

# RESOURCES BY ILANA JACQUELINE PATIENT ADVOCACY

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## STARTING A SUPPORT GROUP

If you've looked around your local area but haven't found a support group that met your needs-- consider starting your own! Below are a few tools to help you create your own support group.

### **Finding a Place to Meet**

It is always best to meet new people in a public setting. Support groups can take place pretty much anywhere that there is a relative sense of privacy that will allow a conversation to take place. You could consider meeting at some of the following places:

- Coffee shop (Get there early to reserve seating.)
- Bookstore (Make sure to ask permission from the manager to allow a small group to gather.)
- Library (They often have meeting rooms available to the public at no cost.)
- Communal work campus (These types of spaces often rent out conference rooms for a small cost.)
- Church or temple (Places of worship also have meeting spaces that may be available for support groups.)
- Community centers (such as a YMCA or JCC)
- Hospital (Many medical-based support groups can reserve space at a local hospital, usually for no charge.)
- An outside space (If you live in a place with a moderate climate, and aren't expecting rain or snow, a park or another space outdoors could be just the right fit.)

### **Who will lead my group?**

All support groups need to have a chief organizer. If you're planning the group, that's probably you! But that doesn't mean you must lead the conversation. Many support groups consult with professionals to lead the conversation, such as a doctor, nurse, therapist, counselor, or psychologist. Clergy and non-profit leaders may also have experience in leading a support group. If you have a candidate in mind, reach out through phone, email, or in

person, and ask if they'd be willing to give an hour of their time to help the group get things rolling.

## Topics to Discuss During Your Group

Every support group is different. Some groups lay out very strict rules on conversation and others are more relaxed. There are groups that operate a topic-based meeting where there are one or two specific topics, such as dealing with chronic illness and losing friends or coping with chronic illness and medical choices. There are also curriculum-based groups that are focused around a reading and a discussion is led from there. Lastly, there is an open-forum layout that encourages free-flowing conversation. There are pros and cons to these methods. You want to make sure your attendees walk away with some constructive advice, the feeling that they've shared and been heard, and the relief of knowing they've made connections with others who are going through the same struggles.

The checklist below will help you make sure you've covered all the areas of necessity during your meeting.

- ◇ Choose and confirm your meeting space location.
- ◇ Decide on a date for your first meeting.
- ◇ Choose and confirm who will be leading the group in conversation.
- ◇ Advertise your group's first meeting by listing it in the local newspaper and on social media. Alert any local related non-profits who can help you find others in your area to invite.
- ◇ On the day of your meeting, consider picking up some provisions like snacks or drinks.
- ◇ Make sure you have copies of a sign-in sheet and a handout with your agenda and discussion

topics.

- ◇ Place signs around the area where your meeting is taking place to help people find the pre-determined area.
- ◇ Pass around the sign-in sheet.
- ◇ Follow your agenda and have a great first meeting!
- ◇ Announce the time, date, and location of your next meeting to your group.
- ◇ Allow participants a chance to break off into their own private conversations with each other.



## Discussion Topic Examples

- What is your story? Tell the group about your experience being diagnosed and how the disease has most impacted your life.
- What coping methods have worked best for you? Exercise? Art? Music? Talk therapy?
- How has your illness affected your family? Have they been supportive?
- How has your illness impacted your friendships? Have they been supportive?
- How has your illness impacted your career? Are you able to work? If not, what has been your experience with trying to obtain disability?
- How have you explained your disease to other people?
- What do you most wish that other people knew and understood about you and your disease?
- What are some things you can do to take care of yourself when you're feeling your worst?
- What feedback do you have on any recent medications or treatments that you've tried? Are there any doctors that you would like to refer to the group?
- What advice do you have this month for other patients who are struggling with something you feel you've overcome?

## Facilitation Tips

- Rephrase and repeat a problem a member is having, explaining it clearly enough that everyone understands the situation.
- Remember to allow each person to share and then allow the group to respond.
- Make sure everyone has a chance to talk.
- Make sure your group understands the issue of confidentiality. Mention that what happens in the room, stays between the people in it. Members should never bring up personal stories of other members with others. They should also never post about anything they have heard in the group on social media.

## Handouts

Here are a few links to some helpful handouts that you may want to use during your meeting

1. **Ask Me 3** (<https://npsf.site-ym.com/default.asp?page=askme3>)
2. **Building a Care Notebook** (<https://globalgenes.org/toolkits/building-a-care-notebook/carenotebook/>)
3. **How to Discuss Genetic Diseases With a Loved One**  
(<https://globalgenes.org/toolkits/discuss-genetics/intro/>)
4. **Becoming an Empowered Patients: A Toolkit for the Undiagnosed**  
(<https://globalgenes.org/toolkits/becoming-an-empowered-patient-a-toolkit-for-the-undiagnosed/introduction-2/>)
5. **Looks Can Be Deceiving** (<https://invisibledisabilities.org/ida-books-pamphlets/invisibleawareness/lookscanbedeceiving/>)
6. **Home Safety for People with Disabilities** (<http://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities>)
7. **Staying Active with Disabilities: Quick Tips**  
(<https://healthfinder.gov/HealthTopics/Category/health-conditions-and-diseases/obesity/stay-active-with-a-disability-quick-tips>)
8. **Learn About Different Types of Service Dogs**  
(<http://www.anythingpawsable.com/types-of-service-dogs/>)
9. **45 Signs of Prescription Drug Abuse** (<http://www.drugrehab.org/the-45-warning-signs-of-prescription-drug-abuse/>)
10. **NORD's Financial Assistance** (<https://rarediseases.org/for-patients-and-families/help-access-medications/financial-assistance/>)