



Support Group Leader Training





BDSRA SUPPORT GROUP LEADER TRAINING

Dear Leader,

BDSRA wants to take a moment to thank you for your vulnerability and willingness to step into a leadership role. Volunteering to share your heart, skills, and experience will undoubtedly have a huge impact on those who walk through this journey with you.

We hope this training gives you some extra tools to be the best leader, friend and support to those in your group. We also would like to acknowledge the hard work and dedication it takes to facilitate a peer support group, and we want you to know we are here to support each of you.

Respectfully yours,

Morgan DeBoth

Morgan DeBoth
Vice President of Support & Advocacy
Batten Disease Support and Research Association

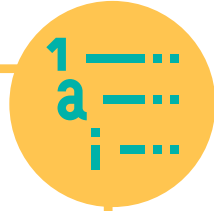
BATTEN DISEASE
Support and Research Association

TOPICS



ATMOSPHERE

In this section, we will begin brainstorming what, when, and where a peer-led support group might take place.



STRUCTURE

We will discuss the possible ways your group can be set up and facilitated. This encompasses open and closed groups.

GROUP NORMS AND GUIDELINES

We will review how to set ground rules for your group as well as mutual expectations.



LEADING YOUR GROUP

This section will discuss the structure of your group. We will talk about how predictable routines can set the tone and pace for your discussion.



COMMUNICATION

We will go over different communication styles of participants, how to redirect conversation, and when to refer out if someone may need more support than your group can offer.



FLEXIBILITY

This section will touch on opportunities and the commitment of support groups. It also will offer other options for those who want to support others but believe leading a group is not a good fit for them.



ATMOSPHERE - SETTING THE TONE

Location



In-person events are ideal for members to create a greater sense of trust and intimacy, for individuals in close proximity, or who are willing to travel as frequently as your group wants to meet.



Virtual events are great for members who are physically far apart from one another. If leading a virtual group, you may have to do additional research on the best digital meeting platform.



Hybrid events may be the most inclusive option for our Batten families. While it may not be an option to meet year-round, a hybrid meeting platform may help members of your group gain trust and grow in vulnerability.

Frequency

Your group can meet as frequently as you'd like. Be aware your group may become emotionally fatigued if it gathers too often or goes too long between meetings.

Meeting Time

Things to consider when setting up a time:

- Work and school schedules
- Varying time zones
- Appointments and prior commitments

To most accurately gauge your members' ability to attend, consider sending out a poll on Google Forms, Survey Monkey or Doodle.

Number of Attendees



Having a large group may seem ideal but it may affect the quality of the group engagement. Best practices show that between 5-12 people is best. This increases the chance that people won't feel left out or feel like things are too intimate if someone does not show up.



Who should you invite?

The Batten community is rare, but vast in diversity. Consider if you want to open your group to a specific CLN, member of the family or where the family may be in its Batten journey. Remember, you are leading this group and you should feel comfortable with who attends. You can be as selective as you feel you need to be to have the best conversation.

SOURCE:

[HTTPS://CDN.YMAAWS.COM/WWW.NASWMA.ORG/RESOURCE/RESMGR/IMPORTED/FCE_2012.9_ADULTBEREAVEMENT.PDF](https://cdn.ymaaws.com/www.naswma.org/resource/resmgr/imported/fce_2012.9_adultbereavement.pdf)

STRUCTURING YOUR GROUP

Gathering a group of individuals from different backgrounds and life experiences can be difficult. In order to create a place that is conducive to building relationships and trust, it is best to start with some form of structure while being flexible to each participant's needs. After establishing who you'd like to invite, it is time to discuss what kind of structure you'd like to have for your group. For this training, we will look closely at two common types of groups:

OPEN GROUP

An open group generally will serve more and a greater variety of people. This will allow for greater diversity from which people might learn more. It also suggests that people will be at various places within their grieving and can be helpful to others who are at a different stage of the process. For participants, an open group also allows them to choose when they come and not feel a need to make a commitment to a series of closed groups, which for some people who are grieving can be difficult—they may feel like attending one week and not another.

CLOSED GROUP

A closed group allows for more bonding among members, which means they may trust and share more, as well as have a greater likelihood of developing new friendships which last outside the group. With this model people make a firm time commitment, which for some bereaved family members can be a struggle. A closed group, unless you offer many groups, means that someone who missed the start of a group may have to wait some time before entering a new one. *This is a reason to be aware of other offerings within your community to which you might refer people.*

LIST YOUR GROUP PREFERENCE AND WHY:

SOURCE:

[HTTPS://CDN.YMAAWS.COM/WWW.NASWMA.ORG/RESOURCE/RESMGR/IMPORTED/FCE_2012.9_ADULTBEREAVEMENT.PDF](https://cdn.ymaaws.com/www.naswma.org/resource/resmgr/imported/fce_2012.9_adultbereavement.pdf)

GROUP RULES

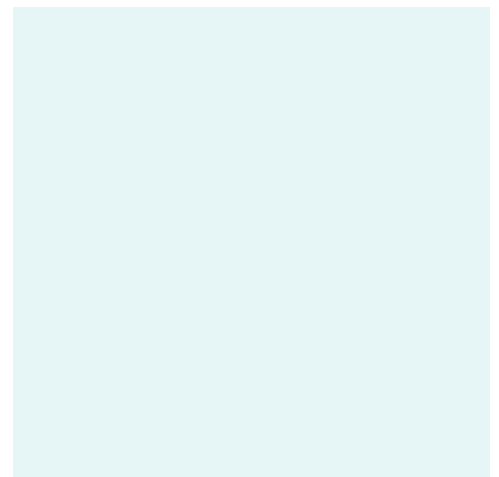
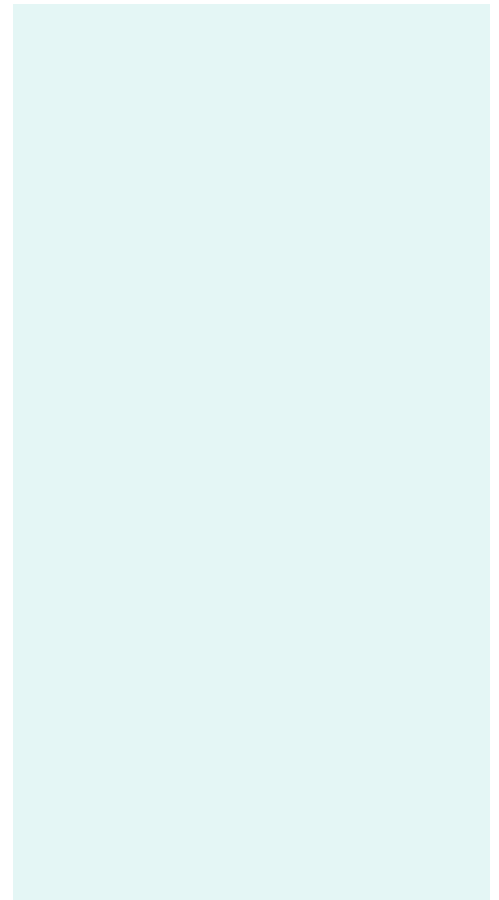
R-E-S-P-E-C-T

Like any group, mutual respect, a degree of confidentiality, and trust are all important factors to keep in the forefront of your mind. When starting a support group, setting ground rules and expectations can pave the way for respectful dialogue in the future. Below is an example of possible rules.

EXAMPLES:

1. Each person's grief is unique. While you may share some commonalities in your experiences, no two of you are exactly alike. Consequently, respect and accept both what you have in common with others and what is unique to each of you.
2. Grief is not a disease, and no "quick-fix" exists for what you are feeling. Don't set a specific timetable for how long it should take you or others to heal.
3. Feel free to talk about your grief. If, however, someone in the group decides to listen without sharing, please respect his or her preference.
4. There is a difference between actively listening to what another person is saying and expressing your own grief. Make every effort not to interrupt when someone else is speaking.
5. Thoughts, feelings and experiences shared in this group will stay in this group. Respect others' right to confidentiality. Do not use names of participants in discussions outside the group.
6. Allow each person equal time to express himself or herself so a few people don't monopolize the group's time.
7. Attend each group meeting and be on time. If you decide to leave the group before this series is complete, be willing to discuss your decision with the group.
8. Avoid "advice giving" unless it is specifically requested by a group member. If advice is not solicited, don't give it. If a group member poses a question, share ideas that helped you if you experienced a similar situation. Remember that this group is for support, not therapy.
9. Recognize that thoughts and feelings are neither right nor wrong. Enter into the thoughts and feelings of other group members without trying to change them.
10. Create an atmosphere of willing, invited sharing. If you feel pressured to talk but don't want to, say so. Your right to quiet contemplation will be respected by the group.

CREATE YOUR OWN:



LEADING YOUR GROUP

PLANNING YOUR FIRST GATHERING

If you are running an open group, this will likely work best with limited structure, as you will need to accommodate people who are coming at different times and different stages of their grief. As mentioned previously, however, it is suggested that even with this format, you allow for introductions and telling the story during each session, and time for the facilitator to summarize and close each meeting. Additionally, many of the activities and topics listed below are also appropriate for an open group.

In order for a group to be most successful, it is recommended that you have some sort of plan prior to each session, bearing in mind that there must be room for flexibility to accommodate the needs of the members at the time of the meeting.

Opening:

Having a set ritual when opening a meeting can help create structure and signal to the group that it's time to begin. This could be an ice breaker, a check-in question or a summary of the previous meeting's events.

Check-in question examples:

- Share two things you are grateful for and one thing you are struggling with.
- Share something you are looking forward to.
- Share a silly story or memory.

Middle:

This is where you dive into the topic of the meeting. This could be anything from handling stress, to managing work and childcare, or lack of support in other aspects of your life.

Closing:

Having a way to close each meeting signals that it's time to end that gathering. This could be a poem, a moment of silence, a meditation, or reflection.

Sample questions to generate good dialogue:

- How are friends and family responding to your loss?
- Where are you finding the support you need?
- Can you share some of your fears?
- What do you wish you had done differently before or after the death?
- Are there times when it doesn't seem real?
- What did you gain from your loved one that you will always have?
- What special quality did they have that you would like to develop in yourself?
- Since no one is perfect, what was your loved one's most irritating trait?
- What is the most difficult time of day? How do you manage it?
- What are your most difficult reminders (such as favorite restaurant, place where loved one died, loved one's favorite chair) and how do you deal with these?
- What new role is most difficult for you?
- Where can you go for help?

What topics would you like to discuss in your group?

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COMMUNICATION & FACILITATION

While many groups just seem to have a “perfect” flow, with people respectfully and meaningfully bonding and connecting, there are times when, as a facilitator, we are faced with some challenges. Typically these occur when people with certain agendas and personalities participate in a group. These might include:

The Interrupter

This is a person who frequently interrupts when other people are talking. Ways to manage this:

- Say “Sue, I can see you have a lot on your mind, but it’s John’s turn to talk right now.”
- If necessary, you might need to be more direct, by pointing out that this person is interrupting. Did they realize? And how can you help him/her to control this?

The Rambler

This is a person who goes on and on, as one thought reminds him of another. This person generally monopolizes the group and can cause people to lose interest. You can try:

- When there is a pause, quickly thank him/her for their thoughts and then either direct a question to someone in the group or make a statement which brings things back to the topic at hand.
- Try to find something within his/her comments which is relevant and build on it.

The Complainer

They seem to struggle with taking responsibility for any of his/her actions, or they find fault with everything, nothing is right or good, or solutions are met with negativism. You might try:

- Using one of the complaints as a launch for the direction of a discussion, by asking if others have a problem with this too, strategizing as a group on ways to address it, or asking how others have solved it.
- Pointing out that sometimes we don’t have control over the way things are, and leading a discussion on how this feels and how we can live with that.

The Expert

This is the person who seems to need to tell fellow participants how they should solve all their problems. You might manage this by:

- Thanking them for their input and then reminding them that what works for one person may not be right for another.
- You may want to remind the advice giver that, in this type of group, most often people have some idea of what they need to do in a problem situation and are not looking to be told what to do.

The Observer

We want to be respectful of people who are shy or uncomfortable talking in a group, and also realize that they can gain a great deal simply by listening. As time goes on, the silent person tends to be ignored and, even when they do want to add something, can’t find a way to interject. You might consider:

- Commenting on nonverbal signals, such as “you look amused, John” or “you seem a bit sad, Sally”, would you like to share how you are feeling?
- Try asking a question of the entire group, which you ask each person to go around the room and answer.

The Enraged

We all know that anger is a common emotion for people to experience when grieving. However, this person is one who can’t seem to move beyond their anger, and at times expresses this towards those in the group, including the facilitator. This can be dealt with by:

- Validating that feeling angry about a loss is not uncommon, and that you can hear how pained and angry he is, but that directing it at people in this group is neither helpful nor appropriate. You might then ask if he has any ideas as to how to manage it better, or ask if it would be okay for members to share how they have dealt with their anger.

BE FLEXIBLE- WITH YOUR GROUP AND YOURSELF

When you've experienced loss, you learn that sometimes you are the person that bad things happen to, and this can make you feel paralyzingly vulnerable. Perhaps loss shattered many of the assumptions you held about the world being a safe place. Now you worry because you're not sure what set of rules the world plays by. Loss and grief can teach you many lessons. Some of these lessons are useful and constructive, while others make life feel a little more challenging.

If at any point you need to step away from leading your group to protect your heart or mental health, it is okay. Protecting your heart and mental/emotional health is so important. You cannot pour from an empty cup.

Below are a few alternatives if you find leading a group too overwhelming or more than you can take on:

- Lead a book club or religious study group
- Gather to paint, sing, or express artistically
- Have an outing that allows for catching-up and vulnerability
- Send meals/cards/gifts of encouragement for families who are struggling



SOURCE:
WWW.WHATSYOURGRIEF.COM

SHARED LEADERSHIP

When planning out your group, you may want to have one or two rotating leaders to prepare for the inevitability that at some point you may not be able to run a group session. You want an alternative person to be there, ready to take the reins and support the group.

This could also be a way to mentor the next leader and support the group as it grows or changes. There may come a day when you are ready to step back from your role as a leader, and it will be helpful if you prepare your group for the passing of the baton to the next leader.



Resources

Mental Health & Grief

Websites:

www.whatsyourgrief.com - A great resource for all ages and types of grief.

<https://findtreatment.gov> - A mental health services locator. You can search by type of need, area, and insurance.

www.dougy.org - Children-specific grief resources for those supporting children through grief and loss.

www.griefrecoverymethod.com - An online grief support platform that is led by licensed counselors specializing in anticipatory grief and loss.

Books:

For One More Day, Mitch Albom

Lovely Bones, by Alice Sebold

Option B: Facing Adversity, Building Resilience, and Finding Joy, Sheryl Sandberg

Remembering with Love, by Elizabeth Levang

The Memory Keepers Daughter, Kim Edwards

The Tao of Pooh, by Benjamin Hoff

The Year of Magical Thinking, by Joan Didion

When Bad Things Happen to Good People, by Harold Kushner

Family Support

At BDSRA, we want to support you and your desire to be a leader in the Batten community. If at any time you are looking for additional resources, mentorship, or leadership opportunities, we encourage you to reach out. We are here to support each of our families as they journey along with Batten disease.

Please reach out to **Morgan DeBoth**, Vice President of Support & Advocacy via email, **mdeboth@bdsra.org** or by phone at **(614) 973-6013**. We are here to uplift, encourage and support you a long every step of the way.

