

Setting up Family and Survivor Support Groups

This guide has been written by members of Disaster Action, who are survivors and bereaved people from disasters. The disasters we have been affected by include the Zeebrugge ferry sinking, King's Cross underground fire, Lockerbie aircraft bombing, Hillsborough football stadium crush, Marchioness riverboat sinking, Dunblane shootings, Southall and Ladbroke Grove train crashes, the 11th September attacks, the South East Asian Tsunami and the Bali, London 7 July and Sharm El Sheikh bombings and other recent terrorist attacks and transportation disasters.

The aim of this leaflet is to help those setting up their own support groups after a disaster by sharing the lessons from our common experiences.

What is a disaster family and/or survivor support group?

A family and/or survivor support group is a group of people affected by the same disaster who support each other by sharing information, giving each other emotional and practical support and/or by focusing on issues important to them. The group can include bereaved family members, survivors and their families and others affected by the disaster. Depending on the circumstances of the disaster and the needs of the members, any group that emerges may be large or small, or divided into smaller sub-groups.

Why do you need a group?

People affected by a disaster often feel that the lasting effects of what has happened to them can only be fully understood by those who share experience of the same event.

Following any disaster, whatever its cause, there are likely to be practical problems to overcome. Any inquest and/or criminal inquiry process can be easier to cope with if you have the support and understanding of others affected. The process of seeking help from government services, voluntary agencies, the legal profession or insurance companies can also seem fraught with difficulty. Support groups, in which you can offer each other advice and suggestions about how to deal with specific issues, can be very helpful. A group can also be a forum for sharing information about matters of importance to everyone.

How do groups help?

The extracts below are personal views based on the experiences of individuals who have been affected by different disasters.

'You do have a common grief, therefore you feel no need to explain your pain or suffering, it is almost like having a shorthand in conversation and feelings.'

'As a group, we were heard by the government on issues such as memorial services. If we didn't have a group, decisions would have been made for us.'

'For some who grieve, to be involved in something positive, to have an agenda to follow (for example a memorial, or an intention never to let this happen again) helps, especially I think for men.'

'People bereaved by a horrific disaster – or afflicted by the shock of having survived one – are consumed by a mixture of grief and anger. These emotions are inescapable but quickly become destructive. The only remedy is to channel them into a constructive activity such as a support group.'

The practicalities

First steps

If you are interested in setting up a family and/or survivor support group but don't know how to get in touch with others affected by the disaster, the responding police service(s) may be able to help. Central government guidance for emergency planners and others responding to the needs of people affected by disasters includes some information on assistance for families and survivors.

Depending on the nature of the disaster and where it happened, the Foreign & Commonwealth Office, and/or the police or relevant local authority may also be able to help. They cannot release contact details of people affected, for reasons of confidentiality. However, they should be able to contact everyone on their list with your request. Or they may help set up an initial meeting for survivors and bereaved families who may wish to attend, as has been done after some other disasters.

What next?

The initial meeting will be an opportunity for you to meet people affected by the same disaster and to find out whether they may want to be part of a group. Getting together for the first time may be a stressful and emotional occasion, but for many people the benefits of contact with others experiencing similar emotions and challenges will be worth it.

Our experience shows that the most harmonious groups are those that establish a clear purpose and aims. These may be very clear from the outset for some groups and for others it may take longer for these to emerge from discussion at meetings and informal get-togethers. Such aims may be to offer each other mutual emotional and practical support, to provide representation with external agencies, to share common experience and information, to campaign on issues specific to the disaster or to organise memorials. It may be helpful to set out a clear statement of aims and objectives for the group. (With the passage of time there is no reason why the focus cannot be changed, if that is what the group wishes.)

How should the group be structured?

There are a number of different options for the structure of family and survivor groups in terms of membership, legal status and management. Some groups have set up an unincorporated association, while others have decided to be as informal as possible. A few have chosen to apply for charitable status.

You may find that legal advice on these options is helpful, particularly in circumstances where the group is given external funding. The important thing is for the status of the group to fit its nature and purpose. If you do seek legal advice, you can find contact numbers for solicitors who specialise in the charity field through the Law Society (see Useful Contacts).

Whatever the nature of the group, committee members will need to be chosen and decisions taken about who will carry out key roles such as arranging meetings, taking notes and looking after the accounts. It may take some time for individuals to feel that they can take on these tasks and there should be no pressure to do so before people are ready. Some groups have found it helpful to rotate these roles so that people do not have a constant time-consuming commitment.

Group meetings (frequent or occasional, depending on the needs and wishes of the group) can then be organised by the committee. The group may choose to distribute a newsletter, occasionally or regularly and/or to set up a website. Some groups have found it helpful to set up smaller, regional subgroups where people can get to know each other better and focus on the issues they have most in common. Good communication channels between members are important and telephone-based

meetings or email forums may make this possible if members live far apart or do not wish to attend all meetings.

Whatever option you choose for how the group is set up, advice and support is available from those who have done this before, and from other organisations.

Setting up and an e-forum discussion group

Given that those affected by a disaster often live all round the UK and overseas, increasingly the opportunity (even necessity) to be in contact using online methods is important. Disaster Action's second leaflet on groups gives guidance and information on options on this area. See [Setting up and Running an E-forum Discussion Group](#) at [\(link\)](#).

How will the group be funded?

Once the aims and objectives of the group are agreed, the group will be in a position to look for funding to cover its expenses. Funding may or may not be available through any disaster trust fund set up in the aftermath, or from other sources such as charitable trust funds, voluntary agencies or government departments.

How long should the group last?

In our experience all groups are different and differing views may emerge on how long individuals wish to remain part of a group. Some groups continue for many years, while others disband after they fulfil a specific purpose. A group should not be judged as a 'success' or a 'failure' because of how long it lasts. Many of us have made friends within our own groups and these friendships have lasted well beyond the formal life of the group.

What can the pitfalls be and how can they be avoided?

Differences within the group

Individuals will respond to a disaster in different ways and have both common and unique needs. While the group will need to have a core set of agreed aims, there are still likely to be different priorities for individuals at different times. Recognising and accepting these differences, rather than seeing them as a problem, may help the group evolve over time and focus when appropriate on the need for a common group response to key issues and concerns.

Differences between family members such as parents, partners and siblings of those who have died in the disaster are, unfortunately, not uncommon in our experience. These differences may spill over into the group.

If the group elects one or more individuals to act on behalf of the group, or to make statements on the group's behalf, it is important to ensure that any messages conveyed to those outside the group – such as the media or government departments – reflect the overall interests of the wider group. Contact with the media can be difficult and it may be that they refer to members as 'spokespeople' when in fact they are commenting on their own behalf.

Will you be able to cope with working for the group?

A potential difficulty for those who take on more responsibility in the group is that the workload is tiring and a source of additional stress, given that the aftermath of any disaster is bound to be hard. You may be struggling to cope with day-to-day commitments in addition to the needs of the group. One possible way of dealing with this is to accept offers of help from friends and relatives. You may be able to get their assistance in the more practical aspects of running the group. Another way is as

suggested above, to rotate roles within the committee.

How can Disaster Action help?

As an umbrella group concerned with the general principles relevant to any disaster, Disaster Action is able to offer suggestions on all the issues above and can be an ongoing source of support throughout the discussions about setting up a group and once it is set up. Individuals, and/or a group, are also welcome to join Disaster Action if they wish to.

Disaster Action would like to thank all those who contributed to the writing of this leaflet.

Useful links and resources

Disaster Action

Disaster Action

Disaster Action was founded as a charity in 1991 by survivors and bereaved people from UK and overseas disasters. We have collective personal experience of over 30 disasters, including rail, air and maritime as well as natural disasters and terrorist attacks in the UK and overseas.

<http://www.disasteraction.org.uk>

Useful Contacts

British Red Cross (BRCS)

The BRC responds to emergencies from major incidents to evacuations, floods and fires and has been involved in disaster support groups in the past.

<http://www.redcross.org.uk>

Charity Commission

The regulator and registrar for charities in England and Wales, they can offer advice on legal issues regarding the group status.

<http://www.charity-commission.gov.uk>

Foreign & Commonwealth Office

If you have been affected by an overseas disaster, the Consular Directorate of the FCO will be involved.

<https://www.gov.uk/government/organisations/foreign-commonwealth-office>

Law Society

The Law Society can put you in touch with law firms specialising in disaster and personal injury litigation. **Telephone** 020 7320 5650.

<http://www.lawsociety.org.uk>