

SUPPORT GROUPS

Getting the Help You Need

When facing a severe, long-term illness like chronic viral hepatitis, nothing is more essential than friends and family who can provide the help, feedback and support families with medical needs require.

That much-needed support may come from a local community group or from people across the country or around the world who face a similar situation. Communication can be through newsletters, e-mail and phone calls.

This support group, which can be as small as two, may interact formally or informally to provide mutual support to those coping with medical issues, relationship issues, feelings of isolation and discrimination.

Support groups can be organized by hospitals or medical centers, or by not-for-profit agencies that focus on family and child welfare issues, chronic illness or foster care and adoption services.

It is important that caregivers also find a friend, a group or an e-mail list that can be a sounding board and resource for those coping with a chronic infectious disease. Here are some things to consider when organizing or choosing a support group.

How Are Support Groups Structured?

There is no one support group structure or model that is best. A support group can be organized by a medical institution, a not-for-profit agency or an organization that focuses on family issues. They can also evolve informally through contacts made between individuals, parents and friends.

The organizational structures of support groups can be broken down into five general categories:

- Facility-based, on-site groups meet regularly at a set location and are led by a trained leader, therapist or facilitator.
- Informal on-site groups meet regularly but lack a trained, designated leader.

- Not-for-profit organization support groups put members into contact with each other and most communication between participants is by phone, personal visits, newsletter or e-mail.
- “Virtual” groups allow people to communicate by an e-mail list or other formats to share information and support.
- “Virtual” duet groups are actually just two members participating.

Each organizer chooses the format, structure and ground rules (such as absolute confidentiality) that meet the needs of the group.

Facility-Based Support Groups

Each support system structure has its strengths and weaknesses. Facility-based support groups come in two flavors: formal and informal.

Formally-facilitated, on-site support groups have a facilitator, a set agenda and a pre-determined time line. Both facilitated group structures offer an excellent starting point for those new to the issues of viral hepatitis.

It is the job of the facilitator—who may be a professional social worker, medical professional or psychotherapist—to make sure all critical issues are addressed, even if they are tough issues to talk about.

It is not uncommon for serious or unpleasant subjects to be overlooked or bypassed in less formal groups because no individual is responsible for raising all critical issues that revolve around this disease.

Also, a professionally-facilitated group will not be adversely impacted by strong personalities that may negatively disrupt or affect the group. It is the job of the facilitator to skillfully keep those individuals in-check so group communication is not hindered. Facilitators ensure all members are heard and keep meetings within appropriate parameters.

In established, facilitated groups, members know what to expect. Facilitators make sure all members are heard and can keep meetings within appropriate parameters. Facilitators, who have educational and experiential information and may even have medical training, can offer both therapeutic and emotional support.

Facilitators can also set and enforce criteria for group membership. For example, they may require that there be a diagnosis of hepatitis B or C in the family and enforce a group commitment to confidentiality.

Facilitators are also effective if the support group is made up of children or teens who need information and direction from professionals.

On the downside, these groups can be difficult to implement and maintain. Interpersonal dynamics, individual agendas and different levels of knowledge and experience among members can be a problem.

There may not be enough potential members within a reasonable geographic area to sustain a group. Experts say six to eight members are optimal so there are enough people to share communication but not so many people to limit verbal participation.

There may be substantial costs involved to cover the price of a facilitator, meeting space and on-site daycare. Consistency, due to irregular attendance and higher than expected discomfort levels, can be a problem.

As with all groups, it may be difficult to find a day and time that works for everyone. Preparation work is more important to facilitation-based groups than it is for more relaxed formats.

A typical support group may include a mental health counselor or psychotherapist whose practice focuses on children, plus six to eight parents who are looking for support and strategies to help them deal with their children's infectious disease.

It is also common to find support groups led by people who may lack medical training (for example, school counselors) but who can help children and their parents deal with emotional challenges surrounding hepatitis issues.

In this group, the facilitator is critical. It's important to select a facilitator who can run the group in a comfortable and productive way. An uncomfortable group is an unproductive group. A facilitator should have a reputation for caring, compassion, self-awareness, authenticity, acceptance of clients and strong observational and communication skills.

The facilitator also needs to understand and accept his or her role. The group facilitator has several "housekeeping" tasks to perform. He or she must start the group on time, promote attendance, develop and enforce the "ground rules," mediate conflicts, help the

group stay focused, ensure that all members have an opportunity to participate fully, and summarize at the end of each meeting.

If the facilitator is a trained therapist, he or she may provide medical or counseling support and help build positive group dynamics. A group succeeds or fails based on the comfort level members have with the facilitator.

Informal On-Site Support Group

Informal support groups work without a formal facilitator and can operate with or without set agendas. These groups are often offered free to participants and have the advantage of flexibility.

Participants can change subjects or meeting length at a moment's notice. The group isn't tethered to the schedule of an individual facilitator, so the group can easily meet in a member's home. The group's informal ambiance makes it easier for members to join or leave based on personal needs.

There is no hierarchy within this group, as there is with a facilitator and group. Group members have a sense of control and group ownership. Given that all of the members are personally dealing with similar health issues, there can be a very strong sense of community, empathy and acceptance.

Unfortunately, informal groups have several drawbacks. Like the formal support group, there must be enough participants to make the group robust, and there must be a shared commitment to meet at the set time. The less formal structure may lead to a more casual attitude toward confidentiality and the group's needs.

It helps if the group has similar issues, either ages of children or ages of participants. In addition, without a facilitator to objectively manage the meetings or provide formal therapeutic services, it is possible for those with strong personalities to overrun the less verbal members.

Informal on-site groups often develop when doctors who specialize in helping children who have hepatitis encourage their patients to meet and talk.

The key to a successful non-facilitated group is a comfortable, supportive and consistent atmosphere. The group should meet every week or every other week because the more its members see each other, the more comfortable they become working and communicating together.

A 90-minute meeting is optimal. Any shorter and the group won't have time to address all of its issues; any longer and the meeting will drag. Always begin and end on schedule. Keep the group relatively small so that there is enough time for everyone to talk but not so much time that members feel pressure to “perform.”

Support Groups Run by Not-for-Profit Agencies

Not-for-profit organizations can provide individuals and families with substantial educational, emotional, and experiential support. Their assistance and guidance is usually free to those who need it. They also often have board members who are specialists and experts in a particular issue or disease.

These organizations may have national offices as well as state affiliates or chapters, newsletters and websites through which they share information and expertise.

Through their websites, they may offer online support through e-mail lists or chat communities. Many, however, do not have the resources to maintain expensive online programs. In an attempt to protect their members' privacy and prevent their exploitation, they may match potential support group members on a more personal basis.

Most have a privacy policy that governs the “who, what, when, where, why and hows” of helping potential support group members connect.

Not-for-profit organizations often have extensive libraries, non-financial resources, and contacts. Many publish regular newsletters and offer members an opportunity to ask questions, exchange ideas, join networks and learn about medical breakthroughs.

Unfortunately, these organizations often lack the resources to address every individual's needs in a continuous one-on-one way. Sometimes the best they can do is match potential support group members with appropriate, ongoing groups or “partners.”

Non-profit organizations are easily located online or through the Encyclopedia of Associations.

Support groups organized by not-for-profit organizations have challenges uniquely their own. Most don't actually run support groups. What they do is connect individuals who become support partners. These non-profits have a tremendous responsibility to their potential group members not to “play fast and loose” with member anonymity.

Before matching potential support group members, the non-profit organization must

develop policies for participation.

- What qualifies a person as a potential support partner?
- How should potential members be matched? Age of the patient, how long people have known about their diagnosis, medical knowledge, drug therapy if any, and severity of medical condition should all be considered.
- What are support partners supposed to do?
- What are the ground rules if people want to connect with each other beyond the meeting time?
- How should the non-profit organization screen for unscrupulous individuals who would take financial or psychological advantage of patients and their families?

Different non-profit organizations will answer these questions differently. The important thing is that these issues be acknowledged and addressed so members know what the ground rules are before they become emotionally invested in the group.

“Virtual” Internet Support Groups

Virtual groups include Internet chat rooms with immediate comment and response capabilities, Internet bulletin boards that allow for messages, comments, and/or questions to be posted online for months. They also include e-mail lists where members post e-mails that immediately are sent to all subscribers.

A virtual forum can support people around the world without requiring their “physical” presence. Members of these virtual communities can reach a wide variety of people who are also touched by hepatitis.

It may be impossible for people to find others within their own local community who are experiencing the same hepatitis-related issues, such as whom to tell or not tell. But online, they can connect with a large number of people who have a wide range of personal and medical experiences with hepatitis that they're willing to share. Group members don't need to wait until a scheduled meeting or until there are enough people to run a meeting.

The relative anonymity of virtual groups can also create a higher comfort level than face-to-face support groups. The access costs tend to be low (although, of course, there

remains a large portion of the population that does not have easy access to the Internet).

Often, people within a community can contact members with whom they share similar experiences and bonds so they can develop deeper relationships either through e-mails or in person through phone calls and face-to-face visits.

The major drawback of virtual groups is that for many people, a virtual community doesn't feel like a real flesh-and-blood community. A human smile isn't easily replaced with a :-) symbol in an e-mail.

The media often run stories of people who use online systems to misrepresent themselves or to take advantage of others. Once online, what most participants would consider confidential information can be made available to the entire online world.

Many people who need support are already in a vulnerable position. Unscrupulous online support group members can take advantage of that vulnerability.

The biggest challenge for online support groups is to find a technology and venue that supports, rather than thwarts, support.

Chat rooms, for example, offer “real-time” support but what kind of support does a parent really get when he/she goes online and there is nobody else there?

Billboards (which allow participants to post messages and check back for responses) also may not provide support when it's needed most. E-mail lists, which allow group participants to mass e-mail other members, can appear impersonal given the wide distribution of a member's e-mail.

Finally, unless the virtual input is monitored, Internet sites can create a smorgasbord for those who would take further advantage of people with hepatitis. Any facilitator who chooses an Internet media to provide group support must keep track of what goes on online.

Virtual “Duet” Support

This support group structure is the most humane. Sometimes two individuals in similar circumstances develop a strong relationship. They contact each other on a regular basis or whenever they need assistance. They may have found each other through a virtual community or they may have connected through a not-for-profit or formal organization.

The “support partner” structure is very popular among people with viral hepatitis who may feel different from, or marginalized by, uneducated, prejudiced or judgmental people around them.

The support partner structure provides easy, if not immediate, access. Help is often only a phone call or an e-mail away. There is no expensive group infrastructure. Dealing one-on-one with another human who is grappling with the same issues creates an environment of empathy and connection. It's not a peer relationship—it's a friendship.

That doesn't mean the structure is challenge-free. A match that works well today may not work well tomorrow. Partner A may move through grieving stages more quickly than Partner B. This can cause frustration on the part of Partner A and resentment on the part of Partner B.

One parent may be farther along in learning about or dealing with disease issues and may be putting more into the relationship than the other partner. When there are only two people involved in a support group, it is difficult to maintain enough objectivity to see when the relationship itself is a “negative growth” factor.

An individual or family member who is coping with the stresses of hepatitis may not be able to provide a high level of emotional support to someone else.

Each individual will have a need for different levels of support and even different types of support groups over the history of the disease. The goal is to find the support that helps the most today.