

Using and adapting NSRF protocols and activities to help facilitate healthcare support groups

By Hetlena Johnson, CFG Coach in South Carolina

Everyone is vulnerable. And everyone, in some small way, has aspects of themselves or thoughts and feelings that they aren't inclined to make public. For vulnerable people living with a chronic disease, attending a support group for the first time can be one of the most intimidating and paralyzing experiences they can imagine.

Many people think of support groups as places to confess their feelings. In a sense, that is what you are supposed to do, without feeling judgment aimed at you for those feelings. As a National Lupus Foundation of America Lupus Support Group Facilitator, I know that our groups have other intentions and goals beyond mere confessionals, but I am adamant about ensuring that everyone who attends one of our meetings leaves feeling as though they have shared something. This sharing can be verbal or physical. For some, it can be as quiet as a smile or simple nod of the head, and for others, it's a heartfelt, tearful expression of feelings they can't express anywhere else. I believe it's imperative that any support group leader be experienced in facilitation and pay attention to all members in the group: to recognize and anticipate the range of support that each individual needs to feel safe, comforted, and empowered.


Lupus is not a very cooperative disease. An autoimmune disease, lupus makes a body's immune system go haywire. Instead of fending off bad cells, it attacks healthy cells and tissues. The illness has a reputation to cause

Photos from Johnson's Lupus Support Group meeting are all used with permission of meeting participants.

inflammation and attack any, if not all parts of the body, including joints, kidneys, skin, and blood cells. No part of the body is invulnerable to attack.

A diagnosis of lupus can be very perplexing. It can take from six months to about three years before a physician will definitively diagnose someone with lupus. Although more than 1.5 million Americans and 5 million world-wide are reportedly diagnosed with this autoimmune disease, many people are still unaware of its existence. As a result of this lack of awareness, many newly diagnosed patients and their loved ones attend lupus support meetings in order to try to find steady ground beneath their feet.

Lupus support groups provide an opportunity for those dealing with this chronic inflammatory illness to release stress and recognize that they are not alone. Because of the meetings' goal of creating community, I treasure my NSRF training. I couldn't wait to take what I learned in CFG Coaches' Training and share it within our lupus support groups.



The dynamics of lupus support groups lead me to use the [Connections Activity](#)  originally (and now [Transitions M](#)). I use it to the max! Before I became a CFG coach, as a Lupus Support Group Facilitator, I'd sometimes just leave the forum "open" for people to share as they wish. By simply giving permission for everyone to speak without any structure or suggestions, the "open" method often increased stress rather than eased it, causing the group to remain silent longer than I had hoped. The longer the silence continued, the more stress it created. When I learned to use an NSRF activity with specific instructions and guidelines, the meetings began with much more sharing, and everyone showed signs of relief throughout the meeting ... and lively, free conversation after the protocols end.

Sharing openly is especially therapeutic for those who are newly diagnosed (within 1-2 years) with lupus. Whether they need to vent openly about medicine, doctors, or pain, someone always speaks out within the time allotted. Sparks begin to fly. I do believe that the Connections and Transitions activity really allows



the support group members to connect and benefit from the experience and knowledge of others in attendance. When they express their frustration and pain, they're met with true empathy—not just sympathy, which can be isolating.

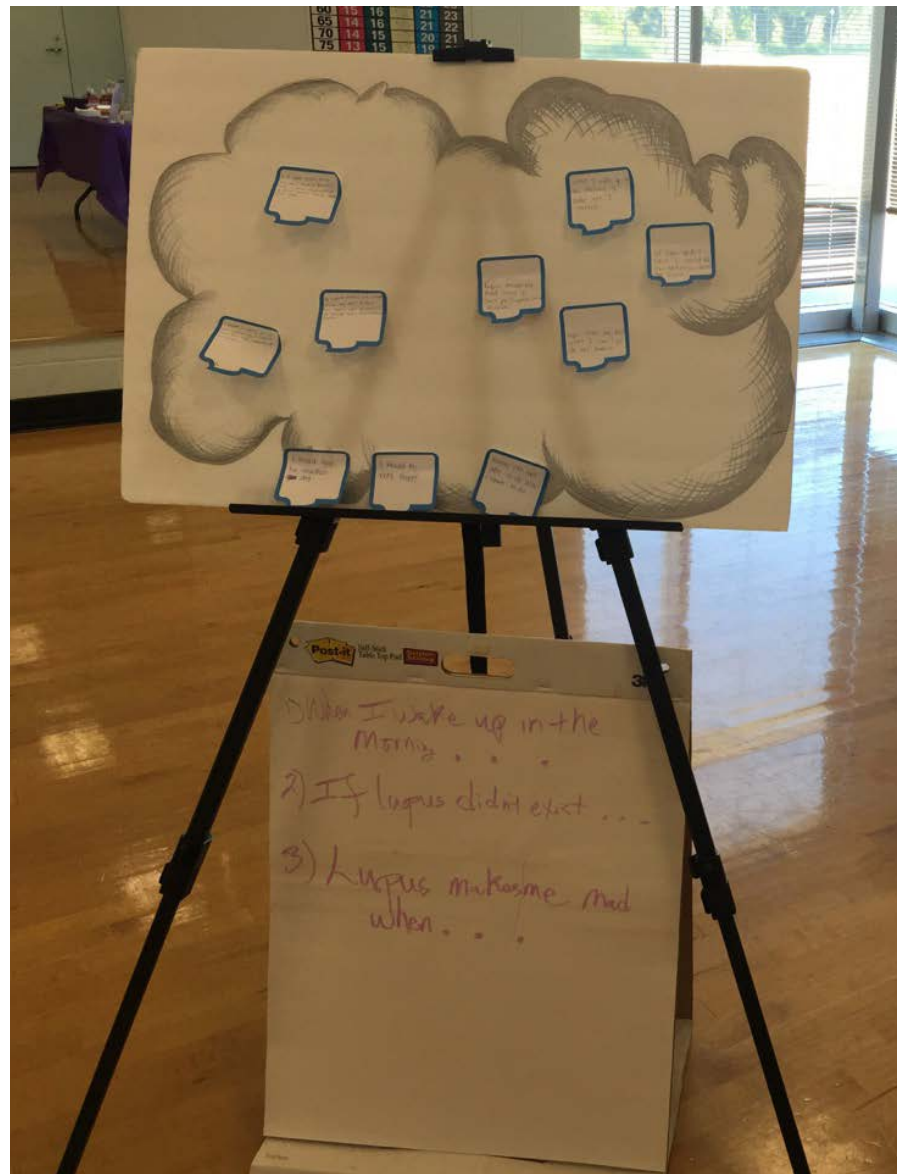
In contrast with Critical Friends Group meetings, in which a known set of people attend a meeting every few weeks, support group meetings can be challenging to facilitate because we never know who's in the room and what circumstances and feelings they'll be expressing. A facilitator must be on guard and use their skills to “feel out” the emotional stability of the group. For more solemn groups, I often use a variation of the NSRF Feedback Nightmares activity after we open the meeting.

I call my version of the **Feedback Nightmares activity**   “Lupus Nightmares” or “Medical Nightmares.” (See pages 10-11.) I believe that this is an essential exercise for lupus support groups, especially for those newly diagnosed. The activity encompasses the very meaning of why they came in the first place - to talk about how awful they felt when a physician confirmed that they had lupus, and their fears for the future.

Because the meeting I facilitate is usually just a half a dozen people or fewer, I describe how the protocol will work and direct each person to relay a short snippet of their individual story to the whole group. Most patients will talk about the progression of symptoms that what forced them to go to the doctor, and they'll speak of the moment a diagnosis of lupus was confirmed. In each story, the attendee emotionally conveys their struggle and typically deep-rooted feelings about the diagnosis. I'd often hear about a physician's poor bedside manner or detached approach when delivering this life-changing diagnosis to this person.

As you can imagine, to a new lupus patient and their family, sharing out these feelings (these “nightmares”) within a trusted group of fellow patients can be quite therapeutic. After the group sharing, I invite everyone to silently reflect for a few moments on the power of the experience we just shared.

The Lupus Nightmares Activity and the Transitions opening takes up most of the 60- to 90-minute meeting time, but I consistently receive positive feedback about how positive the experience has been for the participants. (See pages 10-11 for protocol.)



CFG participants may be familiar with “the parking lot” as a tool for recording thoughts and resources during a meeting; Johnson revised the concept slightly and posts items in “the lupus fog.”

Another important NSRF tool that's been remarkably helpful is the use of the Parking Lot, both for people who're disinclined to speak aloud in meetings and for those who don't want to speak too much or too often. I was absolutely ecstatic when Dave Nelson, the NSRF National Facilitator who led my training, introduced this tool. Dave had set up a poster with a black background and yellow cut strips to resemble a literal parking lot. I loved it! The parking lot allows individuals to share sticky notes with questions, ideas, resources, or thoughts that we would address later in the meeting, without interrupting whoever was speaking or whatever we were doing at the time the question or idea arose.

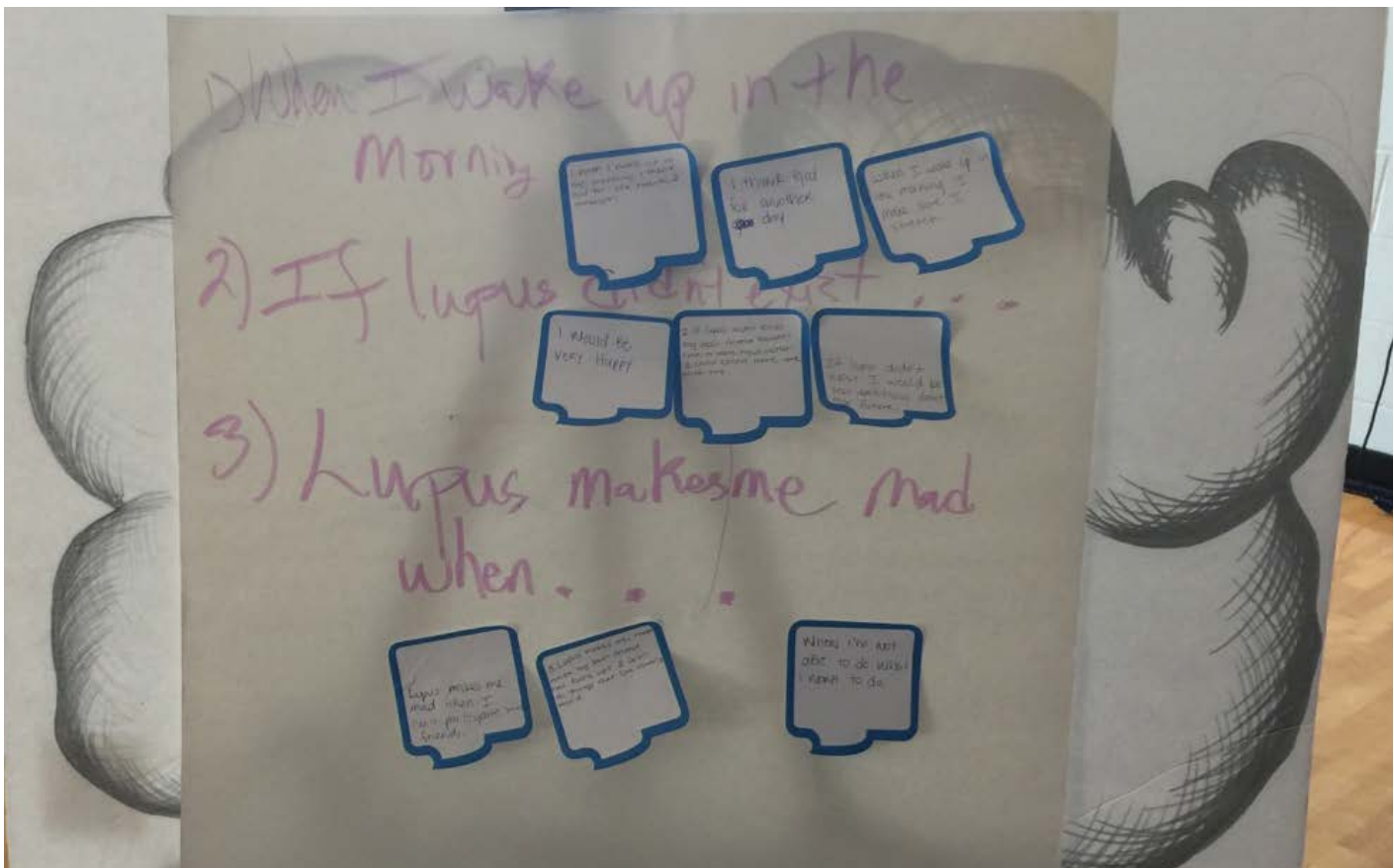
One of the symptoms of having lupus is that you can easily forget things, so the permission and structure of writing down short notes for later reference is remarkably useful. A term used by those in the lupus community is



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Photo Credit: Kina Nicole Photography




"The lupus fog" now with sticky notes organized around specific questions proposed by the facilitator.

"lupus fog." I thought that fog imagery would be especially accurate and useful in this context, so I had a friend draw a cloud on a poster board to represent fog in the parking lot for our meetings. Group members would pick up a few sticky notes when signing in and use them to write down things that were on their mind, before and throughout the meeting, sometimes answering a specific prompt. This was such a success with our participants that I expect our "foggy parking lot" will always be used in upcoming meetings!



In conclusion, the following NSRF protocols and activities have moved my lupus support group meetings from plain to powerful:

1. **Connections**  and **Transi-**

*For more information about lupus, I recommend **Diary of a Mad Lupus Patient: Shortness of Breath** by J. H. Johnson.*

tions  In CFG meetings, you want to do this once everyone is present, but it's a little harder with community organizations. I recommend starting this activity first thing after you settle in a seat after setting up the room. It gives others who are just arriving time to adjust.

2. **Parking Lot.** Allow the group's regular "driving speed and direction" to continue uninterrupted by creating a "parking lot" where participants can post ideas that might otherwise take the flow or content of the meeting "off track." Bonus points if your poster image is personalized to the makeup of the group or team you will be working with.

3. **Feedback Nightmares**   (translated by me into Medical/Lupus Nightmares, see next page). Most people attending support groups come with many "nightmare" experiences around their disease and their experience within the health care system. They also often have a deep fear of possible future decline, pain, or additional diagnoses. They fear the

worst. Being able to share their medical treatments and experiences with other patients helps shift the negative feelings from worries to concern and care.

Purpose: To address patients' fears and concerns around being diagnosed

DO YOU HAVE EXAMPLES OF PROTOCOLS OR ARTICLES YOU'VE ADAPTED OR USED WITH GREAT SUCCESS? TELL US!

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