

Banishing the “Ugly Three”

A Guide for Support Group Leaders
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“The Blind Leading the Blind”

Ai, yi, yi! My feet hurt from walking, my gums hurt from chewing and my you-know-what hurts from sitting. The continual onslaught of pain adds exhaustion to the fatigue I already feel. And that’s just for starters. Adding insult to injury my sensitivity to outside stimuli, including the emotions of others, is heightened. And I’m leading a group for people who are in physical and emotional pain!?

Ever have the unmentionable thought: What on earth am I doing here?
I admit I’ve had that question go through my mind both as a group participant and as a group leader

The Good, the Bad

As a participant the power of attending support groups for me is hearing a variation of my own story and feeling less alone. It is wonderful to be able to connect with others who I know “know”.

My personal difficulty with support groups is that many of the ones I attended focused on pain and suffering. Hearing the struggles with the medical profession, the pain of isolation, anger, “cures” that didn’t work for me, frustration and grief over and over began to send my energy crashing.

I couldn’t find the solace and connection that I first experienced. I thought “Something must be wrong with me” until I began to hear similar stories from others. Stories from people who wouldn’t go back to support groups for the same reasons I had. It seemed we were all hypersensitive to the negative emotions of other members in much the same way we were hypersensitive to light and sound.

. . . and the Ugly Three

In particular, stress, fear (anxiety) and anger (frustration) unleash a flood of neurochemicals that worsen many conditions. In the right dose and the right time these three can be appropriate and helpful – like when you’re chased by a tiger, or audited by the IRS! But if you have fibromyalgia these three, whether you are experiencing them directly or indirectly from others, need to be minimized to reduce symptoms and flares.

As a group leader the administrative part didn’t cause me stress, fear or anger. The stressful part was the energy and focus I needed to listen and create a safe space for people to share - people in pain, feeling stress, angry and scared.

After the group I crashed - sometimes for days. I had lost my resiliency and learned I was just as sensitive to others’ emotions as a leader as I had been as a participant. It was time to develop a new approach to continue doing what I love to do. I decided to approach it on two levels: taking better care of myself and refocusing the group experience from “pain to pleasure” from “being stuck to possibility”.

My starting point was addressing sensitivity to negative emotion. If I was sensitive to other people’s stress, fear & anger then I suspected there were others who also were

affected in a similar way. I set out to minimize my own stress and maximize the more positive and neurochemically helpful feelings like hope, happiness and gratitude.

I'll share some of the things I've done when I've run support groups that worked for me and for participants (I've already shared what didn't work!): So let's take a look at how you can create a safer emotional space for yourself keeping the Ugly Three to a minimum.

Protect the One You Love

It's become cliché, yet oh so true - put on your own oxygen mask before you put it on anyone else. If you don't take care of yourself you won't be able to be present for others. Here's some suggestions to reduce your own stress, anxiety or frustration.

- Perform a ritual. Some people envision being enveloped in an oval of protective energy/light, being surrounded by an imaginary force field or in a safe place. This gives the brain the signal that you are safe and it reduces the stress response.
- Exercise before the meeting. Walk around the block before you go. Get there early and do easy stretches. Unleash some great endorphins to feel good. Strolling is good too!
- Have everything ready to take the night before. I developed a check-list of everything I ever needed and printed out a copy prior to each meeting.
- Leave ½ hour before you think you need to leave. Being rushed or forgetting things increases the stress level and that's NOT what you want to do.
- Rotate responsibilities. Often people will volunteer to do something if it is a **one time** thing. When "opportunities" (code for responsibilities) are broken into small pieces more people are willing to contribute. Like a pot-luck - if everyone brings one dish it creates a meal.

Know Your Emotional Tigers.

It's crucial to be aware of your own feeling. Don't just brush them off or ignore them. They will chase you down to make sure you are paying attention to them!

Some of the more obvious emotions which can enflame chronic conditions like fibromyalgia are: Grieving what was, what could have been; Anger (frustration counts, it doesn't have to be rage); Helplessness; Hopelessness; Sadness about what could have been; Fear (anxiety) of what the future may bring.

Check in with yourself before the meeting whether it's the day before or the hour before. Many times simply by examining and acknowledging how you feel you will feel better. Here's some ways you can take stock of your feelings:

- Ask yourself some basic questions:
What's happened this week/today? How has it impacted me? How do I feel about it? How am I feeling physically? What is my current "attitude?"
- Guess. If you're not sure just intuitively take a look at the basic emotions: mad, sad, glad, afraid and disgust (they're universal!). Keep in mind that emotions are on a continuum, ranging from mild to intense so don't ignore the milder feelings. They are quieter but just as important.
- When you know or have guessed make a list of all the things that are making you mad, glad, sad, afraid or disgusted. Your brain will stop reminding you.
- Journal your thoughts & feelings before the meeting.
- Talk to a friend or family member, talk to yourself.

- Draw a picture (stick figures work) and label what you are thinking & feeling.

Buying instead of Renting

If people feel ownership of the group your attendance will go up and the willingness to take on small parts will increase. Here are some ways to build involvement:

- It takes two! Many support groups have co-leaders. I think that is great.
- Create buddy-systems for all the tasks. Just keep the tasks small.
- Don't ask for volunteers. Be positive and ask each person: "What might you be able to do next meeting?" ("Nothing" is an acceptable choice)
- Have the group decide what the focus of the next group will be. (Give them a forced choice between 2 or 3 options, otherwise you could be there for hours)
- Create roles that can be rotated monthly giving everyone the OPPORTUNITY to contribute in some way. You can start out with one or two roles and add (or delete) as the group builds. One of the great things about modern technology is that there are things people can do even if they can't make the meeting. The more roles or contributions (I try not to call them responsibilities!), the more people feel ownership in the group. Tip: Do NOT check up or remind people to do what they chose to do. The goal is to give you, as the leader, less to do and the participants ownership in the group. If it doesn't get done, it doesn't get done.
- Here are some roles you could consider (Bear with me, I like to give the roles silly titles which brings a bit of healing humor):

Meeter Greeter – Welcomes everyone at the door. They can sit or stand.

Tagger – Makes out name tags.

Follow-up Phoners - Phone or e-mail the newcomers after the meeting.

Music Maven - Choses & brings their favorite CD/tape to play during the meeting.

Caterers – Bring refreshments

Techie - Sends meeting reminder via e-mail

Paparazzi Person: Take digital pictures at the meeting and send them on-line after the meeting to everyone on the mailing list.

Ritual Ring leader – Reads a poem, passes around the Victory Box, decorates the Victory Box, lights the birthday candle, etc. (See **Accentuate the Positive & Make it Fun**)

Biographer of the Month - One person every month tells their life story. This helps participants get to know each other as more than just having fibromyalgia.

The biographer can do anything they want in a set amount of time: Photos, family traditions, hobbies, anything goes.

Elephant Trainer – Brings a "white elephant" for the door prize (See **Make it Fun**)

Jokester of the Month/of the Year – (See **Make it Fun**)

Song Bird – Leads the group in song (See **Make it Fun**).

Structure the Group

I love surprises. However, for many familiarity is comforting and less stressful (If you do want to plan a surprise tell everyone to expect a surprise at the next meeting). Structure also minimizes someone highjacking the time for their own "agenda". You say this has never happened to you? . . .it's happened to me! Here's some simple ways to create structure:

- Send out an e-mail before the meeting with the group date, time topic/activity. Even if it is just a Gripe Group everyone knows what to expect and can decide to go or not based on their energy level.
- Start the group with a positive ritual, like gratitude, and end with a hopeful closing.
- Start on time, even if you are the only one there. Don't train people to come late.
- Have group rules. One of the things I do is pass out a confidentiality contract which makes it more comfortable for sharing. (eg. "If you talk about someone outside the group do not use their name. Talk about how you were impacted not about the person who shared". (If you want a copy e-mail me at judy@creativitytothemax.com).
- Make the meeting a Cellphone Free Zone and have a Scent Free policy.

Set a Welcoming Mood:

You usually have no control over the physical facilities where meetings are held but you can control simple things like greeting people with a big welcome. I think of it as welcoming people to my own home.

- Play soft background music during the group. We know that music is healing. (Music Maven is in charge)
- Have one of the members be Meeter-Greeter-of-the-Month. Wal-Mart does know what it's doing!
- Welcome every new member with something special. (A special name tag, a packet of information from the National Fibromyalgia Association, a daisy . . .)
- Call or e-mail every **new** member after the group to ask how they are doing and if they have any questions about the group etc. (Follow-up-Phoners)
- Smile! The smile muscles are connected to the brain. It's been established that smiling triggers the release of natural anti-depressants. And a smile begets another smile.

Accentuate the Positive

Pick activities/focus that are positive. You can steer meetings in positive, hopeful, fun directions. Remember, the cues that we receive from our physical and emotional environment can be damaging or healing, energizing or depleting.

- Do a sprint lap of Greet & Gripe - Go around room, everyone telling their name and saying the worst thing that's happened since the last meeting. Each person has 35 seconds. It can be done! With groups that have gotten stuck in the negative I've used a timer - playfully of course! Griping/negativity is banned for the rest of the meeting. You can make this fun by keeping a playful attitude.
- Victory Lap - what has worked, what happened that was positive in their life. Go around the room each person sharing their victory for the month. There's no victory too big or too small (getting up every morning and brushing your teeth counts).
- Victory Box - Have people write down their large or small victories that they had that month. Put the victories in a box and watch the box fill every month. At the end of the year have a Guess-How-Many-Victoires-in-the-Box contest.

- Victor not Victim - As people come in they write a victory they've had that month and drop it in a basket. During the meeting everyone randomly picks a victory to read. After every victory there's celebrating applause. OR One victory from the basket is randomly picked to receive a Victory Certificate or door prize or gold star or. . . .
- Practice laps: Toward the end of the meeting or after the Victory Celebration Each person decides on one positive thing they want to focus on in the coming month. People can share suggestions of what has motivated or worked for them.
- Celebrate Family & Friends – Share joys: births, birthdays, graduations etc.

Make it Fun

Laughing and having fun with others is the best (and cheapest!) medicine there is. As my Mother use to say, "It cures what ails you." So within the structure of the group mix it up occasionally and have fun doing it.

- Have a "Stupid Joke" contest. The winner is the "Jokster of the Month/Year"
- End or begin the group with a happy song. Children's songs are great-they are easy and most people know them. The leader can be the "Songbird"
- Valentines Day – Make/say valentines to one of your body parts - something that is working perfectly and never gets credit – like your earlobes or eyelashes!
- Easter - Decorate Fibro Eggs – Make the ones that are cracked beautiful
- Birthdays – When people come for the first time they sign the date of their birth on a small calendar. OR At the monthly meeting ask who have birthdays that month and sing Happy Birthday. OR Send the birthday-person a e-card from the group. Light a birthday candle on a cupcake. Go around the room and each person makes a birthday wish (oral or written) for the birthday-person.
- Every month a different "Elephant Trainer" brings a wrapped (a brown bag will do) "white elephant" to be raffled off. The weirder the "white elephant" the better. Have a 10 cent donation for a raffle ticket. Use the big bucks you collect to buy the birthday cupcake.

I hope this has tweaked your imagination to bring a bit more hope, happiness and fun into people's lives. I know you also have many things that have worked well for you and your group. Send them to me and I'll pass them on! I'd love to hear from you.

My closing "ritual" is a BIG (but gentle) **thank you** hug to each and every one of you who have ever volunteered to lead a support group – You are special people who transcend your own pain and and give of yourselves to create a healing community for people with fibromyalgia. Support On!

