Guidelines for Starting & Maintaining a Peer Support Group

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For more information please visit:

www.canadianBFRB.org

www.bfrb.org

DISCLAIMER:

Please keep in mind these guidelines are suggestions from CBSN & TLC based on years of experience assisting peer support groups to grow and thrive. CBSN & TLC cannot be responsible for the management of peer support groups, but we will work with you as a team to promote your group and will share information to assist you in the organizing process. Peer support groups are intended to provide motivation, education and a supportive community. They are not intended as therapy or treatment for BFRBs or any mental health disorder. Neither TLC, CBSN, nor peer support group leaders are able to provide medical or psychotherapeutic advice or treatment.

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Message from CBSN's Founder

First of all, I would like to thank you for taking the time and having the interest to start a BFRB support group in your local town/city. So many of us have been "stuck in the closet," or hiding these disorders from our own family and friends for years. At one point or another, we all feel as if we are the only ones in the entire world dealing with whatever is going on in our lives. It's the same idea with BFRBs, but most of the time it's multiplied by the fact that we literally are the only ones known in our circle of friends or family who picks at our skin or pull our hair.

I have been pulling my hair since the age of 13 and before 2013, I had NEVER met another person who did the same thing. The first person I ever met with trichotillomania/dermatillomania was a member who showed up to the first ever support group meeting at my house in Toronto. I cannot even begin to explain what an amazing experience it was to finally talk to someone about hair pulling, and have someone understand COMPLETELY without needing to explain in detail. It was such an empowering experience; I knew I had to make support groups available to more Canadians, but HOW was the question. And this is why CBSN has been developed. CBSN believes Peer Support is one of the greatest resources to help isolated individuals deal with their BFRBs.

Even if only one person shows up to a meeting, they still need the support. Personally, what I have found is that you will find that Peer Support is not for everyone. Don't lose faith if someone shows up one week, and not the next. They may return months from now, or they may have things going on that prohibits them attending right now. This is why updating members about times/dates/location ahead of time is extremely important.

You might be thinking, "How can I possibly lead a support group? I have no experience?" Well I am here to tell you that you don't need to have special education or take a course to become a Peer Support leader! All it takes is passion and commitment to make a difference in your life and the lives of others who have a BFRB. Most of the time your *job*, as the group organizer or "leader" is to do some of the following:

- Being the first and last one at the meeting to welcome both existing and new members

- Managing and being in charge of your email account: responding/ contacting people on your group's behalf, including reporting back to CBSN and/or TLC once in a while
- Having to open/close meetings on time – or you can pass this responsibility off as more members attend frequently
- Gathering contact information (names, emails, phone numbers) if your Peer Support members want to connect in between emails
- Arranging a Carpooling List (if applicable)
- Keeping conversation on topic, sometimes cutting in if someone is not sharing the talking time appropriately
- Keeping members up to date on CBSN and/or TLC news or memos

Don't get discouraged by all of these tasks. You will meet other group members who will share the passion to help your Peer Support Group run as best as it can and you can then delegate tasks to share.

Sincerely,

Sarah Robertson,
CBSN Founder

Message from TLC's Executive Director

Dear Friend,

For many of us coping with Body-Focused Repetitive Behaviors (BFRBs), they are a deeply isolating experience. Finding community with other people going through similar struggles is healing in many ways. I credit my own participation in a weekly peer support group with a big role in my recovery, and the *maintenance* of that recovery, from trichotillomania.

The experience of sharing a laugh or a cry with people who really understand was invaluable to me. Getting to know the other wonderful people living with BFRBs made me more sympathetic to my own struggle – less self-critical. And yet the accountability that came with those weekly check-ins to my peers also made me more self-aware (or mindful) of my BFRB behavior, and more motivated to make changes. I learned hundreds of tools and techniques to help resist or prevent my urges. I grew to love the other members of my group – and I cherish many friendships that still endure, twenty years later.

We hope this document helps you get started as a peer support group leader. TLC & CBSN offer many additional programs to support *you* throughout the experience. It can certainly be challenging at times to lead a group – but having done it myself weekly for a decade, I can tell you it was well worth the effort.

I encourage you to give it a try!

With love,

Jennifer Raikes,

Executive Director

The TLC Foundation for Body-Focused Repetitive Behaviors

A. How to START a BFRB Support Group

Starting a successful support group for BFRBs takes passion, commitment and dedication. At first it may seem like you are not reaching out to all the people you can, but in time your group will grow! Not every meeting will have large numbers of members attending, but it is still important to remember why you wanted to start the support group in the first place. Living with a BFRB can be lonely, confusing and frustrating. Having a support group to go to is an outlet for anyone who has questions, needs support, wants to learn different ways to cope, or just wants to meet other people who have BFRBs. By organizing these meetings, you will help not only yourself, but also dozens of people just like you who haven't had anywhere to turn. CBSN & TLC are here to support you at every stage of running a support group - just reach out and we will be there!

The 7 Basic Steps

Every step of the way, contact CBSN or TLC if you have any questions! We can help with any questions or concerns you might have. Email TLC at info@trich.org or call 831-457-1004. Contact CBSN at sarah@canadianbfrb.org

Step 1: Assess Your Readiness

- 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?

A successful support group requires holding consistent meetings, especially at the start. You should be ready to commit to hosting the group on a regular basis – whether weekly, biweekly or monthly - for at least six months until the group takes hold and you find additional participants to share responsibility.

Step 2: Choose a Format for the Group

There are infinite possibilities for how to structure your meetings, and you will likely adjust the format as the group develops. But before you can invite others to join the group, you need to make a few basic decisions.

As with picking the time/location, you need to make choices that work for *you*. If these choices don't meet your own needs, then you will lose motivation to continue leading it – which won't be good for anyone!

Here are some of the things you will want to take into consideration when deciding the group's format:

Who is the group for?

- Ages of the attendees – adult only, parent only, children only, mixed age?
- Is the group open only to individuals with BFRBs – or can friends/family attend, too?
- Can new members begin attending at any time?

Any of these choices can work well, but should be carefully considered. In general, we suggest separate groups for kids and adults, as appropriate discussion topics can be quite different. The HEART support group for kids/teens in Long Beach, CA, holds a separate simultaneous meeting for the parents, who often need just as much peer support as their children!

Most groups welcome new members to begin attending at any meeting. But some successful groups have chosen a "closed" format, which enables a small group of people to meet together regularly without the dynamic of getting to know new people each week. They then hold periodic "open" meetings, which new people can attend.

What is the meeting format of the group?

- Peer led vs. Therapist led – if you choose to work with a therapist, the group may take the form of group therapy, which is a different goal than peer support, and may involve a fee --- the advice in this document is geared to a peer-group format.
- 12 Steps? -- The 12 Step format can work well and is worth reading more about, as it will likely be brought up by group members. Most BFRB …

….groups are not 12-Step in structure, but are structured around attendees checking in, followed by a group discussion. *See "Additional Readings" at the end of this document for supplemental reading and resources for group formats.*

Step 3: Create an email contact for the Support Group

We recommend using the name of your town/city followed by BFRB, or vice versa (for example: BFRBtoronto@gmail.com or torontoBFRB@gmail.com). Once you have this email setup it will be your main tool to communicate with the public. Set up an appropriate signature for the account. We suggest something like:

Your Initials or Name,
BFRB Toronto Support Group
For more info on BFRB's please visit www.canadianbfrb.org or www.trich.org

In addition to your email account, you can create a Facebook page or Twitter account dedicated to sharing news about the support group and for posting upcoming dates, interesting reading materials, news from TLC & CBSN, etc. We suggest sticking to the naming structure "BFRB *your city"*, or "*your city* BFRB SUPPORT" for social media outlets.

Step 4: Choose a day of the week/time that works for YOU

As the leader you will need to be able to attend most meetings. We suggest doing weekly, every other week, or once a month depending on your availability. For example: The Toronto group has meetings every other Tuesday at 7:30-9:30PM, and because of the increase in members it offers a Sunday meeting from 1:30-3:30PM only once a month. It is most effective if there is a regular time/place for the meetings – and that it is held consistently without cancellations.

You also need to choose how long the meetings will be (though of course, as the group evolves, this decision may change.) The best meeting length will depend, in part, on how frequently the group is meeting and how far people are having to travel to attend. In general, we find an hour and a half to be a good meeting length.

Step 5: Find a location

Start by reaching out to your local community centre, library, churches, school contacts, etc. to seek a FREE meeting space. To assist you in this process, we've drafted a letter called "Location Letter Template," which can be found on CBSN's website. You want to make sure you emphasize the meetings are for a *no-fee*, *peer* SUPPORT GROUP. Contact a local government representative to ask if they can assist you. Perhaps you have a personal connection with someone who runs a business/has a boardroom you can use! Use your imagination and you will find a location in no time.

NOTE: *For your safety, we do not suggest running a support group from your home.*

Step 6: Set a date

Once you have a location, make sure to pick a date for your first meeting! Give yourself at least a month's lead-time to spread the word effectively – and for CBSN & TLC to help you promote the group.

Step 7: Promote your Group - Ask TLC/CBSN to help!

Provide TLC and CBSN with a description of your group and its contact information, we can then begin promoting your support group on various Social Media Outlets including our websites. We can also send you educational pamphlets/posters to hand out at meetings.

Spread the word via social media (Twitter, Facebook, CBSN/TLC's website), local news outlets, community calendars, emailing local mental health groups, hospitals, etc. The more you communicate about this group, the more likely it will be successful!

CONGRATS!

It is time to host your first meeting! You will be helping so many people in your community, who will truly appreciate your hard work and dedication for getting this support group up and running.

B. How to RUN a Support Group

So you've done steps 1 through 7 in How to START a support group, now what?

It's time to think about how you would like to RUN your support group. As leader, you are not expected to be a BFRB therapist or even an expert. You are bringing people together, and helping to facilitate effective interaction among the group. It's important to remember that these support groups are PEER run. You are the leader, but it will be a group effort to have these meetings become successful. Be original, and share ideas with other CBSN/TLC peer support leaders so they can let other groups know what you're up to. Get creative, have fun and learn from one another.

Getting the Conversation Started

What to do for your first meeting and how to keep the conversation going:

Opening Statement

Beginning each meeting with an opening statement, like the one created by TLC's founder Christina Pearson (http://www.trich.org/treatment/article-mantain-support-raikes.html) can help to set the tone and expectations for the meeting. It provides some ground rules to refer back to, if discussion strays into unproductive areas.

Roundtable Highs & Lows

The Toronto group starts each meeting by going around in a circle and asking each member a "HIGH/LOW" of their week. A HIGH can be something positive in their life. A LOW can be something not so great in their life. Highs and Lows don't have to be associated with hair pulling/skin picking. *Keep each one short and under one minute*.

Think of Discussion Topics Beforehand

For the first few meetings, we suggest that the group leader come prepared with topics to discuss relating to BFRBs, such as:

How having a BFRB affects self-esteem, relationships, school, careers….
What products can you recommend for hair/skin….
What have you tried in terms of tips/tricks on trying to stop…
Ways to deal with stress…
Have you told friends/family about your disorder…
Have you tried a specific therapy for your BFRB…

BFRB-relevant Documentaries & Videos

The Toronto group also plays short documentaries on hair pulling, skin picking and other related disorders via YouTube. We use a laptop and usually play one or two per meeting. *Each video or documentary usually lasts less than 20 minutes.*

Current BFRB or CBSN/TLC news

Discuss news relating to BFRBs, important news in the BFRB community – events, webinars, research, etc.

You will find that once you get into the swing of things, you won't be able to stop talking! There is always something new someone brings to the discussion that keeps the conversation going. Before you know it, the meeting is over! As a group leader, it is important to have a list of topics you may want to use as a way to get conversations started, but most of the time you will find the meeting runs itself. **As a group leader it is important to just be aware of the time.** Often you will find your group can continue for much longer than a few hours and often becomes a social gathering, which is GREAT! But it may be best to end the meeting on time, so that those who need to get home feel free to leave, while offering the option of continued discussion or socializing afterwards.

Passing The Torch

Once you become an established group and have been running meetings for some time, you can pass the torch and perhaps give individuals the chance to “run a meeting” by having them prepare certain topics or activities that would be of benefit to the group. It is important to understand that as a group leader, you are not there to teach, educate or diagnose anyone. You are there to help make sure things run smoothly and start/end in a certain manner. Remember, it is a PEER SUPPORT group and you are all there for one reason, to find support for dealing with your BFRB.

Other Ideas

If you need to shake things up, why not have your group plan activities to help with the ultimate goal of creating BFRB awareness, and educating others? Perhaps you want to plan a fundraising event in your community – e.g. a potluck party, or BFRB Film Screening - with donations going to CBSN or TLC (depending where you live)! We suggest you leave a jar near the entrance and leave it up to individuals if they want to give a very small donation of $1-2 at every meeting. It’s not mandatory, but it can help CBSN & TLC provide you with resources such as posters, pamphlets, etc.

Keeping Organized & Getting Feedback

Another important task of running a support group is keeping a list of your members/ communicating with them! TLC or CBSN will contact you with any potential members who contact us looking for help. Save them in your email list! Here are some ideas:

- Create a word document and list names, and emails (Usually you can do this by having a **“sign in sheet”** for each new member who attends)

- **Email reminders** to your group members a few days before each meeting

Don’t be afraid to have fun, meet new people, and create friendships! If you need help or have questions, you can always email CBSN or TLC for support.

C. Some Questions & Common Scenarios

Here are some questions you might get from people looking to join the support group, or situations you may encounter when you run the group:

Is there any transportation to the meeting?
This is not the Group Leader's responsibility. You will find in time that most people will offer to give rides and should arrange this on their own.

I'm a parent/friend of someone with a BFRB: can I come to the meeting?
As discussed above, this is an important question to consider when deciding the format of your group. If you would prefer to limit the group to those directly experiencing BFRBs, perhaps, you can have bi-monthly meetings where friends and family members are invited to sit in to ask questions, listen, or learn. If an exception to the normal format is requested by a member, it is recommended that you ask your group members how they feel about it or for ideas of how best to respond.

I am interested in attending, but have no way of getting there, help?
Once again, for safety purposes we do not advise that you initially offer rides to strangers.

Can I have your personal number?
This is up to you.

Someone is a talker.
We all know through school, work, meetings, and other situations, there is always someone who just talks TOO much. As the group leader, it is important to take control of the meeting by reminding people of the time, or redirecting the conversation back to the group. If you have trouble doing this, just say, "Sorry to interrupt – we have to watch the clock."

Someone ISN'T a talker
It takes a lot of courage to come out to a support meeting. Just showing up and listening is a HUGE step. Just don't make the person feel

uncomfortable by pointing out the fact they are not participating. Every once in a while, politely ask them if they would like to add their opinion.

Someone who knows *EVERYTHING*.

This is a PEER SUPPORT group run by a group of like-minded individuals coming together for one reason. Unless they are a licensed medical professional with legitimate credentials, they should not be giving medical advice or diagnosing anyone. It is important that people realize support groups are not for giving or getting medical advice.

Someone is coming who doesn't seem to have an actual BFRB.

The problem with support groups is that sometimes people show up because they may be lonely, think they have a BFRB when they don't or are not really there for the right reasons. It is important to clarify that each group is for people who have a BFRB.

Things to Keep in Mind

It is important to keep in mind that it is human nature to judge people based on their appearance. Sometimes you may have a member who is a hair puller, but they have what seems like perfect hair. Or a skin picker, but you don't see any "flaws" on their body. Many of us are also masters of disguise!

It is important to remember, they may have stopped currently, and they have the same feelings on the inside and share the same experiences you or I have had. Some of us want to stop, some of us are content living with these disorders, and some have already stopped, this doesn't mean we don't share the same feelings, experiences or ideas.

GOOD LUCK!

Additional reading:

You can always find additional sources/content to share at meetings by visiting CBSN & TLC's Websites: www.canadianBFRB.org / www.trich.org

Am I Ready?:
http://www.trich.org/treatment/article-ready-group-sullivan.html

12 Step Information Adapted for BFRBs:
http://www.trich.org/treatment/article-twelve-step.html

Starting & Maintaining A Support Group:
http://www.trich.org/treatment/ArticlesResourcesTreatmentResourcesStartingaSupportGroup.html

Suggestions and Helpful Hints for a Support Group:
http://www.trich.org/treatment/article-suggestions-group-sullivan.html

TLC's Group Opening Statement and Format:
http://www.trich.org/treatment/article-mantain-support-raikes.html