

Obsessive Compulsive Foundation, Inc.

Compulsive Hoarding Website

Online Self-Help Support Groups for OCD Hoarders

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Are you thinking about starting an online support group for hoarders and/or clutterers, or perhaps friends and family? Three online support group "list-owners" share their experiences.

We began our three online support groups for OCD hoarders each out of a desire to work directly with others in our own personal quests for recovery. Each of us recognized that within the isolation of our homes, we weren't reaching our personal goal of a cleared home.

By reaching out to others just like ourselves we changed our own lives in the process.

We would like to encourage others to establish online Support Groups to meet their own needs as well as to provide vital services to the larger OCD community. We have some tips that might help ease the way if you've considered starting a list of your own.

Our own three groups are serviced by "Yahoo!Groups" -- <http://groups.yahoo.com/> -- a free, user-friendly outlet. We have three "sister lists" that each fulfill a different need for their members:

- **Paula hosts H-C (Hoarding-Cluttering)** at <http://health.groups.yahoo.com/group/H-C/>, which is the longest running and largest of the three groups. This is the "launch pad" for those who just learned that they have something called "OCD" or "hoarding." This is where recovery begins for most of us, because there's a bounty of information to help the newly-diagnosed to learn about hoarding and what they can do to help themselves.
- **Doris leads Dehoarding-Goals** at <http://health.groups.yahoo.com/group/Dehoarding-Goals/>. This list was organized for H-C members who were more adept at setting goals and following through on them. There is less "chit-chat" due to less of a need to learn how to unclutter and dehoard. This Group is geared to setting and reporting on monthly goals ... and has direct professional involvement.
- **Phyllis is the manager of Post It-Boast It**, recognized as "Pi-Bi," the newest of the three lists at <http://health.groups.yahoo.com/group/Pi-Bi/>. This list focuses not only on setting goals for dehoarding, but also gets into the "how-to" of housekeeping, healthy lifestyles, and anything else of interest to its members; things affecting them in their uncluttering and dehoarding efforts. Members borrow ideas from professional organizing lists such as "FlyLady" and "Get Organized Now" to help in their efforts to meet the ultimate goal of an uncluttered home, mind, and life. (NOTE: Active membership on H-C is a prerequisite to joining Pi-Bi.)

All of these group have self-imposed membership limitations, which help to make management of the group and meeting the individual "specialties" of each group work well for the members.

There is also a need for different groups about hoarding to meet other needs, especially those of parents and family members of hoarders.

Hint: Here is a link to the OCD groups that are already in existence:

<http://groups.yahoo.com/group/OCDSupportGroups/links>

As more and more people become aware of hoarding, there will be a need for additional basic lists such as H-C.

Based on our experience, we offer some important recommendations to be considered when starting a new group:

- It is essential that the list be professionally assisted by a practicing psychologist and/or medical doctor who fully understands and treats people with OCD and hoarding difficulties. The professionals connected to the list do not need to read each post, but must be available to be called upon to respond to questions/issues that arise.
- The list-owner needs to decide the focus of the group, membership limitations, and what information will be available to the members. List rules must be decided upon and enforced evenly and fairly.
- The above point is important because confidentiality, anonymity (use of aliases), and a feeling of being in a safe place are very important to maintain. This confidentiality and anonymity is also met by having a private list with postings that do not show up in search engines.
- Utilization of files, links, archived messages, literature, polls, etc. are important so that there is some continuity, especially for new members. By having this type of information available on the list Website, independence and self-help can be encouraged.
- Our experience to date shows that required, regular postings by all members -- one post per month minimum -- keeps people engaged and allows members to know who is among them. By prohibiting lurkers and encouraging participation, a sense of family and friendship develops that is difficult "off-list" (a.k.a. outside of the group) because of the isolation that many hoarders experience.
- Novices can learn the ropes of setting up an online group in a short time, thanks to organized groups of fellow list-owners such as the excellent Email List-Managers, found at: <http://groups.yahoo.com/group/EmailList-Managers/>.
- We are also involved in a smaller group of list-owners, whose focus is strictly OCD, called "OCDSupportGroups," at <http://health.groups.yahoo.com/group/OCDSupportGroups/>.

Many of us within the OCD community have chosen "Yahoo!Groups" to host our lists because they are free and fairly user-friendly, but there are other services as well, such as "Topica," "Smartgroups," or listservs such as "Lyris," "Mailman" or "Majordomo."

After you decide which service to host your list, you'll want to consider how to customize the settings. There are many decisions to make regarding the way your list is set up. In "Yahoo!Groups" you can click on the "help" button, which will give you some answers to questions you may have.

- Will you have open or closed membership? Membership must be carefully considered for any list to be successful. Spammers love open membership and so do lurkers. Our personal recommendation for any list that concentrates on compulsive hoarding is to have a restricted membership to help provide the type of safe, secure environment that will benefit the members.
- Do you want information on your list publicly accessible, or will it be for members only? We recommend that you keep the message archive, files, links section, polls and database, in other words, all but the Homepage, closed to all but members.

If you want members to feel safe to post, you will need to make the conditions as comfortable and risk-free as possible. Our experience with our own members is that they do not want their posts to show up in any search engine, nor do they want anyone other than fellow members to have access to them. They want to know the other list members, so having a database or files with member's introductions is helpful.

- Will attachments be allowed or rejected? By disallowing attachments, the risk for viruses is diminished. Yahoo will not archive attachments to messages, so if it is important enough to be said, either put the information into the email message, or provide a link where the information can be accessed.

We would like to recommend that you establish your list and become comfortable with the settings before you open the list up to active memberships. Once your list gets going, there will be a lot of activity that will take a lot of your attention, so take the time in the early stages to get comfortable with the set-up. This pre-membership time will also allow you time to fine tune the links and files, which will be a resource for your members.

For those of us who had neither qualified, trained professionals to turn to, or did not have the resources to access the professional help that is available in our home areas, having an on-line Support Group that focuses on our difficulties, has been the answer for us.

It takes time and effort to manage an on-line group, but the results are well worth it.

Countless people, who have nowhere else to turn, may be the beneficiaries of the opportunity that you provide for them to find information, help, and support in their own recovery or in helping loved ones to recover from hoarding. We wish you luck and hope to have you join us in our efforts to help people recover from this disorder.