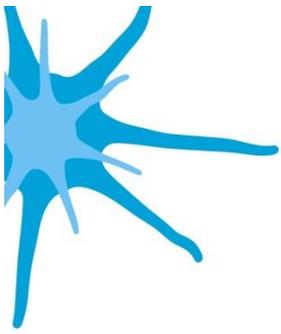


# Supporting you

# Supporting others

How to run a successful epilepsy group



Supporting you

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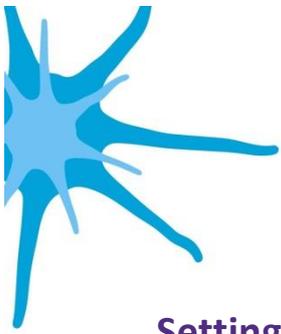
How to run a successful epilepsy group

## Starting a Support Group

This pack may help you if you are thinking of setting up a support group. It also gives you some tips on how to be part of a successful group and some hints on what to do if things go wrong.

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#### Setting up a Support Group – where to begin

Support groups bring people affected by epilepsy together. There can be many different reasons why people want to join a support group and members often find they offer lots of different benefits. These can include:

- being part of a supportive network
- finding out more about epilepsy
- giving and receiving support

Setting up a support group can be a really rewarding experience and can give yourself and others a sense of community and mutual support.

Support groups can take different forms. You may want to have an informal meeting where people with experience of epilepsy meet and chat. Informal gatherings can be very effective particularly to start with. If you decide to have an informal group there is not much organising and coordination to be done. If you feel you want to start up a formal group we have lots of information for you – read on!

#### Informal Support Groups

Easy to run

Take up minimal time

Can create a support network amongst those involved

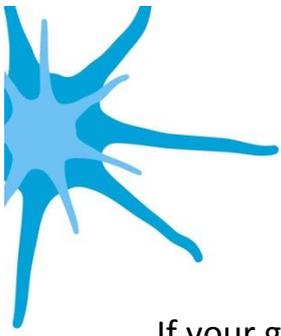
#### Formal Support Groups

Run by committee

Offer organised activities and support

Can bring a sense of community and mutual support

Starting a more formal group is much easier if you can find a team of people who are all willing to help and take on some of the responsibilities. This type of group may even evolve out of informal support group meetings. If you don't know anyone else who wants to help start a support group, finding people to help could be a good place to begin. There are some ideas on how to do this in the 'advertising' section below.



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If your group begins to evolve and becomes more formal, it is good to share the workload as much as possible from the beginning. This can make it easier to delegate tasks as the group grows and develops. Some people may be able to offer a lot of time, others may just want to take on one small task. Be realistic about what you can achieve, both as a group and as individuals.

Before you start, think about:

- What do you want to get from the group?
- What can you offer in return?

Finding out what motivated someone to come along to the group can help identify if there is a suitable role for them within the group.

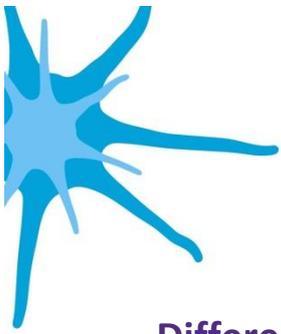
Getting things right from the beginning can make it easier as the group evolves. Here are some tips:

- get to know each other
- welcome new people
- find out what people want from the group
- discover what skills people can offer
- try to communicate clearly within the group
- share tasks and responsibilities
- be aware of how people are feeling and ask for comments
- ensure meetings are at a suitable time and place for everyone
- make sure the venue is accessible

If you create clear group rules everyone should know how they are expected to behave. These rules could include confidentiality and respecting other people's opinions.

Watch out for:

- people not speaking much as they may be feeling that their voice is not being heard
- people not sharing responsibilities
- leaving strong differences of opinion unresolved
- one person taking 'ownership' of the group and pushing forward their ideas all the time



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### Different types of support group

There are many different ways of running a support group and each group is unique. There is no standard 'good model' but it is important to be clear about what your group wants to achieve. People coming along to the group need to know what you are offering. What is the support group trying to achieve? Are you going to meet informally for a chat on a regular basis, or do you want to offer people more than this?

You could think about what type of support your group will offer. There are a variety of options, such as:

- informal meeting
- emotional support
- talks and events
- practical help like transport to appointments or home visits
- social events like cinema or bowling
- on-line or telephone support to members
- linking with an epilepsy specialist nurse or epilepsy fieldworker

The type of things your support group will be able to offer will vary depending on the amount of time and energy group members have to offer and your local resources.

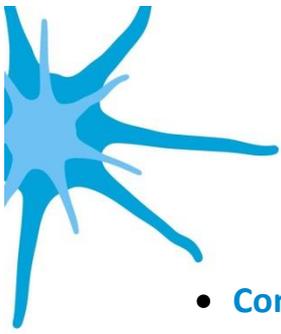
You may want to decide if anyone can attend or if your group will only be open to specific people. For example:

- people who have epilepsy
- parents who have a child with epilepsy
- a certain age group like teenagers or people who are retired
- people who live with (or care for) someone who has epilepsy

Once you have a clear outline of the type of support group your team wants to set up, you may want to consider more practical matters.

### Practical considerations

There are a lot of things to consider before starting a support group. These include:



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- **Contact?** How will people contact your group? You could have one email account that several people can access and a mobile phone number solely used for the group. The mobile phone could then be passed around different group members as necessary. This way the contact number and email address will always remain the same, so you don't need to update your adverts if one person leaves.
- **When?** Will your group always meet on the same day of the week or month or will it vary? How often will the group meet? What time of day would be most suitable? For example, evening meetings may be difficult for people with children and daytime meetings may be more difficult for people who work.
- **Where?** There are different things to consider in finding the right venue for a meeting. These include: accessibility, transport links, parking, privacy, safety and cost. Will the venue change each time or will you always meet in the same place? It can help to meet in a neutral place like an NHS building or community centre.
- **Who?** Who do you want to come to the group and how will you let them know about the group?
- **Formal or informal group?** How will your group be set up and run? See 'Further support' for help setting up a formal group.
- **Name?** What will you call your group?
- **Skills and resources?** What skills and experience does everyone bring to the group? Finding this out may help shape the way the group operates.
- **Face to face or on-line?** In more remote areas support groups may not be able to have regular face to face meetings. You could use SKYPE to have on-line conference meetings, or create a Facebook based support group.

It is worth remembering that people may not feel comfortable witnessing other people having seizures. You could think about what to do if someone in the group has a seizure. Is there someone in the group who would want to be nominated as 'seizure responder' to provide first aid as needed?



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#### **Roles within the group**

Roles within the group should be shared. Each person will bring a unique set of skills to offer and have a different amount of time they can give to the group.

If you are planning a more formal group it can be helpful to create job descriptions for each of the main roles. This can help people decide if they have the skills and abilities to step into that role. You could split the less exciting jobs so they are not one person's responsibility. It is important to find out what people want to offer, rather than expecting someone with a particular skill set to step into a particular role. If a person is unsure about taking on a role, they could 'buddy' whoever is doing the job to find out what is involved. This also allows existing committee members to share their knowledge. You could also consider re-electing the committee each year.

Key posts within support groups include:

- Chairperson
- Secretary
- Treasurer

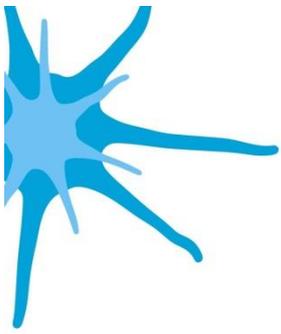
And for some larger groups:

- Fundraiser
- New Member Officer
- Communications and Public Relations
- Seizure Responder

It can be helpful to have an idea of what may be encouraging (or discouraging) people from taking on new responsibilities. Ask for feedback.

You may be able to offer someone:

- the ability to cope better with their epilepsy
- a way of gaining new skills and trying something different
- a way to be part of a team and make new friends
- a boost to their confidence



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Some of the reasons why people may not want to take on a new responsibility include:

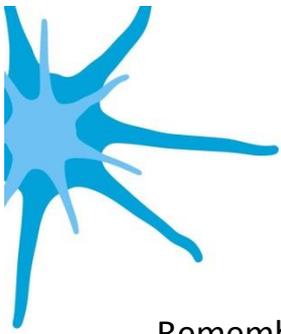
- feeling overburdened or unable to cope
- lack of self-confidence
- not getting on with other members
- frequent seizures or feeling ill
- fearing they will be unsupported in the role

Sometimes you may have to turn down an offer of help in a key role. For example if the person does not have the skills to do a particular task, is not very good at listening, or needs more support to do a task than you can offer. Turning down an offer of help can be difficult, but it is better to do this before someone starts than to let them down once they are established in a role. You could let the person know that you are grateful for their offer of help, and discuss your concerns in a sensitive way. Is there a way you could support this person to take on the responsibility? Is there another task that would be more suitable?

You may decide to run your group without a committee. This can work well for more informal groups and allows everyone to feel equal. It is important to decide who will do particular jobs, for example advertising the next meeting. This can help people to try different things and find out what they like to do or are good at.

### Welcoming newcomers

For some people it can take courage to come along to a support group for the first time. It is really important that new members are made to feel comfortable and leave feeling encouraged to return. New members may feel more comfortable if they have had previous contact with someone who will be at the meeting. This could be someone they have spoken to over the phone or a named contact they have been given.



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Remember that first impressions last, so it is important to get it right. Things to consider include:

- make the environment as comfortable as possible and offer refreshments
- make sure the venue is clearly signposted
- try to keep things informal, relaxed and friendly
- show an interest in the person without appearing nosey
- hand out a leaflet giving more information about the group
- encourage the person to come back

It can help to ask new members open questions (i.e. ones which do not have a yes or no answer). Remember that they may not want to disclose any personal information. You could ask:

- How did they hear about the group?
- Which other members do they know (if any)?
- What are they hoping to get from the group?

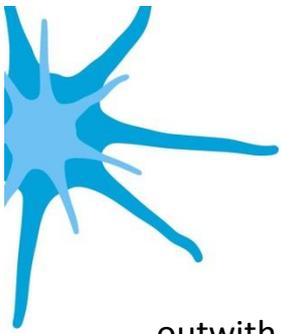
You may want to consider giving one person the responsibility of welcoming new members to the group and helping them to feel settled. Ensure members introduce themselves to the newcomer without overwhelming them. You could encourage newcomers to bring a friend or family member with them, if it would make them more comfortable.

### **Making the most of meetings**

It can help to have a basic plan for each meeting. For example you may want to choose a topic for discussion at the meeting. Some meetings have an agenda, with one person acting as chairperson and someone else taking minutes. Other groups have an activity focus, for example going bowling or visiting a museum. Sometimes you could organise a guest speaker or specific training for group members.

### **Confidentiality**

It is important to create a safe environment within your group. Groups vary in size and nature, but people need to feel confident that anything they share with one group member will not be shared with other group members, or



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outwith the group, without their permission. It only takes one breach of confidentiality to negatively affect the whole group. In a conversation you could say that what you are disclosing is sensitive, and who the information can be shared with. This will help to avoid any confusion. To create a safe group environment you could:

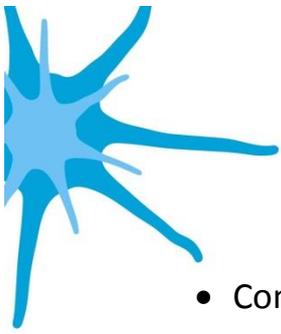
- agree if what is said within the group can be shared or if it is to be kept confidential (explain that confidential means not sharing it with other people outside the room/group)
- create clear rules about how you expect group members to behave
- check that everyone understands the importance of following the confidentiality rules

Some groups have a leaflet to hand to new members giving them more information about the group. This could include a section on group rules and confidentiality.

### Advertising

Advertising is a great way of attracting newcomers to the group. There are a variety of different ways you could do this:

- Epilepsy Scotland can help advertise details of your group on their website, Facebook and twitter pages.
- Find some local papers or magazines which offer free event listings for support groups.
- Put up posters advertising the group in your local area (i.e. shops, dentists, GP surgeries, pharmacies, community centres, hospitals and public notice boards around town).
- Have a visible presence at local community events like an information stand or table.
- Use social media to network with your local community (for example create a Facebook page or use twitter).
- Speak to the editorial staff at your local paper and ask if they will run a story about your group. It is good if this can be tied into a specific event like the group beginning, an anniversary, having a guest speaker or another special occasion.



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- Contact other local organisations who may be able to help promote your group.
- Create links with local epilepsy specialists, nurses or other medical professionals and let them know about your group.

### Fundraising

Your group may want to set up a bank account and raise funds to help cover expenses. These may include venue hire, expenses for speakers, advertising and printing costs, or buying equipment. Successful fundraising can also help to publicise your group. There are a number of ways in which you could raise money. These include:

- bring and buy sale
- sponsored event
- coffee morning
- pub quiz
- plant sale
- silent auction
- tombola
- raffle
- Christmas fare
- pamper evening

You could also choose to raise money to support Epilepsy Scotland's work nationally. If that is something you would like to do, please get in touch.

### Common problem areas

Groups can encounter difficulties which can ultimately cause a group to close. If you are aware of the more common problems, you are more able to identify these and make any necessary changes to your group.

#### 1. Organisational problems:

- a. Not enough people to do all the work:** This tends to happen if one person takes on too much responsibility or if the tasks are not divided up thoughtfully. Also if people repeatedly agree they will do things and then don't. Be realistic about what your group can achieve and encourage members to take on a task they feel comfortable doing.

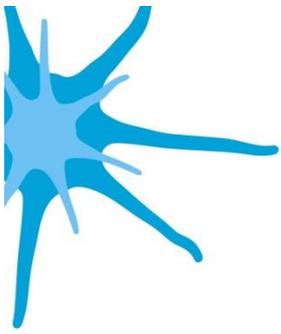


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- b. Financial difficulties:** Look at how much money your group is spending and where your income comes from. Could you reduce your costs by changing to a different venue or run an event to generate funds for your group? You may be able to get a grant to help cover the costs of running your group. You could try your local authority or the National Lottery.
- c. The group is controlled by a few individuals:** If a group does not take into account the needs of all its members, difficulties can arise or people will leave the group. If you have a chairperson, they can help to ensure that different opinions are heard and respected. Limiting the time someone holds a key role in the group can help. Each year all the post holders could step down. This allows group members to nominate who they would like to stand and then elect a new committee (which may include some post holders from the previous year).
- d. Members do not feel included:** It is important that people are willing to be open and honest with each other and that there is good communication within the group. Some people may be less vocal than others, but this does not mean that their opinion is less valuable. A good chair person can help to ensure that everyone's voice is heard. A healthy group will be motivated, have good communication, have a common purpose, respect for all its members and be willing to take on new issues. If people are not able to make it to a meeting, it could be someone's role to keep in touch with them. In some groups, especially in rural areas, members pair up with each other and keep in contact between meetings.
- e. Falling membership:** If your group has problems keeping members or attracting new members you could consider why this might be:
- What would be someone's first impression of the group?
  - Are new members made to feel welcome?
  - Does someone have the role of welcoming new members?
  - Could the location or timing of the meeting be making it more difficult for people to attend?
  - Could new people feel overwhelmed? Why might this be and what could you change?
  - How are you advertising the group? See the 'advertising' section for more ideas.
  - Are people's needs and expectations being met by the group?



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Could you contact people who haven't been for a while and ask them why they stopped coming along?

#### 2. Problems with people:

**a. People not getting on:** Can you encourage people who are not getting on to sit down and talk about why they are experiencing difficulties? It may be helpful if there is a neutral party who can help to listen to both parties and reflect back what the issues seem to be. Perhaps there is someone in your group who has wisdom, diplomacy and tact?

**b. Key members find it difficult to take a step back:** If someone has been involved with the group from the start they can have a strong sense of attachment. This can make it difficult for them to give up their responsibility. The group can work together to gently encourage and support the person to let go.

**c. Inappropriate behaviour:** If you agree from the start how you expect people to behave and create clear group rules to reflect this, it can help to identify inappropriate behaviour. This can then be resolved with reference to the group rules you have agreed on and with the support of the group. Remember these rules may develop or change over time as the group grows.

**d. Dominating behaviour:** If one person is dominating the group the chair person or committee members may want to become involved. They could have a quiet word with the person encouraging them to include other members.

### Resolving disagreements

Disagreements amongst groups of people are part of a natural process. They can generate healthy discussion, allowing people to see things from a different viewpoint. This can be a learning experience and lead to personal growth. Strong disagreements, if handled sensitively, can also allow relationships within the group to grow as people understand each other better. This can improve how a group is run in the future. However, this kind of conflict is problematic when it has a negative impact on the group, for example diverting people's

**Helpline:** 0808 800 2200 **Text:** 07786 209 501 **Email:** [helpline@epilepsyscotland.org.uk](mailto:helpline@epilepsyscotland.org.uk)



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energy away from the main purpose of the group or threatening to break down the structure of the group.

Successfully resolving such disagreements can have many benefits. These include a better understanding between members of the group, a healthier way of working together, and helping to develop personal understanding and awareness.

To try to resolve a disagreement there are a number of things to keep in mind:

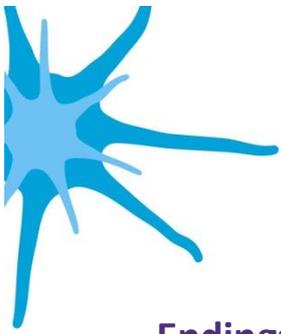
- be clear of the facts and try to understand why the conflict came about
- remember that differences are normal and try to keep things in perspective
- be respectful to the individuals involved
- learn from this and try avoid similar situations from happening in the future

If you are trying to resolve a serious disagreement, the first step may be to invite those involved in the disagreement to meet and outline what is making them unhappy. The chairperson or a small sub group could agree to listen and try to identify the issues and help resolve things. Alternatively those who are unhappy may wish to make their points before the whole group. It may be better if this discussion is helped along by someone who has had previous experience in resolving disagreements. The people involved in the conflict are central to the process of resolving it.

The stages in resolving a disagreement are:

1. discussion
2. negotiation
3. finding a resolution
4. making changes

If it is not possible to resolve disagreement within the group, you could ask a third party to help. Ideally this should be someone with mediation skills. It is important to be clear how the third party can best support you. Are they there to allow everyone to have their say and make sure they are listened to, supporting the people to resolve things themselves? Alternatively you may want them to play a more active role in helping to resolve the disagreement.



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### Endings

Support groups come and go and this is a natural process. Support groups arise because of a need. If this need changes, or people move on with their lives, support groups can come to an end. If people stop coming to your support group the first step is to try to identify why this may be. Some of the common reasons are listed above. If you can't identify a reason it may be that people have received the support they needed and have moved on with their lives. This type of ending is positive and can be a sign that the group has been successful.

### Further support

#### Epilepsy Scotland

Epilepsy Scotland can help support groups in a variety of ways:

- by passing on your contact details to the people who call our helpline looking for support in your area
- by helping to promote your group via our website and social networking pages
- by giving support and information to groups by email, phone, text message or social media
- providing information to display at events

#### Setting up a formal group

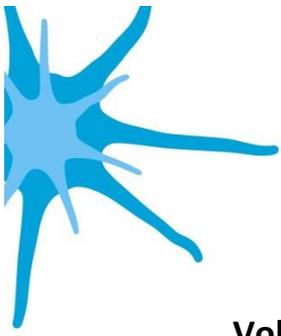
If you are thinking of setting up a formal group the following organisations can give you information and advice:

**Scottish Council for Voluntary Organisation (SCVO)** will be able to help you decide which type of group would be most suitable, and how to go about setting this up.

Telephone: 0800 169 0022

Website: <http://www.scvo.org.uk/>

Email: [enquiries@scvo.org.uk](mailto:enquiries@scvo.org.uk)



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**Voluntary Action Scotland** will be able to put you in touch with your local 'Third Sector Interface'. Each local authority area in Scotland has a 'Third Sector Interface' to support, promote, develop and represent community groups and voluntary organisations.

Telephone: 01324 692025

Website: <http://www.voluntaryactionscotland.org.uk/>

Email: [info@voluntaryactionscotland.org.uk](mailto:info@voluntaryactionscotland.org.uk)

**Office of the Scottish Charity Register (OSCR)** will be able to support you if you want to set your organisation up as a charity.

Telephone: 01382 220446

Website: <http://www.oscr.org.uk>

Email: [info@oscr.org.uk](mailto:info@oscr.org.uk)

This guide is not an exhaustive list of issues to consider but we hope this gives you some ideas for your own group. We are always happy to receive any feedback and if there is anything else you think should be included in this guide, please contact us.