

Lupus Nightmares Activity

Medical Nightmares Activity
By Hetlena Johnson for the NSRF, 2015

Facilitation Difficulty: 

 50 min.

 4-10 people

 No preconference

with lupus. To collaboratively share experiences, understanding, tips for coping, and living with lupus.

Notes: During the pair share, if someone does not want to participate, suggest they act as “a cloud in the room” observing and listening, and adding their perspectives when moved to do so. If you use the “cloud” option, ask those participants for their feelings at the end of the protocol. Because many patients can get angry and really start to talk negatively about the doctors and the experience, I usually gauge when I need to take a little control of the discussions before they get too expressive. I’ve begun suggesting some norms or agreements at the start of meetings, but still, emotions run high in these medical support groups. I have had a few interruptions where someone wanted to know the name of the doctor or medicine that was problematic for the speaker. This is usually when I take on a more facilitative role during the feedback and chart that information, or make a note on the parking lot for later reference. If members start expressing a specific physician’s or center’s name, use judgment in recording this on the projector/board. Everyone’s experiences are different! Near the end of a support group meeting, because of the heaviness of the emotions, I usually use the pause and reflect method for debriefing the group.

Preparation: Use agendas, projector and technology to set up a statement about what lupus is. If desired, facilitator can prepare notecards or strips that have the definition of lupus to handout to the participants. Consider using a poster size picture or a projection of the body on which to chart symptoms of the disease.

1. **Set up:** (2 min.) Welcome the group. Explain the importance of confidentiality to the group and ask for everyone to commit to that confidentiality. Set up the activity something like this: *“I will ask everyone to remember a time when they experienced a ‘lupus nightmare,’ a time when what was happening to them felt like a nightmare come true. Then you will be sharing that experience with a partner. Human nature is to compare your problems constantly with that of others and judge yourself or them accordingly. By sharing without judgment, every participant can feel the freedom and relief of ‘telling somebody’ that can result. After we share, we’ll all reflect on this experience.”*
2. **Reflect:** (3 min.) Ask participants to sit back in their chairs, close their eyes, breathe in through the nose, and slowly exhale through the mouth. Ask participants to *“Remember when you experienced the nightmare-phase of getting diagnosed. What symptoms lead you to go to the doctor? What did you hear and experience negatively that lead up to the diagnosis? How did you feel as you were going through this process of being diagnosed? If you are a family member of the patient, what feelings have you experienced through this process?”* Ask participants to open their eyes and write down on sticky notes a few words that describe how they felt. Give participants a hint, such as *“How did you feel when your doctor gave you your diagnosis, or told you that you may only have a few months or years to live?”*
3. **Pair share:** (10 min.) Pair participants with people they don’t know in the group, if possible. Direct participants to share their lupus or medical nightmare with their partner. Participants should record a reminder of their partner’s story by jotting down some key words in their notes. After five minutes, prompt participants to switch to the other participant.
4. **Group share options:** (15 min.) Version 1. Going around the room, each participant reads off the words they used to describe their reflection. If necessary, the participant can use more than one word.

Version 2. Handing around a ball or stuffed animal to signify which person should speak, each participant tells their nightmare in turn. If they feel a little shy, they can just read off the words they used to express how they felt. If necessary, the facilitator will write the feeling words on the board (or use the projector).

Version 3. Going around the room, in pairs, one participant tells his partner’s story in brief. The speaker uses their notes to remind them of what the other person said. Then swap partners, and the other person speaks about the first.

5. **Receiving feedback:** (5 min.) Refer to the feelings charted on the poster (or projector) and notice what was shared. Discuss common and different experiences and feelings.
6. **Debrief and reflect:** (10 min.) By this time the atmosphere of the group can vary from somber to humor-filled. Use your best judgment in debriefing this activity—silent reflection, written, or open forum. Let the group compare and see that everyone has a nightmare experience that can relate. Let the group point out the good and bad of the feedback gathered.
 - *How do you feel about being diagnosed with lupus?*
 - *Was it difficult to control your anger about being diagnosed? Why or why not?*
 - *What do you feel was the “real” nightmare in your experience?*
 - *Is it difficult for you to write/share your experience? How do you feel about sharing your experience with others in the group today?*
 - *Can you find anything positive from your experience?*
7. **Collect:** (1 min.) At the end of the exercise, gather the sticky notes and place them on the wall nearest the exit. Say something like *“We invite you to leave these feelings in the room instead of carrying them with you any longer. The feelings were natural and appropriate to the time and situation, but now you can move forward in your actions and your feelings.”*

© 2015, NSRF®. Permission is granted to copy for use in classrooms or in meetings including Critical Friends Group® meetings. For other use, please call the NSRF office at 812-330-2702 or email nstrf@nstrfharmony.org. Protocols are most powerful and effective when used within an ongoing professional learning community facilitated by an NSRF-certified CFG® coach. To learn more about professional learning communities and trainings for new or experienced coaches, please visit the National School Reform Faculty® website at www.nstrfharmony.org.



*Can you find anything positive
from your experience?*