HOW TO START A NEW ONLINE COMPUTER MUTUAL HELP GROUP

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ABSTRACT

The increased availability of lower cost computers and the Internet is making it possible for needed new types of mutual aid self-help groups to now develop online. Many of these groups were previously unavailable in the community as traditional face-to-face groups. For those interested in starting such a computer-aided mutual help group, or helping others to develop one, here are some suggestions for more easily doing it. These ideas can also be used by existing traditional self-help group organizations interested in expanding their outreach online.

A recent Harris research poll of more than one thousand Americans found that the Internet health sites, which they most often visited online for health information, were created either by medical societies or "by patients' advocacy or support groups" (*Washington Post,* February 16, 1999). The vast majority of national and international self-help organizations in the United States are already available through Internet Web sites or e-mail addresses. But many more self-help support groups, especially for those persons with rare illnesses and more severe disabilities, can be started by taking advantage of the free tools and opportunities available on the Internet.

If you would like to have an "online" group where your members can share their experiences, strengths, and hopes from their homes or work places, you can do it in four primary ways:

1. using a *message board and/or a chat room at a Web site;*
2. using a *forum or chat room on a commercial service,* like America Online or Prodigy;
3. developing an *e-mail discussion group or "listserv";* and/or
4. developing a *newsgroup.*

First, on an online "message board" people can post, respond to, and check for new messages twenty-four-hours-a-day. Messages are posted under a specific subject or question and, with their replies, are organized as "message threads." In a "chat" or conference, people participate all at the same "real time," usually a scheduled day and hour, just like a "real world" group meeting. While newcomers usually romanticize about having real-time "chat" meetings, our experience has been that message boards are much better, richer, and more helpful. People often take time working on their responses to posted questions. One can therefore think of message threads as self-help support groups run in slower but usually more thoughtful motion than in the "real time" chat meetings. Much more "mutual help" is shared online through message boards than in real-time chat meetings.

HAVING A FREE MESSAGE BOARD AND/OR CHAT ROOM BY PIGGYBACKING ON AN EXISTING WEB SITE

If you're looking for a place on the Internet for your members to help one another, there are several Web sites that offer interactive message boards and sometimes real-time chat capabilities to existing self-help support groups and networks. A key advantage to having your meetings on the Internet, rather than being limited to only one commercial service (like America Online), is that your meetings would be available to everyone worldwide who has online access. If you think you (or your group) can handle it, you could develop an online group presence on one (or more) of the following Internet forums.

Community-Support.Com

(http://www.support-group.com) is a Web site with over 150 Support Link areas dealing with a wide variety of specific illnesses and problems. Each Support Link area has a bulletin board, related Web site links and related Internet resources, a section for "Local Support Groups & Organizations," and more. Real-time online chats are also available. The Sysops (system operators) are Archie and Annette Hensley in Florida, who provide this Web site as a public service. First look over their Web site carefully. Then, if you would like them to consider starting a new section for you and your group to run, e-mail them with your request. They expect that you will monitor the messages regularly, and that you will add related Web sites to any special section that you start. Support-Group.Com has a high volume of traffic. But, like any other site that you establish, traffic to your area will depend largely upon: your group's having a Web

site that refers people to Support-Group.Com; and your mentioning the site in your promotional material posted to other related sites and databases.

drkoop.com

Under guiding principles established by Dr. C. Everett Koop, drkoop.com encourages everyone to take control of their own health through knowledge and connection with others. They have sixteen message boards under topics like physical conditions, parenting and children's health, addiction and recovery, mental health, women's health, men's health, and aging healthy. Health chat rooms are also available, where currently more than 100 chat groups meet on a weekly basis. Preregistration is required to gain access. After visiting drkoop.com's Interactive Communities, if you have a question or need help in starting a group, e-mail their Online Help Manager (feedback@drkoop.com).

Association of Cancer Online Resources

(www.acor.org) is a non-profit patient/family-run organization that provides over seventy-five online support groups (mostly e-mail discussion groups) related to different forms of cancer and non-malignant tumors, both for the patients and their caregivers. They also help those seeking to start and run a needed new online support group for any type of cancer or tumor disorder for which there is no existing online group. If you are so willing, contact founder Gilles Frydman (gilles@dorsai.org).

Mental Health Net Forums

(http://forums.mentalhelp.net) has over twenty password-protected (pre-registration required) message sections and chat rooms (e.g., anger, borderline, multiple personality disorder, self-mutilation, etc.). So if there is no online group for your mental health concern, e-mail webmaster Mark Dombeck (mark@cmhc.com) and indicate your interest in working on the creation of a new forum here.

Neurology WebForums at Mass. General Hospital

(http://neuro-www.mgh.harvard.edu/forum/) If your group or support network deals with a neurological condition, this is a good place to have discussion on message boards, with chat areas available in their linked Web site. This is where Mass. General Hospital's John Lester has 110 different topical forum message boards. E-mail him if you would like to see a forum named for your condition, but remember that it must be related to neurology. Similar neurology-related message boards are available on Med Help International in the Cleveland Clinic Neurology Forum (http://medhelp.net) hosted there.

Rare Genetic Diseases in Children

(http://mcrcr2.med.nyu.edu/murphp01/homenew.htm) was developed by parent Paul Murphy and sponsored by NYU Medical Center and has "Gateway Kiosk" moderated message board forums, to include a "Support Group Forum." It is not set up with disease-specific forums, but illness-specific message headings.

If none of the above are acceptable to you, you can search the Internet to find Web sites that deal with your group's issue. Some concerns may already have a message board, and "webmasters" of others may be willing to help you and your support group by adding one.

ARRANGING FOR SUPPORT GROUP MEETINGS
ON THE COMMERCIAL SERVICES

Many online message boards and "real time" meetings are hosted on the commercial services (like on CompuServe, America Online, Prodigy, etc.) where it is easy for paid members to use message boards and/or meet in "conference" or "chat" at scheduled times. Usually the chat meetings take place at a particular preset weeknight or weekend time. But, as we mentioned at the start, you should consider a good interactive message board to meet your needs. So . . .

1. Check to see "Is there already a message section for your concern?" Ed Isenberg, who started the Chronic Fatigue section on CompuServe, suggests that you first send e-mail to the specific "Sysop" (Systems Operator) of the Forum(s) most appropriate to your issue. For example, on CompuServe, there's the Health & Fitness Forum and the Chronic Illness Forum. On America Online, there's the Better Health Forum for most illnesses. Introduce yourself to the Sysop and ask what area of that Forum is most appropriate for your issue. The Sysop might suggest using a particular section until you have enough critical mass to warrant a section of your own (as determined by the Sysop).

2. If no section exists for your concern, find an appropriate forum and just begin by posting a new message, asking a question or requesting others with similar experience respond, and making your concern real clear in the subject title that you give. This hopefully will begin a "message thread" relevant to your illness/ concern to which people will reply. With time, add more questions, news, and resources.

3. If you're with an existing self-help organization that doesn't have a message section or scheduled chat on the commercial service you use, consider asking your national organization to place a short item in their national newsletter, describing your interest and asking if others who use that commercial service are interested in exchanging experiences and ideas on-line (be sure to include your e-mail address).

4. When you desire to have an actual online conference, attend one or two other online conferences to learn how they are run (with a facilitator who keeps track of whose turn it is to speak). In conference, people usually request to comment by

typing "!" or indicate they have a question by typing a "?". Then they are recognized by the facilitator, in turn.

5. A good way to initially attract people to an online conference is to have a guest speaker. If you have a particular guest in mind who doesn't subscribe to that particular commercial service, you would have to find someone who does and who lives near the guest and would be willing to help host the speaker. Arrange for (and confirm) the speaker well in advance, and make the Forum Sysop aware of your efforts. Ask the Forum Sysop if a forum announcement could be made of your conference. Post a message that describes the guest speaker's background, the subject of the presentation, and its importance.

6. Another way to plan an online conference is simply to invite other Forum members to participate. Ask them what discussion topics interest them most. Once you have five or more people, set a tentative date for the online conference, e.g., possibly a Sunday afternoon, say at about 3 PM Eastern. Then, consider posting messages in related Forums to publicize your first and subsequent meetings.

7. For message sections and conferences, constantly try to recruit others interested in helping you to develop your online group activities. If you try to do this just by yourself, you very well will be setting yourself up for burnout down the line. Indicate to others that this is something you cannot do alone— but if they are willing to help, you can do this together, e.g., taking responsibility for responding to the messages of others on the topic.

Tom L, who started CompuServe's "Mental Health Forum," offers the following advice: "Rome was not built in a day. For frequently asked questions about your topic, create a Library file so that you can send folks who display interest to it. Include information about your online activities. Be patient, and realize that it is the constancy of messaging that gathers a group together. Be willing to show support and concern for other forum members who share the same needs as yourself, and they can perhaps offer you information on how to cope in a particular situation. Don't argue with folks who are born to argue. You are there for sharing, and hoping, and to educate on your topic. Arguing doesn't help the cause, even if you are trying to prove a point. Remain welcoming, and nonjudgmental. Be demonstrative, and exhibit by your messaging how you feel."

DEVELOPING AN E-MAIL DISCUSSION GROUP

E-mail discussion groups, sometimes referred to as mailing lists or listservs, were previously much more difficult to create and run. However, a few Web sites are beginning to host mailing lists, making it simple to develop and run these discussion groups. For example, a good site for developing an e-mail discussion group is Onelist at www.onelist.com. There one can create a free listserv for any issue. While these mailing list hosting sites are free, there may be advertising that may appear at some time in the future on those sites in order to finance the free hosting services.

DEVELOPING A NEWSGROUP

To review a listing of the many newsgroups that already exist and are primarily related to self-help group concerns, see the directory of over 200 maintained by psychologist John Grohol at his "Psych Central" Web site http://psychcentral.com/news.htm. Newsgroups are not always as easy to access as other forms of online groups. This is because not all local Internet service provider companies, which people pay for their Internet access, carry all newsgroups. Often a particular newsgroup has to be requested before an Internet service provider will carry it. For comprehensive guidelines on how to develop a newsgroup, as well as suggestions on developing an e-mail discussion group, read Dr. Grohol's guidelines located at: http://psychcentral.com/howto. htm.

OPPORTUNITIES FOR EXISTING SELF-HELP GROUP ORGANIZATIONS TO SURVEY THEIR MEMBERS AND CONDUCT ONLINE OUTREACH

One helpful strategy, for existing self-help organizations planning their online presence, is to survey their existing members in order to find out: how many members of their self-help group are already online; what commercial services (CompuServe, America Online, Prodigy, etc.) and Internet resources (Web sites, listservs, or newsgroups) they use; if they know of any members who are computer resource people or "techies" willing to help with an Internet site or activity; and if they would be interested in being a group representative on any of the commercial or other online locations. A questionnaire might find that a few members are both: already using related Web sites, listservs, or newsgroups for their support; and that these members might be willing to spread the word about your group's work at these "online outposts."

If your organization uses one of the commercial services, another idea is tapping into the "Refer a friend, and get a rebate" offers that these services provide. Your group's account could be credited for free time on most services, if you pass on to the service the names and addresses of potential new service members interested in opening an account. It seems to make sense that any members interested in getting online, request it through a member who is already online.

OBTAINING A WEB PAGE FOR AN EXISTING SELF-HELP GROUP

If you are starting or have already started any new type of national or international support network, operating "in the real world" as it is referred to online, an Internet Web page will be an extremely valuable way of people finding information on your group. Most of the existing national and international self-help organizations now have Web pages on the Internet and are reporting increased referrals

as a result. At a minimum, you could simply arrange to have a Web site with brief text that doesn't need much upkeep at all. You could even just have your flyer retyped onto the Web site, so that people on the Internet could find out about your network when they did a search. You can also add to it a printable member application form, so people could mail in their membership application. If you have an online meeting place, you could refer people to its location on your Web site, too.

To develop a Web Page page for your support groups/network, you have a number of options. First, the Internet Service Provider (ISP) that you personally use for your Internet access may already offer you a free Web site with your account (some ISPs will permit you to use your personal Web page for a support organization, however many will charge you higher "corporate" Web site hosting prices; in either case, you still have to learn how to build a Web page yourself).

Second, some smaller self-help organizations have found individuals who volunteer to simply put up a simple Web page for free. This can be through a member who works in a high-tech computer job, or even at a university, e.g., Claire Patterson who started the Trigeminal Neuralgia Association had a physician whom she met at a conference offer to do one for her on his university's server. Faculty at a local university could therefore be approached and asked.

Similarly, you could seek to develop a partnership with one of the larger online information providers, who would be willing to develop and maintain a Web site for you on their existing computer "server." For example, one non-profit organization, Med Help International, has provided basic home pages for a number of national and international self-help support groups for very little cost.

Lisa Carroccio, who heads the international Children's Liver Alliance, suggests that some self-help groups could consider forming alliances with other related groups or non-profit organizations to share in the costs of the development, maintenance, and hosting of a multi-group Web site. Several non-profit organizations, including her Alliance, the WorldTransplant Fund, and the American Share Foundation, came together to form the American Share Coalition on Transplantation (http://www.asf.org/). In this informal coalition, organizations retain their separate identities and purpose while dividing Web site costs equally. Coalition members all have separate Web pages within one Web site, yet provide links to the other coalition members' sites, thus increasing their individual Web site traffic.

An increasing popular way of having a Web site and online mutual support is to simply add a message board to any Web site you already have. This requires you, your ISP, or a technical support person helping you to build it. You also will need to recruit online group co-leaders to monitor, respond, and help you run it on usually a daily basis.

One example of a message board on a Web site is the "Totally Hip Support Group" (http://www.totallyhip.org—click on "bulletin board" for message forum) started by Linda May Bowser, who has had two hip surgeries, and her "hippie" friends. With technical help, a number of groups also place and archive

their newsletters on their Web site, e.g., Vickie Machado (http://ourworld. compuserve.com/homepages/kawasaki) who started the Kawasaki (Disease) Families' Network.

If you develop your own Web site, be sure to add a disclaimer to it. Almost all Web sites have one, e.g., "While many find the information and experiences that we share helpful, it is in no way a substitute for professional medical care. Our support network does not engage in the practice of medicine. In all cases, we recommend that you consult your own physician regarding any course of treatment or medicine."

FEEDBACK APPRECIATED

Finally, our American Clearinghouse (www.selfhelpgroups.org) would be interested in learning about other strategies or resources that groups and supportive professionals have found helpful. Experiences and questions, sent by e-mail or traditional "snail-mail" postage, are most welcome.

Direct reprint requests to:

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