



# HCSP FACT SHEET

HCV ADVOCATE

• HCV EDUCATION AND SUPPORT •

## Finding a Support Group

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### Foreword

Many people with hepatitis C feel isolated and find it difficult to cope with living with a chronic illness such as HCV. Family and friends can be a great source of comfort and support, but support from people who have faced some of the same fears and challenges can be crucial in helping people understand, manage and live successfully with hepatitis C.

A support group can offer a place to explore the emotional and practical issues of living with hepatitis C in a safe and nurturing environment. In addition, the information shared by peer members can be helpful in making decisions about a wide variety of HCV-related issues, such as stigma, disclosure, disease management and medical treatment options. Family members may also need help and support when they learn that a loved one has a potentially life-threatening disease, and in coping with and supporting a loved one undergoing HCV medical treatment.

Many HCV peer-led support groups have emerged to address the need for support and education in the hepatitis C population. In addition, many of the people who have come together in support groups have been the same individuals who have emerged as HCV advocates/activists.

Support groups can be divided into two basic types: informational (or educational) and emotional, although most support groups provide aspects of both, but will focus on one area or the other. Informational support group meetings typically have a lecture format that includes a guest speaker. In emotional based support groups people typically discuss many of the emotional issues of living with hepatitis C.

A wide variety of people seek out and attend support group meetings:

- People who have been recently diagnosed with HCV are usually interested in educating themselves about the disease and talking to other people living with chronic hepatitis C.

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

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## Finding a Support Group

- Hepatitis C is a highly stigmatized disease and for some people a group is a “safe” place where they can talk and seek advice from people who have gone through or faced some of the same issues that other people with hepatitis C face.
- People considering HCV therapy can receive help with their decision-making process and talk with others about what to expect and how to prepare for treatment.
- People currently undergoing HCV therapy can receive emotional support and learn coping strategies to help them deal with the physical and psychological treatment-related side effects.
- People with symptomatic HCV can benefit from the emotional support and the chance to discuss the various issues that surround living with a chronic illness, as well as the strategies to help manage some of the common symptoms of hepatitis C.

Support groups are usually, but not always, led by hepatitis C positive people who have not been professionally trained as therapists or counselors. It is very important that people seeking a support group explore different groups to find well informed facilitators and to make sure that they are a “good fit” with the group.

The first step is finding a support group. Get recommendations from HCV positive friends and acquaintances, healthcare providers, and agencies that work with people living with HCV and the internet. The HCV Advocate Web site ([www.hcvadvocate.org](http://www.hcvadvocate.org)) has a national support group listing that is regularly updated. (See Resources)

Unfortunately, some people may not have access to a support group in their area. These people may find internet resources, online HCV email lists or discussion groups beneficial. You can also check the local paper or call one of the organizations listed at the end of this fact sheet for referrals to support groups. If possible talk with the support group leader. This will help you

to decide whether an initial visit is warranted.

Some questions to ask:

- Is the support group facilitator knowledgeable about hepatitis C?
- What is the typical size of the support group?
- Is the support group leader a healthcare provider or is the group linked to a healthcare advisor?
- What is the focus of the group?
- Are there ground rules that everyone agrees to follow?
- Who usually attends the meetings? Is the group geared to one particular aspect, such as treatment, or primarily focused on one population?
- When does the support group meet?
- How often and at what time does the group meet?
- Is this a strictly emotionally focused group or are there informational meetings?
- Does the support group feature speakers? If so, how frequently?
- Are there membership fees or dues?
- Is the support group held in an area that is considered safe?
- Are family members/friends allowed to attend the group?
- How is confidentiality dealt with?

If you are able to talk with someone “live” before sitting in on a support group you should also use your gut reaction. Is the person warm and fuzzy? Is the person too warm and fuzzy? It is pretty easy to tell after a couple of minutes if the support group leader is conducting a group that you would like to attend. However, the best advice would be to ask if you could “sit-in” on one meeting.

Once you have a chance to attend the group meeting, ask yourself the following questions:

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- Is the information and emotional support unbiased?
  - How is the tone of the group – is it positive and upbeat?
  - Is the group leader able to “leave” his or her ego at the door?
  - Is the information just about treatment or does it include a broader range of topics?
  - Is the atmosphere of the group a place where you would feel comfortable and safe to talk about personal issues?
  - Does the facilitator keep the group discussion moving?
  - Does the facilitator allow time for all group members to talk?
  - Are the group’s members open-minded and non-judgmental?
- Did you feel supported by the other group members?

This list of questions is by no means exhaustive, and once you get started you will probably think of more specific questions to ask.

Write down notes and questions that came up for you during the group session. Talk briefly with the support group facilitator or other members after the meeting about any issues or concerns that you may have. If you do not find that the group is a good fit for you, try another support group, or, even better yet, start your own support group. If you are interested in starting a support group, please check out our *Support Group Manual* (2 parts—*Handbook & Lessons*), which can be downloaded at [www.hcvadvocate.org/community/Groups.asp](http://www.hcvadvocate.org/community/Groups.asp)

### *Related publications:*

- **Hepatitis C Support Group Handbook**  
[www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Support\\_Group\\_Handbook.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Support_Group_Handbook.pdf)
- **Hepatitis C Support Group Lessons**  
[www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Support\\_Group\\_Lessons.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Support_Group_Lessons.pdf)
- **HCV Advocate Support Group Locator**  
[http://linux.hcvadvocate.org/cgi-bin/sg\\_lookup1.cgi](http://linux.hcvadvocate.org/cgi-bin/sg_lookup1.cgi)

### *For more information*

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| <ul style="list-style-type: none"> <li>• <b>HealthPro</b><br/><a href="http://www.healthpro.us/maps/index.htm">www.healthpro.us/maps/index.htm</a></li> <li>• <b>Hep C Connection</b><br/><a href="http://www.hepc-connection.org">www.hepc-connection.org</a></li> </ul> | <ul style="list-style-type: none"> <li>• <b>Hepatitis Foundation International</b><br/><a href="http://www.hepfi.org">www.hepfi.org</a></li> <li>• <b>HepCBC</b><br/><a href="http://hepcbc.ca/">http://hepcbc.ca/</a></li> </ul> |
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