

BOOST Program: Bringing Out Our Strength Together

Facilitator Manual

Note to facilitators:

Your role on these calls is to facilitate a safe and open space for participants to share their feelings and experiences surrounding their diagnosis of epilepsy. Instead of giving direct advice, you are encouraging a non-judgmental discussion between participants. Facilitate discussions by asking open-ended questions, as well as asking for clarification or elaboration when appropriate.

Each weekly session is one-hour long. Please use the below outlines as a guide for facilitating and timekeeping.

Week 1: personal experience of epilepsy

1. Introductions (25 min)
 - a. Introduce self and qualifications, experience with epilepsy (if applicable)
 - b. Introduce program, what it is/is not
 - c. Ground rules of group (e.g. not interrupting, non-judgment, confidentiality)
 - d. Safety precautions (e.g. protocol if someone begins to have a seizure mid-call)
 - e. Time for questions
 - f. Invite participants to introduce themselves briefly: who they are, where they're from, who they live with, etc. plus a fun fact to break the ice
 - g. Thank participants for sharing
2. Group discussion (30 min)
 - a. Introduce first topic, personal experience of epilepsy, and invites participants to share their own experiences. Some potential conversation starters:
 - i. How has epilepsy affected your life?
 - ii. How has epilepsy affected your family?
 - iii. How has epilepsy affected your work?
3. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 2: personal experience of mood problems (depression, anxiety, stress)

1. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
2. Group discussion (40 min)
 - b. Introduce this week's topic, personal experience of mood problems, and invite participants to share their own experiences. Some potential conversation starters:
 - i. How have mood problems, such as depression and anxiety, affected your life?
 - ii. Have you noticed any relationship between your epilepsy and your mood? If yes, how so?
3. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 3: seizure triggers

1. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
2. Group discussion (40 min)
 - c. Introduce this week's topic, seizure triggers, and invite participants to share their own experiences. Some potential conversation starters:
 - i. Have you noticed any patterns in triggers for your seizures?
 - ii. Have you noticed external triggers vs. emotional or behavioral triggers?
 - iii. How have you modified your lifestyle to avoid triggers?
 - iv. Have your triggers changed over time?
 - v. Have medications changed the way triggers effect your seizures?
 - vi. Does anyone keep a seizure diary to help monitor triggers?
3. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 4: concerns related to epilepsy treatment (e.g. medication adherence, side effects)

1. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
2. Group discussion (40 min)
 - d. Introduce this week's topic, concerns related to epilepsy treatment, and invite participants to share their own experiences. Some potential conversation starters:
 - i. What sorts of concerns do you have related to your epilepsy treatment?
 - ii. What are some of the challenges you have encountered related to your treatment?
 - iii. Do you feel supported by your healthcare provider?
 - iv. Are there things you wish would improve regarding your treatment?
 - v. If you met someone who is newly diagnosed, what would you tell them about your experience with treatment?
3. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 5: changes in seizures over time

1. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
2. Group discussion (40 min)
 - e. Introduce this week's topic, changes in seizures over time, and invite participants to share their own experiences. Some potential conversation starters:
 - i. Have you noticed any changes in your seizures over time, e.g. frequency, length, or severity etc.?
 - ii. Have you identified any reasons for these changes?
 - iii. What have you learned about yourself and your seizures over the years you have lived with epilepsy?
 - iv. Has anything become easier or harder over the years you have lived with epilepsy?

- v. How has the perception or understanding of epilepsy changed over time, such as in pop culture, the media, or personal experiences?
 - vi. Have your thoughts and feelings about your seizures changed over time?
 - vii. Has the way that epilepsy affects your life changed over time?
- 3. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 6: the impact of behavior (e.g., sleep, substance use) on seizures

- 4. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
- 5. Group discussion (40 min)
 - f. Introduce this week's topic, the impact of behavior on seizures, such as getting good sleep or staying up late, or the choice to use substances or not, or the way we choose to eat, interact with others, how we choose to live our lives, and invite participants to share their own experiences. Some potential conversation starters:
 - i. Have you noticed any relationship between your behaviors and seizures?
 - ii. How do your seizures affect your behavior and vice versa?
 - iii. What is the relationship between sleep and your seizures?
 - iv. What is the relationship between substance use and your seizures?
 - v. Have you altered your behavior because of your seizures? If so, how so?
 - vi. What behavioral lifestyle changes have you made due to your seizures?
 - 1. Food?
 - 2. Exercise?
 - 3. Sleep?
 - 4. Music?
 - 5. Communication?
 - vii. What is the relationship between food and your seizures?
 - viii. What is the relationship between substance use (alcohol, cigarettes, marijuana, other recreational drugs, etc.) and your seizures?
 - ix. What behaviors make your seizures worse? Anything related to behaviors that make them better?
- 6. Wrap-up (5 min)
 - a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 7: social relationships and epilepsy

- 7. Check-in (15 min)
 - a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
- 8. Group discussion (40 min)
 - g. Introduce this week's topic, personal experience of mood problems, and invite participants to share their own experiences. Some potential conversation starters:
 - i. How has epilepsy affected your social relationships?
 - ii. How has your social relationships changed before and after your epilepsy diagnosis?
 - iii. Have you experienced discrimination because of your diagnosis?

- iv. Are there things you do differently in social interactions because of your epilepsy?
 - v. Do you find it comforting to speak with others who also experience epilepsy?
 - vi. Do you think people have wrong perceptions or stereotypes about individuals with epilepsy?
9. Wrap-up (5 min)
- a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group and reminding everyone when the next group will be taking place.

Week 8: review of the BOOST experience

10. Check-in (15 min)
- a. Welcome participants
 - b. Invite people to share how their previous week has been and how they are doing today
11. Group discussion (40 min)
- h. Introduce this week's topic, review of the BOOST experience, and invite participants to share their own experiences. Some potential conversation starters:
 - i. You now have a chance to share anything you would like about how this program has been for you.
 - ii. What has it been like to share your experiences in this space?
 - iii. What has it been like to hear the experiences of others with your diagnosis?
 - iv. What have you learned from these discussions?
 - v. What suggestions do you have to improve this program?
 - vi. Are there other topic areas we didn't cover that you would suggest we consider for future sessions?
12. Wrap-up (5 min)
- a. Conclude discussion by thanking everyone for sharing their experiences, highlighting shared experiences among the group. Thank them for their participation in the program and direct them to resources.