group members to:

- get acquainted
- clarify personal goals and group goals
- learn the procedures to be used in group (the ground rules, see below)
- learn how the group will function and how to get the most from the experience and
- discuss the possible dangers or risks involved in participating in group and how to minimize these risks.
- discuss confidentiality and limits of confidentiality

The preliminary meeting allows people to have a clear understanding of group goals and group interactions and whether they would like to become group members.

Setting ground rules for a support group

Ground rules must be developed and agreed to by all members in the group. It is one of the most important steps to take before the first meeting. Ground rules help to make sure meetings are not chaotic and help members feel safe enough to talk about personal issues or offer advice to others. Draft a ground rule list, discuss reasons for the ground rules, and ask members to comment. Members may have additional rules or changes to the ones you suggest. After a discussion of the rules, they should be adopted by all members of group. If group members take part in building the ground rules, they are more likely to follow them later. Common ground rules include:

- Confidentiality: What is said inside the group stays in the support group.
- Respect: Show respect for other members with differing views, sexual orientation, or cultural differences.
- Aggressive behavior: Verbal or physical violence is not allowed.
- Punctuality: Arrive on time.

- Doctor bashing: Don't let people go on at length about problems with their doctor; it can make other members feel uneasy about their own treatment.
- Civility: Give everyone a chance to speak, to be heard and to be supported. Don't interrupt or monopolize the conversation.
- Keep discussion in the first person – always use “I” or “me” statements.
- Negativity: Try not to focus only on the negative.

Setting goals

Members and leaders must set goals for themselves, both at the first meeting and at each session for maximum learning to occur. Asking members to tell one another about their specific goals, about why they want to be in group and writing it down helps to focus members on their goals, thoughts, feelings, emotions and behaviors they wish to change.

How to structure the meeting

Some people with hepatitis C find they tire easily, so it's important not to have meetings that go on too long. Normally an hour and a half works best for groups. Other thoughts:

- A “health break” halfway through is recommended but it should be short so that any issues brought up in group before break can be resumed with little effort.
- It is important that the length of time agreed by members be followed, that meetings always start and finish on time, as a matter of respect to all members.
- Any decision to run late must be agreed to by the entire group. The facilitator and other members can choose to stay late to talk with a member who needs additional support.

It is also important to decide if the group is ongoing or time-limited. Time-limited has some advantages in that members know the start and end date; this works well for members who do not want to commit to a support group over an extended period of time. Time-limited groups also allow facilitators to see if they are suited to running a support group before they start an ongoing group. An ongoing group is good for those looking for long-term support, but it is harder to sustain/maintain.

Providing educational materials

- Having information about hepatitis C enables people to make a wide variety of decisions about their health, as an active participant in their health care. If you do provide educational information, be sure it is reliable and up-to-date.
- If you are giving people information sheets, etc., with links to Internet sites, remember that not everyone has access to the Internet, or knows how to use it.

Overcoming common problems

Problems can occur in any group. For example, a member repeatedly shows up late for support group meetings; someone talks too long at check-in; someone monopolizes the conversation; or there may be a group member who frequently makes comments or ask questions only to the facilitator. Silent moments, a completely silent member, dealing with incorrect information, inappropriate jokes, anger, crying and side talk all pose challenges to the facilitator and to the group.

Take heart that trouble is generally infrequent. Here are some facilitator tips for overcoming problems with group dynamics.

- Refer to the ground rules when appropriate. Ground rules should help you avoid or handle most of the problems that can occur.
- Have the group develop and agree to new ground rules if a situation regularly occurs that isn't covered by your original set.
- 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 refocusing the group.
- Talk about how we are affected in a personal way by these behaviours, and say that being honest, sensitive, caring and respectful of others is of utmost importance.

Remember that the entire group is responsible for maintaining the harmony of the support group—not just the facilitator.

Sample support group format

- *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 two to three minutes, but should not last longer than five 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 peer facilitator may also introduce a question into the general check-in such as: “When you check-in, please describe how you are feeling.” (Encourage members to go beyond using “Fine” or other 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 should be discussed at each meeting. You may want to arrange for a speaker to come to group.
- *Ending the Group: (10 minutes)*
It is important that each member be able to bring closure to the group meeting. Allow about five to ten 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, (i.e., Serenity Prayer, silent meditation).

Additional Resources

Here are a few websites with useful information on hepatitis C:

www.hepcinfo.ca

CATIE Hepatitis C website

www.hcvadvocate.org

Hepatitis C Support Project

www.dieticians.ca

Dieticians of Canada

www.liver.ca/files/Brochures/Eng_Hep_C_WEB_revised_Sep_08.pdf

Canadian Liver Foundation

www.hemophilia.ca

Canadian Hemophilia Society

www.phac-aspc.gc.ca/hepc/

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