

National support groups - questions before you start

group action pack

Starting up

You are probably thinking of starting a national group because you see the benefits of bringing together parents of children who share your own child's condition. It is helpful at this stage to consider what is most important to you - would you be happy just being in contact with another family or do you think there is a need for something more structured? Do your family commitments limit the time you have available to spend on a national group?

You should carefully consider whether starting a national group is right for you and your family and whether now is the right time. You can always reconsider your position in the future if you decide not to go ahead at this stage.

Once you start, you will be getting enquiries from all over the country. It is unlikely that you will be able to meet with any other parents at this stage. However, contact by letter and telephone can be just as effective in building support and sharing experience and information.

Questions to consider

Why do I want to start a group?

National groups are set up for a number of reasons. Contact with other parents is the most common. Sharing experiences and information is also important, especially when your child has a particular condition or disability. If you have only recently been given your child's diagnosis it may not be the best time to set up a group.

Is there a group already covering this condition?

Find out if a group for this condition already exists. If so, you might like to offer to help in some way. Alternatively, there may be a local branch where you will be able to meet other parents on a regular basis. Where a national group already exists Contact a Family would not recommend setting up another.

contact a family
for families with disabled children

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Incorporating
The Lady Hoare Trust

What type of group should I start?

It is not necessary for groups to provide a wide range of information, hold events, raise large amounts of money or register as a charity, although some groups will want to do all of these things. There are many very small and informal groups in existence which provide a valuable service to the families they are in contact with.

All groups are different but they usually fit into one of the following categories:

Type	Activities
Website	Website with information about the condition and usually details of how to access a chat room or message board facility for members. There may or may not be a telephone number to contact a representative, but if there is not this will exclude families without internet access.
Parents network	These usually have a small number of families who contact each other on an informal basis. The aim is simply for families to provide mutual support. They need a contact person who will link in any new families who contact.
Contact group	A group with a larger number of families taking on more functions e.g. newsletter, annual event. May be a registered charity or considering registration.
Support group	A larger group with a committee, list of aims and formal membership. It is likely that a group of this size will be a registered charity.
Umbrella organisations	These provide support and representation for a number of related disorders e.g. Headlines for craniofacial conditions and CLIMB for metabolic disorders.

A network may be the best option where;

- the time you have is limited
- there are only a very small number of families affected by the disorder in the UK
- you want to concentrate on support and contact with other parents
- you are not looking to set up a formal group

Even if you would like to set up a more formal group it may be best to start with a network while you contact other families and they decide if they are interested. This may take some time. When you have a number of families interested in running a group you can then make things more formal.

What will be involved?

During the early stages the most important tasks will be making contact with other parents and raising awareness of the group's existence. You will probably have to write to

interested professionals to let them know that a group is being set up and ask them to pass on the information to other families (see below). You may want to draw up a standard letter that could be sent out to interested parents, introducing yourself and telling them what the group is trying to do (see below). You must stress to parents or professional workers that you are not a medical information service - if you do have some information on the condition it should be clear that this has been written by a medical professional who is a specialist in the condition.

What skills will be needed?

It is important that you know how to listen and respond sympathetically and sensitively to parents who telephone or write to you. For many you will be the first person they contact who has some idea of what they are experiencing. You should be able to write letters that are supportive and it is essential to deal promptly with enquiries. Organising your time and the workload are important skills, especially as you will have other family commitments. As the group grows you will be able to involve other parents in sharing tasks.

Will it intrude on family life?

The support of your family in this venture is essential. It will help to organise the time you spend on the group so that it does not intrude too much on family life. It will also help if you can share group tasks with others. You should make other parents and professional workers aware that you are a parent caring for a child with the same condition. Telephone calls can be the most intrusive element to deal with, especially in the evening when you are trying to put the children to bed. Using an answer phone at these times, or arranging a mutually convenient time to call back, are possible solutions. It is better to contact other parents when you can give them your full attention rather than rush a conversation.

How much will it cost?

Some costs will be incurred in the early stages, but these should be minimal and will include postage, photocopying and paper. As the group develops small fundraising events may provide the money needed to keep the group going. Some parents may come up with alternative offers of help, such as providing stamps to send out information.

How much time will it involve?

This is difficult to predict and will depend largely on the rarity of the condition and the suspected number of affected families. Raising awareness of the group's existence in the early stages, through letter writing and personal contact, will take time. However, this responsibility could be shared with other parents. As the group develops the time needed may be less. It may help if you allocate a certain time in the day to deal with tasks, such as responding to letters.

Who will contact me?

Most enquiries will come from parents, family members or friends of the family caring for a child with the same condition. Professional workers, such as health visitors, social workers and community workers may also contact you for information, usually because they are involved with a family caring for a child with this condition and would like to know more about it. Occasionally there may be enquiries that may be better referred onwards, such as

where a family has not been given a diagnosis but thinks their child may have the same condition. Here, it is best to refer the family on to Contact a Family which can offer general support while they are seeking a diagnosis.

How will I be able to help?

The most important help you can give families contacting you is to let them talk about their situation and listen to them. This does not mean you will have to take on the role of a counsellor. Many parents contacting you will not have anything specific to ask but will just be pleased to talk with another parent who understands some of what they are experiencing.

What if I am unable to help?

Sometimes you may be asked for information you are unable to supply. You will need to make it clear, especially to professional workers, that you have limited information available. For more specific enquiries about issues such as education, benefits or individual problems you can refer enquirers on to the Contact a Family Freephone Helpline. You may not be able to help a family with their specific enquiry, but you can refer them to other sources of help and information.

Will other parents be involved?

Involving other parents will help to share the various tasks the group requires. However, it may take time to develop such involvement as it will depend on individual circumstances and the willingness of others to become committed.

What happens if family circumstances change?

Most parents caring for a child with a specific condition or disability will find themselves having to cope with the changing needs of the child, as well as the needs of other family members. This can make it difficult to cope with other demands on time. You may find that family demands make it difficult to manage the group, or that you need to stand back from the group for a while or even permanently. If this happens, everyone will appreciate that your family must take priority.

Who will support me?

It is important that you feel you have support. This may be friends or family, but very often there will be another parent, maybe someone in the group, to whom you can turn when there is a difficulty. Contact a Family development staff can also offer advice, support and a listening ear at any stage.

If you have decided you would like to set up a national group and are interested in the next steps, see the guide *Starting a national group* (Contact a Family, Group Action Pack).

Contact a Family development staff are available at any stage of the group development if you would like to speak to someone for advice.

This guide is part of the Contact a Family Group Action Pack. For more information please visit <http://www.cafamily.org.uk> or telephone 020 7608 8700.

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