

## **Starting and Maintaining a Support Group**

by Jennifer Raikes

I host a weekly support group in Manhattan which I started with three friends, and the help of TLC, five years ago. We meet in my apartment for an hour and a half on Tuesday evenings. Usually, about six or seven people attend each week, out of approximately 25-30 current members. This article was written to accompany a workshop I gave at TLC's 2001 Conference.

### **Why Start a Support Group?**

To answer that question, I asked some of the members of my New York City support group why they come to meetings. I hope their answers (which are attached) will inspire you to start a group in your area. I believe that support groups can be helpful in every aspect of recovering from trich from reducing our pulling behavior to the most important goal: feeling happier.

On the most practical level, the group is a great source of information about trich resources. We share opinions about doctors, hairdressers, trich "toys," medications, and relaxation techniques. We also help to keep each other aware of our recovery goals and cheer each other on.

The experience of being in a successful support group is much deeper than anything concrete that we do for each other. Some of it comes instantly - the immediate relief of connection - but most of the benefit grows with time and intimacy. Not every meeting is upbeat, but the overall process is joyous.

Between 2-4% of people have trichotillomania. So however alone we feel, we are in fact surrounded by fellow hairpullers. If you would benefit from the experience and encouragement of other people who are living with trich, it is entirely possible to get yourself that help by starting a support group.

### **Getting Started**

#### **Assess Your Own Readiness To Start A Group**

What are your expectations for the support group?

How do you hope to benefit?

How will it affect you if the group does not meet your expectations?

Are you likely to move soon?

Are you coping with high levels of stress at the moment?

How much time do you have to devote to it?

#### **Choose a Time, Place and Format**

##### **Time**

As the person who is putting forth the energy to start and maintain the group, it is vital that you pick a time (and place) that fits your own schedule. You may want some input from other

potential group members, but it will be impossible to please everyone - so don't make this a democratic decision.

#### Place

There are many options of places to hold support groups. Local hospitals, libraries, churches, dance studios, or community centers may all have rooms they will lend or rent out for a small fee. Another choice is to hold the meeting at your home (or rotate meetings between the homes of various group members.) There are pros and cons to each choice. It might be more comfortable and convenient for you to hold the meeting at your home, but will you be concerned about the safety of inviting in strangers? Other issues to consider in choosing a location are: privacy, allergies, and accessibility.

Format (Once we're all together, what do we do?)

Attached is the outline of a basic format suggested by TLC. Our New York City group follows this structure with some variations. There are infinite possibilities for how to structure your meetings, and you will likely adjust the format as the group develops.

A few choices to consider:

- How often should the group meet?
- Should this be a therapist-led group or a peer group? (Or some combination - perhaps a local therapist would like to lead the group once a month with peer-led meetings between?)
- Do you want to follow a 12-step approach? Utilize self-help tools such as the two books "Help For Hairpullers" or "The Hairpulling Habit and You"?
- Is the group restricted to people with trich or are friends and family members welcome at meetings?
- Is it for adults or children or both?
- Are both men and women welcome?
- Is the meeting open to new members? Is consistent attendance required?

If there are any expenses involved in running the group, you'll need to decide how to collect donations to cover those costs.

Again, if you are the primary force in starting this group, it is important that it meet your own basic needs or you will burn out quickly.

#### Get In Touch With Other Pullers

Initial contact: About a month before you want to hold your first meeting, draft a letter stating the time, place and date of the initial meeting, and how to reach you for more information. TLC will mail this letter to everyone from your area who has ever contacted TLC for information.

Also consider posting flyers on community bulletin boards or a small advertisement in a local paper. Some people have even gone on local television news programs. Continue to keep in touch with TLC about your group. We publish information in the newsletter and on our website

letting members know about local support groups.

How will support group members continue to get information about meetings?

A phone message? E-mail? I chose to set up a voicemail number for our support group, so that I wouldn't have to give out my home phone number. Each week I leave a message and members call the number to find out where the meeting is happening and to let me know that they'll be attending. We also have an "e-group" e-mail account so that those of us with computers can write to each other during the week.

### **Maintaining the group**

#### **Support**

Keeping a support group going is a challenge - but a rewarding one. The group is a relationship between people who may be very different, despite this important problem we share. We are at various stages of recovery (or lack thereof!). These differences can make it difficult to meet everyone's needs. But in my experience, they also make the group richer by providing diverse perspectives.

The general attitude should be one of support for each other. That may sound obvious, but it is very common to feel a need to justify our pain by minimizing that of others. Often we've come to group after years of pulling, and our suffering may not have been taken very seriously in the past. Many of us want to say, "My pulling is so much worse than yours!" It is important to remember that we can't measure the pain of trichotillomania by the quantity of hair lost. Everyone at a support group meeting has chosen to give up their free time to be there. That says a lot about what we've all been through.

#### **Persistence**

There is no one recipe for how to make a group work. But persistence is a key ingredient, especially if you are starting the group alone. There may be many meetings at which attendance is disappointing. I know that I've often been the only person to show up for the meeting. (Those were occasions when I was very glad I'd chosen to host the meetings at my own home.) Group members who seem committed may stop attending without a goodbye. I have found that attendance at meetings ebbs and flows mysteriously. But it has always revived after a short while. New members join and old ones re-surface.

#### **Communication**

As with all relationships, open communication is necessary. That's obviously true for conversations about trich. But it is also necessary to be able to discuss issues about the group itself. This can be socially awkward. For example: "I am not getting what I need from this group because too much of our attention is focused on one member's problems." Or "I feel that the tone of our conversations has become too negative." It is tempting to remain silent or quit group rather than talk about problems openly. As the host of a group, I ask you to please speak up. There may be other members who have noticed the same problem. You are responsible for creating the group you want, or at least giving it your best effort.

Positive comments and new ideas are also important. Ideas like, "I'd like to find a way to support each other more actively between meetings." Or "Let's have a meeting where we invite our friends and family."

### **Individual Therapy**

We all have problems in addition to our trichotillomania. Sometimes these are important to share at a meeting because they impact our pulling. But it can be very difficult when other problems dominate group discussion. The support group can do a lot of great things, but it is not intended to solve all problems or substitute for individual therapy or medical attention when it is needed. It may be important to urge members who exhibit signs of depression, or other problems, to seek help outside of the group setting.

### **Stick to a Schedule**

Have a scheduled start and end time and stick to it (at least approximately.) This will avoid a lot of frustration. Even when the meeting is going great, people need to get home to their families (or beds) at a reliable time.

### **Kick Start**

Finally, every now and then, the group may need a kick start. Should things stagnate or you lose motivation, it may help to hold a brainstorming meeting to select discussion topics for the meetings. Or arrange for guest speakers, or organize a special event. Some events we've held in New York over the years include: a picnic for members and their friends and families, a knitting lesson, talks by doctors who treat trichotillomania, and a hypnosis session.

### **What Does the Support Group Do For Me?**

#### **Voices of the New York City Trichotillomania Support Group**

I have found being part of our support group helpful on many levels. I think the most important thing it does for me is it operates as a kind of statement to myself that I'm committed to working on this problem. One of my biggest challenges historically with my hair (and, I think, with other problems in my life generally) is that I tend to minimize it and ignore it, kind of pretend it isn't there and it doesn't bother me. But, of course, it is there and it bothers me ENORMOUSLY. By setting aside one evening a week to devote to my hair, I'm committing myself to work on this problem. Whether I succeed in being "pull-free" or not, the group gives me a supportive environment where I can acknowledge and try to work on this problem. And that has been very, very helpful to me.

Also, our group helps my attitude towards myself as a puller. Before I knew others who pulled, I felt pretty bad about myself. I sort of ruled out ever feeling totally attractive because of the pulling. I stared at people's hair longingly, kind of hopelessly, knowing (or believing) that I could never have it, so I'd never be totally attractive. I think I feel generally a lot better about myself since being part of our group. Although I still feel worse about myself when I'm going through a bad pulling spree, it is very helpful to have the group to act as a sounding board, and to

let all those horrible feelings of insecurity and unattractiveness out.

Also, I think its helpful to look around and see all the wonderful, beautiful women (and men!) in our group and know that you guys are all struggling with the same thing. It puts things into perspective, and helps me realize that I should not judge myself because of my pulling.

Finally, I really think that the group helps my ability to control my pulling. When I hear positive stories about people doing well, it makes me very hopeful. And the more hopeful I am, the more energy I seem to have to put on the bandaids, "talk" my hand down from my hair when it goes up there, etc. So the idea that it IS possible to get this condition under control, that it will not necessarily always be in control of me, really helps me motivate to stop. I wish I had that motivation from within, but I'm coming to realize that it seems to come from you guys!

Catharine, NYC

This is a response from a very tired trichotillomaniac, but I'll try to pass on a few thoughts about why it's worthwhile to be in a support group. I'm not alone. I can talk about what I've been unable to speak to others about almost my whole life without shame or fear. I've learned to not hate myself for my trich and to be kinder to myself. I've learned a lot about trich and about myself. I like my peers and enjoy your company. The group gives me hope and support (such a cliché!! for a support group!!!!) The group has helped me thru a lot of hard times in the recent past. Speaking about my past, the group has provided me with a venue to talk about its horror and to move it from a cerebral experience to a feeling one. It has given me the vision that the rest of my life does not have to be plagued by the impact of this past.

Marian, NYC

I can't explain the feeling that one has when they are able to get together every Tues with people who know about your secret. Finally, able to talk freely about hairpulling, knowing that everyone in that room knows how you feel. Realizing that you can be completely honest. For me, being honest is really helping with the healing process. I know when I talk about hair pulling to non-pullers, I am more superficial. Sometimes, just keeping a secret (meaning the pulling) makes matters worse.

Then when you tell someone it is healing.

For me, just knowing that I am going to be with people who pull every Tues. is healing for me. Just to sit in the same room. To know that these people are struggling just like me and we are going to talk about it. You don't have to pretend everything is OK, because if I am pulling, everything is not OK.

Caroline, NYC

To be a part of a support group enables me to hear thoughts that had been running through my

head come to life through the expression of others. With no pressure of having to talk if you don't want to. It makes me feel less alone. Just knowing you are not alone makes it all worthwhile. But it is also a great place to share information, remedies, stories and advice.

Margot, NYC

Being part of a support group is a freeing experience for me. For the hour and a half I'm there, I no longer feel ashamed about my lack of hair. I know that for that time no one is judging me based on the amount of hair I have or don't have. I no longer feel scrutinized, under the microscope by people who don't know or understand what it is to pull their own hair. I feel part of a group, something larger than myself. There's a definite sense of comradery and acceptance.

Corrina, NYC

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## Opening Statement for Support Groups

This format is what we use at TLC in our support groups. It is suggestive only, and can be recopied and adapted however you like. Note that although it is compulsive hair pulling that has brought us together, the format addresses eventually becoming free of compulsive behaviors in general.

Instead of using the format below, some groups choose to follow a 12-step format. Or, your group may choose to use "The Hair Pulling 'Habit' and You" book as a workbook to follow. Whatever format you choose, remember that as groups change and evolve over time, their needs may also change, and the format of your group may need to be adapted accordingly. Good Luck!

Welcome to the \_\_\_\_\_ group. This group is based on the process used by the Trichotillomania Learning Center to assist in the healing from the effects of compulsive hair pulling in our lives. Donations are accepted with gratitude, and applied toward operating expenses. There is no financial obligation to participate as a member of the group. You have paid the price of admission with your life experience, which brings us together. As with 12-step meetings, what is said here tonight is confidential, and should not be discussed outside the meeting. This is a safe and non-judgmental place in which to explore and heal, and one of the major goals of the group is to assist each individual in moving beyond compulsive behavior when they are ready.

The format of the meeting is this. First each of us will check in. This is done with absolutely no cross talk, and should take no longer than 3-5 minutes per person. Listen to what is being said. The archetypal voice of trichotillomania is expressing itself through each of our lives, and we are here to honor the need, heal the wound, and grow each according to our own destiny, learning to live in balance with the forces of life. After the sharing, the meeting is opened up to become a discussion group. Remember, the goal is not confrontation but support. It is important to remember that many, many tiny changes over time, add up to transformation, so keep the focus of the meeting on willingness to change. It is the responsibility of group members to stay in the present, keep discussion on themselves, and help the group stay focused on issues of recovery.