

# **SICKLE CELL**

## **GUIDELINES FOR SETTING UP AND RUNNING A SUPPORT GROUP**



**INFORMATION, COUNSELLING  
AND CARING FOR THOSE WITH  
SICKLE CELL DISORDERS  
AND THEIR FAMILIES**

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## Introduction:

The Sickle Cell Society (called in these guidelines “the Society”) is a national charity (registration number 104 6631) founded in 1979 by people in North West London who were sufferers from sickle cell disorder or had sufferers in their families or were working professionally with sufferers.

This group successfully increased local public interest in sickle cell disorders, provided support and practical assistance to sufferers and those looking after them, and raised money to improve screening and treatment in local hospitals.

The Society believes that the group’s success is owed largely to the close involvement in it of people who suffer the effects of the disorder. It is they who, after all, have most to gain from, and so most motivation to obtain, relief from the disorder. At the same time the efforts of those who do not suffer this way are also essential if the disease is to be effectively tackled, and such people should also be encouraged to join in.

### **1. Why the need for Support Groups?**

The society believes that great benefit to sufferers and their families can come from such groups and wishes to encourage their formation in all areas where there are people liable to sickle cell disorder.

There are many advantages to a Support Group, to the Society and to the general cause of tackling sickle cell disorder.

Support Group linked to the Society has support from the Society. The society is well known nationally and activities organised in its name are likely to attract more attention.

The Society, which receives calls for assistance from all over the country is able through Support Groups to know the services available in each area and ensure that people are directed where they will get most benefit.

## **2 What is a Support Group?**

1.1 A Support Group is a group of people who support the aims and objectives of the Sickle Cell Society deciding that they would like to work together to provide services in their local area.

1.2

1.3 As far as the law is concerned it does not matter much whether the group describes itself as a support group or as a local group or any other name. In practice the society encourages the use of its name e.g. "Berkshire Sickle Cell" or East London Sickle Cell Society".

## **3 How to set up a Support Group**

### **3.1 Make contacts**

It is advisable to make contact with a variety of local organisations. These might include the Haematology Department at any local hospital, the Social Services Department of the local Authority, the local Community Relations Council, the Community Health Council, and any West Indian or African organisation which are active in your area. Do not be disheartened if some of these organisations give you qualified or no support.

### **3.2 Inaugural meeting**

The next step would depend partly on circumstances. It could be to hold an inaugural meeting to which you should invite all who express support together with anyone else interested. Get as much publicity in advance for the meeting as you possibly can. This will enable you to reach as wide a section of those affected by sickle cell disease as possible.

At the meeting you could have a speaker from the Society as well as local ones and then have a discussion on setting up a Support Group and its activities. It is also a good idea before the meeting to have asked a few people whether they would arrange a time for their first meeting.

### **Alternative**

An alternative is for a number of individuals to form a committee without a public meeting

Whichever way the group is set up it is important to have a variety of different interests involved in its running.

### 3.3 Committee

3.3.1. At its first meeting the committee should appoint officers ( if that has not already been done at an inaugural meeting) and arrange for its own procedures, including handling money, dates and times of meetings and who is to do what.

3.3.2. The second task for the newly formed committee is to get on with the arrangements for the activities of the support group.

3.3.3. The third task will be to make long term administrative arrangements for the support group (e.g. annual general meetings, election of committee, etc.).

A reasonable active Support Group will have a committee which meets at regular intervals. There will usually be a secretary who will be responsible for convening meetings, taking minutes and conducting correspondence. It is important that accurate minutes of decisions are taken as this can avoid arguments in the future.

There is also likely to be a Chairperson whose main duty is to preside at these meetings.

A Finance Officer or Treasurer is a necessity where any cash is handled.

## **2 Functions of a Support Group**

### 4.1 Mutual support and assistance

One of the most useful functions of a Support Group is to enable people affected by sickle cell disorder to associate, exchange information and give each other practical assistance and moral support. It gives a tremendous psychological boost to an isolated family coping with sickle cell disease to meet others in the same predicament. Mutual self-help is a means of involving a whole range of people with different abilities in a Support Group. At the same time it can be the beginning of pressure for improvements in local facilities relating to sickle cell disorder.

The form of these activities is not important. They could be either regular (e.g. monthly) or more informal contacts at whatever times and place suits the participants.

## 4.2 **Public education**

A second activity (which normally requires more financial resources) is a programme for public education about sickle cell disease. Meetings, lectures, slide shows, film shows and classes can be organized. Leaflets can be issued, advertisements displayed and press and local radio and television publicity obtained. Educational programmes can (in addition to their educational value) have the effect of drawing into the group more people who are interested in joining in its activities as well as attracting finance.

## 4.3 **Improving health service provision**

The monitoring of local provision in hospitals and the health service in respect of sickle cell disorder is again something which a Support Group would wish to carry out. It is worth comparing the facilities in your area with those available in other areas both in Britain and abroad in order to find out what improvements can most beneficially be applied in your area. Obviously this kind of activity is made more effective if there are good relations between the Support Group and the local health service, but if the health service locally is resistant to changes and suggestions then the local people will have to find means of getting it to be more responsive.

## 4.4 **Recreation and social activities**

Another function of Support Groups is organising social events and recreation for people affected by sickle cell disease.

## 4.5 **Fund-raising**

Another major activity of a Support Group is fund-raising. Many forms of fund-raising are possible: collections, dances, concerts, sponsored walks, grants from local authorities, etc.

The Society can provide assistance, both material (e.g. literature, newsletters, film shows equipment, etc.) and moral (technical advice, speakers, encouragement) with all these activities and particularly help where a Support Group meets opposition from within the local health service.