



Starting Your Own Support Group

Anyone can start a support group. They are usually started by people directly affected by a condition or situation, and who want to help others with a similar experience. Service providers may also start a support group to address the needs of their target community and they often work well when they are used in conjunction with other services in the community.

Starting your own support group can be a highly rewarding activity. It can allow you and others access to people who are in the “same boat”, and can give you the chance to share your experiences. Here we have compiled a list pointers to consider when starting your own group.

Before Starting

- Think ahead and be clear about how much time, energy and resources you have available, and the kind of group you hope to develop.
- Do your research; see if you can find any established support groups for the same condition and/or situation. Pre-existing groups are a great resource; they can give you insight into what was involved in setting up the support group. Try to talk to the contact person and attend a meeting if possible.
- Have a look at other groups’ aims and objectives – are they different to yours? Consider whether there is a need for the particular support group you have in mind, or if pre-existing support groups already meet your needs.
- Consider if your group is local, national or even internationally focussed. Some support groups have national and international connections that strengthen their approach and outcomes.

Where to Begin

- Decide who is likely to be involved in getting the group started, will you involve a health professional?
- Decide on who your support group is aimed at, is it individuals personally affected by a genetic condition, or for family members and carers, or both? What about health professionals and other interested people?
- Is there any exclusion criteria?
- Be prepared to be flexible on this as it may be in the best interests of the group, especially when just starting out.

- Think about what you will call your group. Branding is important in associating a cause with a name.

Purpose and aims of the group

- Discuss the aims of the support group with members; what are you all hoping to get out of the group?
- Are you aiming for a Victorian group, or a National or even International group?
- How many members will the group be able to accommodate?
- A statement of purpose is useful as it describes the group's fundamental intention, and can help to focus the group
- Create a list of aims and objectives that the group would like to achieve
 - Is the group for peer support?
 - Is it to inform people about the condition?
 - Will the group be involved in lobbying and policies to try and influence positive change for people affected by the condition?
 - Is the group's main purpose to raise public awareness?

Costs

- How will the group pay for its activities?
- Will a membership fee be charged to cover items such as postage and phone calls?
- Will there be a fee to attend activities?
- Will the group seek donations?
- Who will manage this money? Consider assigning a group treasurer.
- Consider costs involved in providing refreshments, venue hire, flyers, photocopying, administration...
- Your local council, MP or library may be of assistance in donating a room or providing some funding.

Time

Choosing a convenient time for meetings depends largely on the type of group and its members. Evenings may be ideal if members attend school or work during the day, but if members are too tired at night, a weekend meeting might be best. Try to keep meetings brief; it is more likely that people can give up 2 or 3 hours than their whole day to attend meetings.

Location

- Selecting a location may require detailed consideration
- Some groups meet in members' homes, with each member taking their turn. This may suit the nature of your group perfectly, or it may result in potential privacy, liability and/or security issues.

- It is also preferable to be able to have a consistent meeting place to avoid members missing meetings due to confusion.
- Larger groups may need to be held at a local hospital, school, college, community centre, or library. Again weigh up the pros and cons of these locations, for example some people may have concerns regarding their privacy when meetings are held at public places such as libraries during opening hours.
- Try to make meeting places as central and accessible to your members as possible
- Consider public transport, parking, safety, wheelchair access, facilities and crèche availability
- If the members of your group are housebound, unable to travel, or individuals are reluctant to participate in face to face meetings, you may want to consider creating an online support group.

Frequency

- Decide how often to meet.
- Frequency will probably depend on the emotional and practical needs of the members and will relate to the nature of the support group itself
- Frequency may also change with needs, if an urgent issue arises for example
- Meeting once a month may be easiest to remember, such as the first Saturday of the month
- Try to decide on a schedule and keep to it to ensure the group is reliable.

Establish a contact person

A contact person is the first line of communication between the public and the group. The contact person answers questions about the group, gives details about meetings, and provides referrals and/or support to interested callers. Establish preferred contact times, and an after hours contact such as an answering machine service and/or an alternative contact number.

Recruit members

Advertise your group! Use a variety of ways to get the word out:

- Talk to others who may have an interest in the same issue
- Speak to health professionals such as your GP and specialists who may be able to pass information on to potential members
- Use flyers in appropriate places (remember to ask permission)
- If possible advertise in a community paper, or enquire about having a story written about your group.

The First meeting!

There is no absolute right way to run a meeting. Working from a guide or agenda can help reduce nerves and keep the group focused. Your meeting may be an informal meeting where people share their experiences over a cup of coffee, or a more structured meeting adhering to specific agenda items.

Ensure that the meeting takes place in a relaxed, safe and friendly environment. Remember people may be sharing their experiences for the first time.

Suggested format for meetings

1. Meet and greet
Provide name tags or a sign in sheet and/or information pack including the group's statement of purpose, aims and objectives, group rules, relevant contact numbers and potentially a disclaimer if appropriate.
2. Welcome
Start on time and open with a brief welcome, introduce yourself, explain the location of toilets and other relevant facilities, state the purpose of the meeting (often the purpose of the first meeting is organisation), and note the closing time of the meeting.
3. Introductions
Go around the room and ask people to introduce themselves, their reason for attending and what they hope to achieve. Clarify that disclosing personal details is voluntary.
4. Establish Ground Rules
For example, privacy and confidentiality, one person speaks at a time, respect for other members in the group at all times.
5. Brainstorm ideas and objectives
Narrow the list to the main goals that are achievable.
6. Closing the meeting
Set a date, time and place for the next meeting and delegate any tasks. Ensure that people know that they have the opportunity to attend a few meetings before feeling obliged to join. Some attendees may wish to exchange contact details. Thank people for coming.

Organise your meetings

- After the first few meetings, decide how often the group will meet with input from members. Try and keep the meetings at the same time, day of the week and venue if possible to allow members to plan their lives accordingly.
- Decide on topics - will each meeting have a particular discussion topic?
- Should there be guest speakers?

- Will they be informal sharing of experience over coffee?
- Should family members attend, or should there be a separate group for them?

Group Activities

- Will the group have a formal or informal group structure?
- Will the group provide telephone support?
- Will communication be via phone/email, internet, newsletters...?
- Will there be planned social activities?

Privacy

Have a clearly defined privacy statement right from the start to ensure shared experiences stay amongst the groups. This will help people to feel more comfortable contributing to the group. General privacy rules also apply to the use of social media and group communications, such as the use of photos and personal stories.

Equip your group with resources

Participate in peer support programs such as those run by the GSNV so that members of your group are best equipped and competent to provide peer support to those in need. Consider contacting relevant professionals who members can be referred onto for further support if need be, or have them present at occasional meetings to provide information for all members.

Tips

- Remember that a support group is fluid. After you set up your group, you may find that members would like a different time, place, or frequency to the meetings. Be prepared to make compromises and changes as your group grows, it may be in the group's best interests.
- Try not to offer advice, particularly not medical or treatment advice. Whilst support groups are a great way to meet up with others 'in the same boat' it is important to recognise that everyone's experience will be different and what has worked, or been the experience for one person, won't necessarily be for another.

The GSNV can assist you in starting your new group through:

- Organising a meeting with the Education and Peer Support Coordinator to discuss setting up your support group
- [Peer Support Training](#) workshops
- Support for Peer Supporters
- Small Grants Project - advertised in GSNV newsletters
- Advertising your group and events in the GSNV Newsletter
- Listing your group on the GSNV Website
- Referring other interested persons to your group
- Information sheets for support groups
- Provide Information packs for enquiries
- [Quick Links](#)

If you need further help or have any questions regarding starting your own support group have a look at our list of resources, or feel free to [contact us](#).

References:

Start a Support Group By Amber J. Tresca

<http://ibdcrohns.about.com/od/mentalhealth/ht/Start-A-Support-Group.htm>

<http://www.haruteq.com/howtosupport.htm>

<http://www.autism-help.org/family-starting-support-group.htm>