Guidelines for delivering bereavement support groups





Foreword

I am delighted to write the foreword for these national guidelines for the delivery of bereavement support groups. They have been developed through a collaboration between the National Bereavement Alliance and Support After Suicide Partnership, with input from a wide range of providers of bereavement support groups. The guidelines are also informed by the Bereavement Care Service Standards, published by Cruse Bereavement Care and the Bereavement Service Association in 2014.

Bereavement groups are frequently the main source of available support for people who have experienced the pain of grief and loss. Finding support following a death is key to ensuring that the lives of those bereaved can be rebuilt. It is vitally important that this type of support is of the highest standard, in order

to reduce the isolation that can be caused by bereavement, as well as alleviating emotional distress and suffering.

These guidelines will be an invaluable source of advice for individuals and organisations, who are currently running a bereavement support group, as well as for those who are planning to set up a new one. They will also provide an important resource for those who are responsible for commissioning services to ensure consistency in the provision of support across the country.

Julia Samuel, MBE

Founder Patron, Child Bereavement UK Patron, Support After Suicide Partnership, Author of *Grief Works; Stories* of Life, Death and Surviving





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National Bereavement Alliance

National Bereavement Alliance

The National Bereavement Alliance is a group of more than 50 national, regional and local organisations supporting bereaved people and those caring for them. We share a vision that all people have awareness of and access to support and services throughout their bereavement experience. All members of the Alliance contribute to this vision through their own aims and objectives, in various ways and at various times. We collaborate strategically to provide a collective voice representing the needs of bereaved people and those supporting them.

www.nationalbereavementalliance.org.uk

Support after Suicide Partnership

Support After Suicide Partnership is a collaborative network of organisations across the UK who strive to provide timely and appropriate support to those bereaved or affected by suicide.

www.supportaftersuicide.org.uk

Acknowledgements

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A particular thank you to Saira Waheed for co-ordinating this project.

Introduction

"Grief is like waves coming in from the Ocean.
At times, the waves are small and barely noticeable.
But, when you least expect it, a huge wave pulls your feet right out from under you.
No two people ever see these waves exactly the same way, and no-one reacts in the same way to each incoming wave."

Alan Wolfelt (1992)

The Center for Loss & Life Transition, Colorado, USA

Many of us may experience the death of a much-loved friend, partner, or family member at some point in our lives. How we manage our loss is different for every individual and it is generally accepted that there is no right or wrong way to grieve. The manner in which we cope with death can be affected by our relationship to the deceased, the nature of the death, our cultural and/or religious beliefs and our gender.

These factors can influence the type of support we receive, whether from friends and family in our communities, or if we feel the need to seek specialist support.

Bereavement support groups tend to be set up where a need has been identified for further support to help with adjustment and coping following a death. Support groups also have the additional benefit, valued by many who attend, of meeting others who have shared a similar loss.

We have come together, as organisations that provide bereavement support and group

work, to share knowledge and learning gained through our collective experience in order to produce guidance for individuals and organisations who may wish to start a bereavement support group. This is not intended to be prescriptive but to raise awareness of issues that might arise to help ensure bereavement groups are sustainable and safe, for those who attend them those who are coordinating and facilitating the groups.

This guidance applies to both professionals who may facilitate bereavement groups as well as peer facilitators. We address the question of whether a peer facilitator is ready to support others who are similarly bereaved to themselves, and that adequate support is being provided to peer facilitators.

The guidance will help groups meet the Principles for Bereavement Care Services and the Standards described in the Bereavement Care Service Standards (BSA and Cruse Bereavement Care 2014).

This guidance is written for those planning or running support groups for adults (18 years of age and over). The main body of the guidance is generic, addressing the practical issues of setting up a support group, whether peer facilitated or delivered by professionals who have qualifications and training in occupations such as psychology, counselling, nursing or social work. We have included separate sections covering specific types of bereavement support groups.

Our intention is to assist providers of bereavement support groups to provide evidence, through reference to the guidelines, that they are adhering to nationally-agreed voluntary standards when reflecting on their practice, shaping their service and applying for funding.

Fundamental principles for Bereavement Care Services (BSA and Cruse Bereavement Care, 2014)

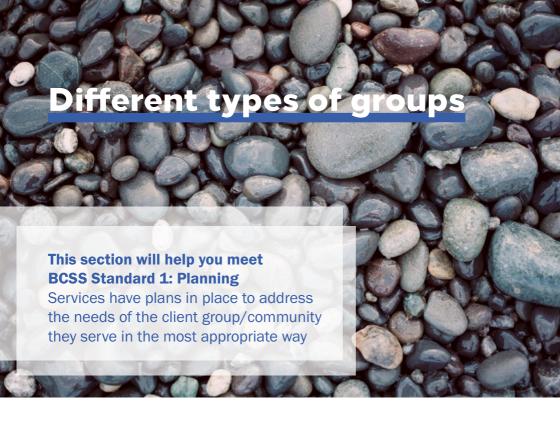
Confidentiality: services should respect the confidentiality and privacy of each bereaved person and any information shared by them, with due regard to safeguarding, consent and data protection

Respect: services should respect the individuality of each bereaved person's grief and needs, with each person treated with compassion and sensitivity

Equality and diversity: services should be non-discriminatory and delivered without prejudice, recognising and responding to personal beliefs and individual situations including (but not exclusive to) age, culture, disability, gender, sexuality, race, religion and spirituality.

Quality: services should ensure that all those delivering support to bereaved people, have the skills, knowledge, training, supervision and support relevant to their role. Services should work to improve what they offer through evaluation.

Safety: services should have robust processes for recruitment, including appropriate levels of clearance with the Disclosure and Barring Service (DBS) and ongoing staff and volunteer development. There must be due regard to safe and ethical practice in order to protect bereaved people and those who work with them. The necessary processes for safeguarding must be in place and accountability evidenced through an audit trail.



Who is the group for?

There are many different types of bereavement support groups. It is important to be clear at the outset whether the group is intended to provide support for general bereavement or for a specific type of loss where those who attend may share their experience of loss.

It can be easier to gather enough people to make a group viable if it is open to people bereaved of all relationships (e.g. child, partner, parent) and by all causes of death. However, the variety of experiences in such a group can make it more of a challenge for members to find common ground.

What type of group will it be?

Different types of groups can be organised to meet different needs. Some groups are primarily social: an opportunity for people to meet others in similar circumstances and to realise that they are not alone in their experiences, to build confidence and to make new friendships. Others will have more of a focus on the experience of the loss and the rebuilding of life, while others still will be fully therapeutic groups.

These different purposes will influence whether the group is ongoing or time-limited, open to everyone or closed (see below), who facilitates it (see page 13) the content of the sessions, and the type of assessment that is appropriate before someone joins.

Ongoing groups are those that people can start attending at any time, and stop attending when they no longer feel the need for this type of support. This type of group can be easier to sustain for organisations with small numbers of potential attendees, as they do not have to keep finding enough people to make the group viable, so people are less likely to have to wait before attending.

Different types of ongoing groups include:

 open informal 'drop in', community café, help point or compassionate community style meetings.
One advantage of this type of group is flexibility, with people being able to dip in and out according to their needs

 structured, facilitated groups which people are 'selected' into, and can carry on attending for as long as they like or for a certain period of time. These groups may require a commitment to try and attend each time, to bring some continuity to a membership that changes over time

Having a turnover of group members can be helpful to those who join the group early in their bereavement and see others who are 'further along' in coping, and getting ready to leave the group, which can inspire hope.

Conversely, it can be difficult for newly bereaved people if they meet group members who are still not coping after several years. Also, it can be challenging for the longer bereaved people to keep hearing the rawness of the more recently bereaved as they join.

If people can attend the group for as long as they like, this can also create a resource issue with difficulty making space for new people to join.

The frequently changing membership of this type of group can be challenging and it may be difficult to maintain trust. Some people, who may be vulnerable, can become dependent on the group for their main source of support and experience emotions of rejection and abandonment if the group is no longer able to continue. The group may not be sustainable if, for example, funding to rent a venue comes to an end or if facilitators leave and cannot be replaced.

One way of managing these challenges can be to establish criteria for leaving the group (eg when the support is no longer needed or has become social, or when the group is no longer helping), or limiting the number of sessions per person.

Closed, time-limited groups are usually run for a set number of sessions (usually 6-8). Participants are expected to attend the first session and cannot join the group part-way through.

This can have the benefit of building trust between participants within a short space of time and avoids issues of dependency. The group may have a maximum number of members set in advance. The group provider may also have developed a programme for the sessions which are designed to promote a deeper understanding of grief and loss. Disadvantages can be that a fixed number of sessions may not be enough for some people and it is important to ensure there is appropriate signposting to other support when the group comes to an end. It can also be difficult to recruit sufficient numbers of people to attend at the same time. especially in rural areas where transport links can be poor.

Being inclusive

Whether ongoing or time-limited, open to all or restricted to those who have had a preparatory telephone call or meeting prior to joining, it is important that the group is accessible and welcoming to all who might benefit from it. This will lead to questions about the venue and timing (see below) but also the content and ground rules of the group. Consider how diverse social, religious and cultural attitudes and beliefs among group members will be managed, as well as different experiences, personality types and coping styles.

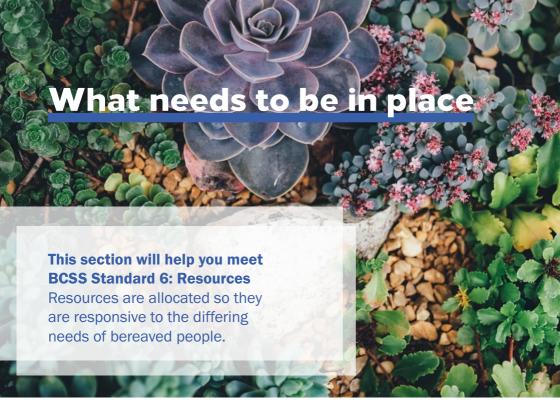
Is a new group needed?

Once the target group and the type of support has been identified, the next thing to consider is whether a new group really is needed. It may be that there is already a support group that meets the identified need that could be better advertised, or which needs help with fundraising or finding a new venue to keep it sustainable.

Who will be responsible for the group?

If a new group is needed, it is generally preferable to deliver it under the auspices of an umbrella organisation with protocols and policies already in place, rather than attempting to deliver a support group independent of any organisation. Many of the organisations that have contributed specialist sections to this guidance have networks of local groups: contact them for advice. A list of national organisations who offer support can be found at the end of this document.

'Going it alone' carries risks for facilitators and group members. Facilitators must make sure they are complying with all legal requirements, and make it clear to group members that they are attending at their own risk.



Once the need for a group has been identified, a decision has been made to deliver a support group and whether to do this with a host organisation, a set of logistical decisions must be made. This includes the resources that will be needed, including a venue and facilitators, and the legal requirements, which are outlined on page 28.

Where will the group happen?

- Is there easy access (being mindful of the Equality Act)?
- Is the venue accessible by public transport (especially relevant in rural areas)?
- Is there adequate parking available?
- Are there toilet facilities (including disabled facilities)?

- Is there the use of a kitchen for making tea and coffee?
- Is the venue secure so that once a meeting has started, strangers can't access the room?
- If the group is to run in the evening, is the venue on a well-lit street and safe?
- Does the venue have comfortable and sufficient seating?
- Is there a quiet space away from the main meeting room should a participant become distressed and need to talk to the facilitator alone who may need to assess risk? (This would not necessarily have to be a separate room but somewhere relatively private.)
- Is the venue or room likely to be uncomfortable for some people who might attend, e.g. if using a church hall, is there overt religious imagery which might offend someone with different beliefs or values?
 Or if using a hospital or hospice venue, will this be associated

- with painful memories for some participants?
- Is the venue affordable and within the budget of the group providers?

There are examples of support groups delivered in a private home. Where the need for a support group has been identified and there is a lack of funding to pay for a venue, this might be considered to be the only option. However, this course of action is not recommended for the following reasons.

- The home owner or landlord's insurers may require an additional premium for Personal Liability Insurance if members of the general public attend, or may decline to provide cover
- Personal safety for the group coordinator could be put at risk when advertising the group unless access is restricted to invitation only to people who are known to the home owner or the coordinator
- It could be difficult to manage boundaries if a vulnerable

participant comes to the house without prior warning, in distress, on a date or time when the group is not being delivered

 It may be difficult to prevent other members/ pets of the house from disrupting the session

These suggestions will help you meet BCSS Standard 4: Support and Supervision

Services provide access to support and supervision to ensure safe working practice and afford staff and volunteers the opportunity to recognise the impact of this work on them.

and Standard 5: Education and training

All staff and volunteers who come into contact with bereaved people have the necessary skills and knowledge to provide support to these people.

When will the group happen?

Support groups held during the day are not likely to be accessible to people who are working, but some people may find it more difficult to go out at night. Carrying out advance research into who is likely to want to access this type of the support group would be helpful if the group is to be successful and well attended. There are certain days that are set aside for worship in specific religious groups and, if the group is to be inclusive, these days should be avoided.

Who will facilitate the group?

Bereavement support groups can be facilitated by suitably trained professionals or volunteers, who may have prior experience in supporting bereaved people 1:1 or lived experience of bereavement. The type of support being offered will help determine the most appropriate type of facilitator.

Facilitators may, or may not, have a psychology, counselling, nursing or other professional training with specific knowledge about the particular area of bereavement support offered by the group. Further training for facilitators, both in group facilitation and in bereavement,

at a level appropriate to the type of support being offered, should be addressed by the umbrella organisation.

Where there is no such organisational training available, volunteers with lived experience will benefit from undertaking training delivered by national bereavement organisations, both in bereavement awareness and in facilitating groups.

When a facilitator has lived experience, it is important to check that they have addressed personal issues around their own bereavement which may impact on their ability to facilitate a group.

Some key facilitation skills include:

- Modelling respect, active listening and tolerance
- Supporting group members to have as much of a voice as they want
- Confidence to remind participants of the ground rules and to challenge difficult behaviours supportively on behalf of the rest of the group

- Keeping the group to time and managing endings well
- Facilitating others' participation and not making it about them

Attributes of a support group facilitator

A support group facilitator should not:

- Believe the group is 'their group' – there should be an understanding that the group is for the benefit of the bereaved parents who attend
- Dominate the discussion when facilitating a support
 group facilitators need to be at
 a stage where we do not need
 to share our story other than as
 appropriate
- Dictate what the group will discuss – facilitators can guide the discussion or suggest a topic but the interaction should be happening primarily between group members
- Attempt to run a therapy group

 particularly important if we
 are running a peer support
 group. This is not counselling

or therapy and we should not try to offer professional support if we are not qualified to do so

- Breach confidentiality in order for group members to feel safe they must understand that nothing they say within the group will be shared outside of the room and group members, unless there is a specific reason to do so i.e. a safeguarding issue
- Preach or give advice group facilitators must offer a balanced approach and without suggesting or intimating that there is a 'right way' to grieve

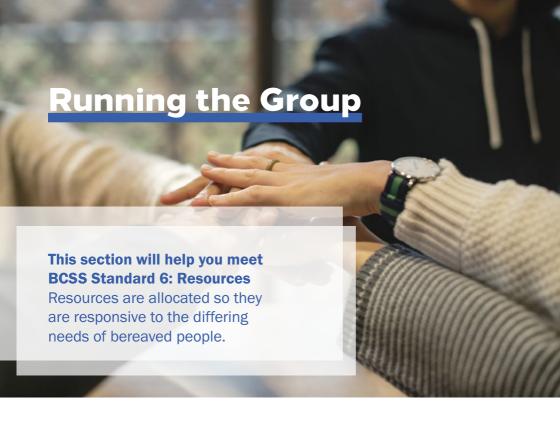
For more information about facilitation skills and dealing with difficult situations in bereavement support groups, see Dodie Graves (2012) in the Resources section below

It is advisable to appoint at least two facilitators to run a support group. This provides flexibility to how the group runs: for example, if a participant becomes distressed, one facilitator can take them aside while the other continues with the rest of the group. Having two facilitators also means they can provide a sounding board for one another in a co-supervisory capacity. There are times when one facilitator may not be available, and it is important to consider whether this would mean the session can still go ahead with just one facilitator and the impact of these outcomes or whether the session should be cancelled, a third or reserve facilitator can help mitigate this.

Supervision for facilitators

Those facilitating groups should have regular support and supervision, as well as ad hoc support, to maintain safety and address any issues emerging for facilitators. This could include face to face or telephone support. For example, cofacilitators may have a debriefing session together as well as meeting with, or talking to, their supervisor after each group meeting.

Umbrella organisations may be able to provide this supervision or signpost to where it is available.



Establishing guidelines for the delivery of a support group can be protective, not just for the facilitators who run the group, but also for all group members who will feel safe in a protected environment where guidelines and boundaries have been agreed at the outset.

Consider the following practical suggestions in relation to the type of support group you are planning:

- Would new group members be asked to complete a registration form with contact details, assured that their data will be stored in compliance with the GDPR (2019)?
- Would you ask for consent, through a tick box, to contact a group member outside of the session to notify them if a session has to be cancelled for any reason?
- Would you ask for consent for facilitators to contact a group

member to make sure they are safe should they leave a session quickly or in distress if this is an agreed course of action by facilitators under these circumstances?

- Would you ask for consent for facilitators to contact appropriate services in the event of a serious concern about risk of harm to self or others?
- Are group members provided with "safety netting" numbers, e.g. the Samaritans freephone number and other sources of support?
- Is there a complaints policy which is advertised? If there is no "umbrella" organisation, can an independent agency be approached to provide this service or mediate in the event of a complaint?
- If the group is run under an umbrella organisation, be mindful of their policies for running a group

What format will the group take?

Some groups, of the community café/help point style, will be very informal, with an opportunity for people to meet socially and no specific agenda.

For groups that are more structured, whether ongoing or time-limited, it is helpful to determine in advance a format for how each session will be run. This can always be adjusted following feedback from group members.

Making decisions about how long to hold the meeting for (normally between 1.5 and 2 hours), and when to stop for refreshments and socialising (either half-way through or following the meeting) in advance will make sure that everyone attending is clear about what will take place.

A structured meeting might, for example, use the following format:

 Refreshments, with facilitators on hand to welcome people as they arrive

- Introduction and welcome to any new members (if the group is ongoing)
- Discussion on any previously agreed topics for the session
- Facilitators encouraging and ensuring each group member has time to express his or her opinions, making sure no individual dominates the session
- Break for refreshments and socialisation (facilitators ensuring no group member is left alone unless they want to be)
- Returning to the session to continue the previous discussion, or read a poem or piece of relevant literature
- Ending the session with facilitators checking out how people have experienced the group. Endings are very important particularly as the themes which are discussed can be very emotive endings should be 'flagged up' so that everyone knows the meeting is coming to an end and also for those who have not been able

to speak have an opportunity to do so if they wish. A reading, poem or summing up at the end of the meeting is helpful to 'ground' participants and prepare them to go back to the 'outside world'

For time-limited groups, it will also be helpful to prepare the format for the programme as a whole, identifying what topic will be the theme for each session.

The first session of a timelimited group can include joint agreement of ground rules for how group members and facilitators will act towards one another. It can be helpful to allow suggestions to come from the group, but also to have some ideas prepared in case prompts are helpful. These could cover confidentiality, sharing group time equally, being mindful of language and respecting each other's opinions and beliefs.

Setting ground rules at the first of the group's sessions, and encouraging the group to take individual and collective ownership of them, allows facilitators to gently remind participants of what

was agreed if difficulties arise in later sessions.

For ongoing groups, consider asking participants in the first few weeks to develop some ground rules together, which can be added to a Welcome Pack (see below) for new joiners, and can be explicitly voiced at the beginning of each meeting and agreed by group members. This can increase the sense that the group is for everyone.

Accessing the support group

The type of group you run will have an influence on how you make people aware of the group, and how facilitators and group members assess whether it is the right fit for them at the moment.

This section will help you meet BCSS Standard 2: Awareness and access

Services facilitate individual choice; are clear about what they can offer and to whom; know their limitations within defined boundaries and are able to signpost as appropriate.

Advertising the Support Group

A fully open 'drop in' style group can be advertised quite widely. Consider advertising the support group though social media and local radio, at local community centres, GP practices, and other relevant statutory and third sector agencies in the town or area where the support group will be delivered.

For a closed group (whether ongoing or time-limited), take care not to make too many details public, so that people cannot turn up unannounced. Even for an open group, consider how much detail should be given out publicly.

- Regarding safety for all group members, should specific details, i.e. the date, time and venue, of the meetings be advertised?
- Could a contact number (using a pay-as-you-go mobile phone or SIM dedicated to this purpose) be advertised so that an introductory telephone call can take place before giving specific details of the meeting?
- Would the requirement to make an introductory phone call deter some people from attending? Email contact might feel less threatening for some
- Could a dedicated email address be advertised for

potential attendees to use for contact to request more information?

 Keeping details of the meeting private might reassure more vulnerable group members that nobody can attend unannounced and without prior warning

This section will help you meet BCS Standard 3: Assessment

Bereaved people have their needs assessed in a manner appropriate to the service being offered. This will be a continuous and ongoing two-way process that ensures both risk and potential for resilience are identified. An appropriate plan is put in place to meet the identified needs of the bereaved person.

Assessing the fit of the group to the person's needs

Having an initial telephone call or email contact as described above will help the facilitator and the potential member to assess whether the group is the right fit for their needs at the moment. Participants may be pre-screened and assessed, either by telephone or face-to-face at an initial meeting. This can explore expectations, vulnerability and resilience and readiness to ioin a group. There are various tools to help assess someone's grief and their readiness for this type of support. The National Bereavement Alliance signposts to these on its website. It is generally advised that there should be a diminishment of trauma and a capacity to listen to others before attending any type of bereavement support group.

Facilitators of closed groups both time-limited and ongoing - are more likely to be able to advocate a time frame within which bereaved people can reap the maximum benefit from attending. An open drop-in, café-style group, is open to everyone. It may be difficult to say to someone, who may have no other source of support, that it is not advisable for them. to attend a support group immediately following a death. It is helpful to include

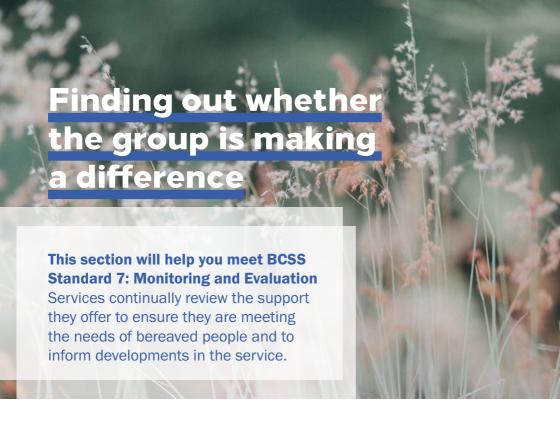
information about the group that participants may benefit from waiting for a minimum period or until they feel ready to hear other people's stories of grief before attending. Early group members could be asked what advice they would give to others in these circumstances, and this could be included in a Welcome Pack (see below).

Advance information about the group

Whether the group is open or closed, information is likely to be needed about the group and how it will run. Developing a Welcome Pack for each new group member, which could either be mailed in advance or given to group members at the first session they attend, can give reassurance, and help people decide whether the group is right for them at the moment. This could include:

 Information and guidelines about how the group is delivered, including any ground rules

- Agreed contact details for the facilitators, if and when they are available outside of the group meetings
- The registration form and explanation about how data will be collected and used in line with the GDPR
- Literature relevant to the type of bereavement the group is providing support for
- "Safety netting", e.g. a Samaritans card
- The complaints policy



Evaluating the group

Evaluation helps as it:

- Provides feedback on group members' experiences
- Helps potential future members decide whether the group is for them
- Guides facilitators when they are reviewing or improving the service
- Makes the case for funders of the service

The way in which the group is evaluated will depend on whether it is open or closed, ongoing or time-limited, and how it is structured. The three most useful sources of information will be monitoring information, user feedback/satisfaction and evidence of change

Monitoring information

This helps to check the activity of the group and whether it is meeting its target audience.

A simple monitoring form can be completed at the end of each session, with basic information

about how many people attended, and any other useful information (e.g. gender, type of bereavement). Registration forms can add information. Don't collect information that you won't use. Collecting this information will enable statements such as: '42 people attended the group last year, making a total of 378 visits to the group, which cost an average of £1.78 per person per session. Two thirds were women. and the most common type of bereavement was sudden illness. The most common reason for attending the group was to hear how other people were coping'.

User feedback/satisfaction

This helps build a picture of how people feel about the group, what they find helpful or unhelpful, and whether they have any suggestions for improvement. This can be captured through simple anonymous feedback forms that people complete at the end of a session or at the end of a programme. Collecting this information will enable statements such as '87% of people said they found the venue convenient, and 92% of people agreed that they

had felt listened to during the sessions. 85% of people would recommend the group to others in similar circumstances.'

How things have changed

This type of information helps to build a picture of the difference that the group has made to people's lives. It is the information that managers. funders and commissioners are likely to be most interested in. If people are completing questions about their coping, distress and symptoms before they come to a group as part of an assessment, they can answer the same questions at the end of a closed group, or after a certain number of sessions of an open group. Collect information that is relevant to the aims of the group. Structured, validated questionnaires are available to use for these purposes. The National Bereavement Alliance and Support after Suicide Partnership have suggestions on their websites.

Collecting this information will enable statements such as: 'After 8 sessions, 81% of people felt more able to tell the story of what happened and 72% were

able to sleep better. Two out of three participants felt more hopeful about the future.'

The National Bereavement
Alliance website has details of
evaluation measures being used
by other bereavement services,
and brings together services
interested in improving their
evaluation and assessment.

Resources

There are many resources that might be helpful. We have outlined some of them below. More resources can be found on the NBA's website:

www.nationalbereavementalliance.
org.uk

Books and websites

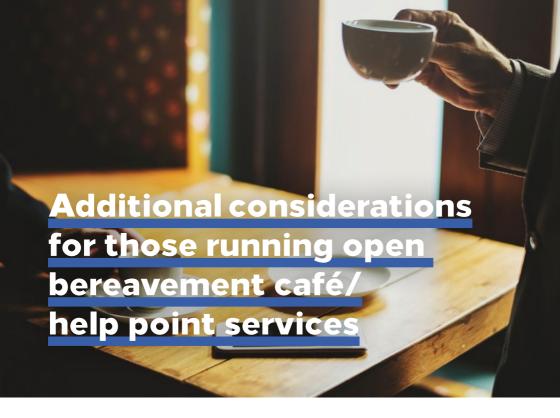
Dodie Graves (2012) Setting up and facilitating bereavement support groups: a practical guide. London, Jessica Kingsley Publishers.

www.jkp.com/uk/setting-upand-facilitating-bereavementsupport-groups-2.html Bereavement Services
Association and Cruse
Bereavement Care (2014)
Bereavement Care Service
Standards. London. Available at
www.cruse.org.uk/bcss

Training

Many national and local bereavement support organisations provide training, both in bereavement awareness and in facilitating groups. The National Bereavement Alliance website has details of courses offered by its members.

www.nationalbereavementalliance.
org.uk/training



Ian Leech, St Giles Hospice Community Engagement and Supportive Care Manager

St Giles Hospice have developed the Bereavement Help Point model across their catchment area in the West Midlands. The Help Points grew out of a clear need within the community. Several years ago, St Giles had an ongoing bereavement group, Monday Club, which provided transport to bring former carers in to the hospice once a week to meet together. The group was very much a service, rather

than an enabler, and it was not clear how it was helping people in their bereavement. At the same time, the 1:1 bereavement service that the hospice offers was under pressure, and not all bereaved families needed or wanted that type or level of support. Combined with a desire to meet the needs of bereaved people not already in contact with the hospice, St Giles needed to think creatively about how to support people to help one another.

Helen Chetwynd, counselling and bereavement lead, had the idea for the Bereavement Help Points service. She said "The original idea behind the project was to reach as many people in the community as possible, to provide the place and the dedicated bereavement support volunteers for just a few hours a week, for people to meet, talk, grieve and take care of each other, so we didn't have to turn distressed and grieving people away."

Since the first Help Point opened in Lichfield, the scheme has gradually expanded so that it is now offered in 13 different places and times during the week. This means that anyone getting in touch can be offered support somewhere across St Giles' catchment area within 48 hours. Working in partnership with Cruse Bereavement Care, Uttoxeter Cares and other agencies, the help points have around 1000 visits each quarter.

Running a fully open help point is very different from running a closed bereavement group that people are referred or selected into. This has implications for the venue, volunteer training and skills, and the way the group is set up.

- If the group is hosted by an organisation such as St Giles, then this provides an obvious referral route for some attendees. But for the group to be fully open, publicity needs to be widely out there in the community: leaflets in GP surgeries, information posters, and eventually word of mouth
- Although there is no need for people to say they will be coming in advance, having a phone number on the St Giles website has been helpful for those who would like to hear more about the Help Points before deciding if it's for them.
- It is important to think through what it's like for someone coming for the first time. The venue can help with this: a window in the door means new attendees can look into the room before venturing in.
- One of the Help Points meets in the community room of a supermarket, so people can combine coming to the group

with doing their shopping.
Having something else to do
alongside can make it easier to
come to the group

- When a new person comes for the first time, one of the volunteers welcomes them, makes them a drink and then sits with them before gently introducing them to other members of the group
- It is important to keep a welcoming and inclusive atmosphere. It is ideal if conversation can flow naturally towards and away from the direct subject of loss and bereavement. Attendees are then able but under no pressure to talk about their experiences
- By its nature, a Help Point is fully open to the community and to people bereaved in different ways. It should be prepared to welcome people from every walk of life, with the full range of personalities, needs and experiences beyond their bereavement. Consider how volunteers will be supported to signpost vulnerable visitors

- appropriately and to manage unexpected or difficult behaviour
- As well as safeguarding and legal back-up from the host organisation, in this case the Hospice, volunteers need initial training, ongoing support to deal with tricky group issues, and top up training so they are up to date with the range of other support in the community. This means they can connect group members to other activities and help them grow in confidence
- At the Help Points, there is no pressure to 'move on' from attending – people can keep coming for as long as they find it helpful
- It is important to consider how the group will continue to be welcoming to new joiners. The whole point of the help point is to reduce isolation, and volunteers may need support in thinking through how they can help avoid cliques forming
- Occasionally, the group may need help in managing further change and dynamics, for

example if friendships or romantic relationships develop between members. Some group members feel able to celebrate others building a new life, while for others it can be a challenge and remind them of what they have lost. Staff and trained volunteers can help the group come through these difficult times

 Mix the social and the informational. At each session it is helpful to have information available about loss and bereavement, and about the wider services available in the community, as well as making sure people have the chance to chat with others in the similar circumstances

In St Giles' experience, the help points have helped local bereavement services to offer alternative support to those on their waiting lists. Some people realise that what they need is to get together with others, rather than the 1:1 support for which they are waiting. This means that services are freer to offer therapeutic support to those that need it most. Although it can feel tricky to

evaluate help points or other types of drop-in support, it is possible – and having feedback helps to secure the service.

A short evaluation form can be given out every so often which asks attendees what they were expecting, how they found the group to be, and any suggestions for improvements.

Suicide Bereavement Support Groups

This section could also be helpful for people delivering generic bereavement support groups as people affected or bereaved by suicide may also access support from different types of group support.

Anne Embury, Suicide Liaison Service, Outlook South West (Cornwall & Isles of Scilly)

www.outlooksw.co.uk/ suicide-liaison-service

There are a number of different organisations in the UK that deliver support groups specifically for people who have been bereaved by suicide, and this intervention remains the most common source of support for suicide bereavement. It carries many additional factors not shared with other types of traumatic grief. Shame and stigma surrounding suicide reinforces the isolation of grief, and meeting others who have experienced a similar loss can be therapeutic in itself.

The World Health Organisation (2008) suggests suicide bereavement support groups may provide:

A sense of community and support

An empathic environment giving a sense of being understood

The hope that 'normality' can be reached eventually

Shared experiences in suicide bereavement, such as difficult anniversaries or special occasions

Opportunities to learn new ways of every day functioning A sounding board to discuss fears and concerns

A setting where the expression of grief may be shared,

confidentiality is observed, and compassion and support are offered

Information and support about suicide and suicide bereavement

Survivors of Bereavement by Suicide (SOBS) deliver "open", or ongoing, support groups in many parts of the country.

An example of closed or timelimited groups for people bereaved by suicide include the 6-week Samaritans/ Cruse collaboration "Facing the Future". Another example of a time-limited support group, with a specific emphasis on psychoeducation (information giving) is described in this section.

In Cornwall, a dedicated suicide bereavement service is commissioned by NHS Kernow, the County's Clinical Commissioning Group, and delivered by Outlook South West who have developed an 8-week "closed" Grief Education programme informed by World Health Organisation guidelines, and based on research carried out in Australia

& New Zealand supported by a Fellowship from the Winston Churchill Memorial Trust. This intervention, facilitated by trained counsellors, is suitable for those who are at least six months post-bereavement (and preferably post-inquest) to ensure a diminishment of trauma. The course aims to encourage participants to provide mutual support through sharing helpful coping strategies in a "safe" and emotionally contained environment.

"Meeting people who all know exactly what I'm going through, and being able to open up without the worry of upsetting any one."

Helen, Cornwall

"Meeting the others in the group. Having the room to express feelings, finding support, acceptance and a space to be."
Jo, Cornwall

A psychoeducation support group model is where the group has multiple aims: education, mutual support and coping development. The underlying premise is that people bereaved

by suicide benefit from learning more about suicide and the grief and loss journey. Such a support group may be led by a mental health professional (e.g. a counsellor or psychologist), perhaps in collaboration with a person bereaved by suicide. A psychoeducation model is adopted as there will be part of each meeting devoted to talking about some aspect of grief in order to educate group members and express, validate and normalise experiences. Mutual support is encouraged in group discussions throughout the meeting.

(Lifeline Australia)

Research has identified that those who have been bereaved by suicide are at an increased risk of taking their own lives than those bereaved by other sudden deaths. By definition, therefore, people who are bereaved by the suicide of a close friend, family member or partner, have the potential to be vulnerable

and at risk. It is important to reflect on what type of ongoing "out of hours" support might be available to group members should they need it.

Questions that might be raised for consideration are:

- Does the umbrella organisation consider it necessary to gain consent at the outset, to contact an attendee's GP or local mental health services in the event of concerns about their wellbeing?
- Does the umbrella organisation have a policy on confidentiality, e.g. when safeguarding concerns may arise or there is disclosure about risk?
- Should there be guidance developed about the sharing of photos or memorabilia which may be important to some group members, but may feel intrusive or distressing to others?
- Is there guidance about the celebration of special occasions? For example,

Christmas can be a particularly difficult time and imagery involving a tree could be distressing to some people, if their loved one died in a certain way

 Should self-care be reinforced at the end of each meeting to encourage participants to monitor their own wellbeing and seek external help if they need it?

In the extreme, and hopefully very rare, situation that a group member might take their own life, has there been given thought and consideration to developing a support group postvention plan taking the following factors into account:

- How should group members be informed about a death, and what additional support could be put in place?
- Should support or condolences be offered to the deceased's

- family if the group coordinators do not have prior consent to contact them and participants have been assured of confidentiality at the outset?
- What would the policy be on facilitators attending the funeral without permission from the deceased's next-ofkin who may place blame on the group for not keeping their loved one safe, or may not know they attended a support group?
- What additional support is available to the group facilitators affected by the death who may feel responsibility, and even selfblame, for not preventing the death?



Suicide Bereavement Support Groups are frequently facilitated by people with "lived experience" who may have found that the best way to provide support to others who have experienced a similar tragedy is to start a support group themselves. It is important for those who want to facilitate a support group to reflect on the following questions:

Can I cope with the inevitable stresses which running a suicide bereavement group will involve? Am I ready, in terms of having processed my own loss sufficiently, so that I am able to help others process their losses?

Am I offering to do this because my experience of belonging to a group was positive and I would like others to have the chance of that too?

Do I now see myself as an expert on suicide bereavement who can advise others – or can I recognise that I am only an expert on my own loss?

Is there unfinished business?

Am I offering to do this because my guilt makes me feel this Is something I should do?

Do I have the time and energy to learn how to run an effective group?

(Dunne, 1992)

Training for facilitators should be delivered by the "umbrella" organisation, if there is one. It is also recommended, where possible, that facilitators of suicide bereavement support groups, whether volunteers or professionals, undertake ASIST (Applied Suicide Intervention Skills Training), SafeTalk, or similar training in light of the research-based evidence that people bereaved by suicide are at substantially increased risk of suicide themselves. Facilitators of suicide bereavement groups need to have the skills and confidence to address suicide risk within the group. Whether undertaking this role under the auspices of an "umbrella" organisation, or independently, it is worth considering approaching your Local

Authority's Public Health service to see if they would consider providing group facilitators with funding to undertake suicide prevention training if no other sources of financial assistance are available.

Suggested resources

Towards Good Practice:
Standards & Guidelines for
Suicide Bereavement Support
Groups, Practice Handbook:
Suicide Bereavement Support
Group Facilitation
Lifeline Australia (2009)
www.lifeline.org.au

Preventing Suicide: How to Start a Survivors' Group World Health Organisation (2008) www.who.int/mentalhealth/

www.who.int/mentalhealth/ preventingsuicide/resource _survivors.pdf

Support Groups for Suicide Loss: a Handbook for Aotearoa-New Zealand, *Mental Health* Foundation of New Zealand Bowden, C., University of Victoria, Wellington, New Zealand Waves: a psycho-educational programme for adults bereaved by suicide.

Cruse Bereavement Care, Volume 30, Issue 3. (December 2011)

Wertheimer, A. A Special Scar: The Experiences of People Bereaved by Suicide Routledge (1991)

Pitman et al (2014) Effects of suicide bereavement on mental health and suicide risk The Lancet Psychiatry. 1(1) 86-94

Pitman et al (2016)
Bereavement by suicide as a risk factor for suicide attempt: a cross-sectional national UK-wide study of 3,432 young bereavement adults

BMJ Open

Dunne. E. (1992). Psychoeducational intervention strategies for survivors of suicide. *Crisis*, 13(1) 35-40.

Jordan, J & McIntosh, J, Eds. Grief After Suicide: Understanding the Consequences and Caring for the Survivors Routledge (2011)



Jen Coates, Sands Stillbirth and Neonatal Death Society **www.sands.org.uk**

Points to consider

We would recommend two Sands (or similar) trained befrienders for each group. Alternatively, a group could be facilitated by a befriender plus an experienced parent who is comfortable not sharing their story unless they are asked about it (and then, only told in a shortened form of one sentence).

Sands provides training weekends for group facilitators on a regular basis throughout the year. Currently bereaved parents should be two years post bereavement before attending this training.

Any venue should be neutral and not in a hospital. It should be accessible, both physically and culturally – i.e. not in a pub.

If any existing group members are pregnant, let newly bereaved attending know that someone is pregnant after loss, so that they are aware. Some groups have separate pregnancy after loss support groups, as the anxiety in subsequent pregnancy is understandably extremely high.

Specific suggestions for facilitators

Greet parents as they arrive. Position yourselves in the group so you can see the other befriender and so that, between you, you can see the faces of all the participants.

At the start of the meeting, say something like 'We are all here as we have suffered the loss of a baby whether it is as a stillbirth, neo-natal death or whether it is a result of different decisions having to be made part way through the pregnancy.'

We support anyone affected by the death of a baby. Be prepared/trained to challenge any judgement or unsupportive responses. Regardless of whether you anticipate difficulties around some aspects of people's experience, you could, at the beginning, state that the group is nonjudgemental and prioritises respect for everyone present. Explain that there will be a break, and the time of end of meeting. Refer to the difficulty for new parents of coming along to a first meeting – it takes courage and it's the club no-one wants to belong to.

Invite attendees to introduce themselves if they want to.
Name only or they can tell their story depending on how they feel. If long story, ensure everybody has an opportunity to talk if they want to. Explain that it's fine not to talk – no pressure to speak if they don't want to.
Some will not share their story for many weeks

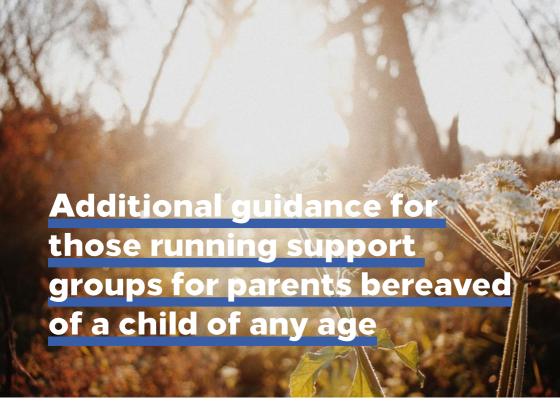
Mention and acknowledge any key date e.g. Mothering Sunday, Fathers' day, Christmas, any difficult events (or press coverage) coming up. A good time to do this is after the break, as draws people back together again.

Get to know the stories of those attending so you can anticipate any difficulties/ challenges/similarities for other group members If you can, have a list of those potentially attending and meet them early if necessary at the venue.

Be aware of any particular discussion topics which could be problematic for any attendees. Also be careful to avoid using information which has been given to you personally eg beforehand or on the phone and not publicly discussed. Be aware that there may be legal cases around medical negligence which may be in process, so that you can support a parent to end a topic of conversation or end it as facilitator

Be flexible around the break to address needs of participants. It's okay to leave at the break if someone needs to.

Confidentiality – explain to the group that we have all had very different experiences which affect us all differently so please respect this and the confidentiality of this setting.



Carolyn Brice,
The Compassionate Friends
Dr Ann Rowland,
Child Bereavement UK

www.tcf.org.uk www.childbereavementuk.org

The grief of bereaved parents and siblings is devastating and overwhelming. In experiencing an expected, sudden or violent death of a precious son or daughter, parents endure a profound rupture, a loss so painful that changes their lives forever in a multitude of ways.

Support groups for bereaved parents can help to:

- reduce the social isolation frequently experienced after the death of a child or baby – frequently not knowing anyone with a similar experience and particularly after the first few weeks or months of loss when family members and friends return to their own lives
- provide a hugely valuable safe place where parents can speak honestly about how they are really feeling

- provide a place where parents can find understanding, recognition and normalisation of the intensity of early grief and the long-lasting impact of child loss
- provide a space where new members can meet and hear from others who are further on in their grief which can help to encourage and sustain more newly bereaved parents – demonstrating ways they might survive such a devastating loss and offering comfort and hope for a future without their child
- offer support, understanding and friendship long after family or friends' support has diminished

The aims of a support group

In setting up and facilitating a support group for bereaved parents it can be helpful to keep these aims in mind:

- Ensuring a safe, welcoming place to meet
- Parents are supported to express and experience the pain of grief

- Parents are supported to become more confident and in control, with fewer negative feelings, i.e. offered hope
- Ultimately, parents are helped to integrate the experience of their child's death into their lives, i.e. to find ways to manage their loss whilst continuing to maintain a bond with their deceased child

Facilitating a support group

Support groups for bereaved parents can be peer-facilitated by those with personal, lived experience of child loss or be facilitated by professionals. Key skills and support include:

• Understanding of the impact of the death of a baby or child on an individual, the couple relationship and on other relationships within families e.g. relationships with grandparents, and the impact on social networks: many bereaved parents report feeling unsupported by close friends and go on to form new relationships that they find more supportive

- Understanding of the needs of bereaved siblings
- Sensitivity with strength –
 empathy/ability to hear/
 witness the distress of
 parents. Also a good degree
 of self-awareness in order to
 be able to remain mindful of
 the wellbeing of both group
 members and oneself (whether
 a bereaved parent or not) and
 thus able to identify when you
 might need additional support
- Ability to hold the boundaries and not collude in blaming etc.
- Able to hold the equality within the group, to prevent repeated discussions related to hierarchy of grief, death of an only child etc.
- Ability to hold impartiality in discussion of views across, gender, faith and in couple relationships
- Support/Supervision available to consider the impact of the distress on you as a person

Additional considerations

Structure and consistency

On the loss of a son or daughter, the bereaved parent is thrown into a world of chaos and often feels they have lost control of their lives and the lives of those close to them. The death of a child - of whatever age - is outside of the 'natural order': no one expects their child to die before they do. Experience shows that groups for bereaved parents survive and thrive best when they have a structure. This doesn't mean they need to be directive - simply that there should be a clear structure to group time i.e. a beginning, middle and end. See page 17 for more ideas.

There may also be also a place for and benefit of informal, less structured meet-ups outside of the main support group.

A child is a child

The loss of a child is devastating, whatever age that child dies. However old the son or daughter is at time of death, he or she is still the child of the parents,

and the pain and anguish for a parent of an older child is akin to that for a young child.

It is ideal if parents bereaved of a son or daughter of any age can be welcomed to the group - infants, toddlers, school-age children, teenagers, young or older adults. However, it is worth considering that in a mixed group that includes parents bereaved by stillbirth, baby death and child death, the discussion around memories can be more difficult given the very different time scales and chances and opportunities available to make memories. If groups are separated, e.g. between those bereaved of a baby and those bereaved of a child, at what age is the division made? Child Bereavement UK has found it helpful to ask parents to make their own decision as to which group might best meet their needs.

Time since the death

However the groups are organised, the facilitator needs to be aware that length of time of life is no indicator of depth of grief and intensity of loss, and to ensure that there

isn't any 'hierarchy' within the group over whose loss is more difficult or painful.

Bereaved parents may join a support group at any stage of their loss, whether newly bereaved or a few years or longer time bereaved. Where possible, the support needs to be there for as long as the individual needs to access it. Newly bereaved people often look for proof that things can get easier. It can be hard to see/hear others further along in their grief still expressing pain etc., but equally it can be very encouraging to see that despite their grief others are continuing to go about their daily lives, go to work, look after other children etc.

Manner of death

If the group includes a mix of causes of death, it is important that parents are aware of this before attending the group and also important to acknowledge at the start of the group that every circumstance is different but that there is no hierarchy of grief. Some causes of death e.g murder and suicide can necessitate investigations and inquests which can impact

on grief, when people feel ready to join groups, and the focus of their discussions.

Sometimes the manner of a child's death can lead to differences or hurtful comments from group members. For instance, the stigma felt by some parents whose child died as a result of drug or alcohol use, or by suicide, can create a barrier for them in sharing with other group members whose children died by more 'socially acceptable' means, for instance road traffic collision. long term illness, or sudden infant death, and so on. It is important, therefore, for the group facilitator to ensure that the focus of the group is on what unites bereaved parents - rather than what divides them - and to be aware of and pick up on any judgemental language that group members might use - for instance around children making life 'choices' around substance use, or 'choosing' to die.

The concentration of, particularly, newly bereaved parents on the manner of their child's death can create a despairing downward spiral to the atmosphere of the support group. If this group hopelessness continues month after month. this is often when bereaved parents report that they feel worse after attending a group or where group numbers begin to decline. If the facilitator senses this to be the case, action should be taken to try to bring the group to a more hopeful place (without minimising the pain and hopelessness bereaved parents feel), perhaps by asking group members how they cope on the dark days, or having a meeting where happier memories and photographs are shared. In this way, it can be helpful to focus on the life of the child - their personality, talents, nature, and so on - rather than always on the manner of death.

Additional factors to be considered that can arise because of the differences in people's situations

The criteria for attending a particular group is key to consider. There are no set rights or wrongs but many things to consider that might affect the dynamic of the group.

Who can atted the group: is it just individuals and/or couples attending or can others attend e.g. a grandparent if a parent doesn't want to attend alone? Couples attending together can be supportive, but can leave single parents or parents whose partners do not want to attend feeling less connected. Again parents need to know what to expect before arriving at a group.

Are there a mix of parents whose first/only child has died and some who have other children? People need to be aware of this before they attend. The facilitator needs to make clear there is no hierarchy of situations, but also manage the group so that discussion of siblings, and their needs, is encouraged and not avoided but does not dominate the conversation.

Have you considered how you will manage the situation when parents become pregnant while attending the group? How is this managed by the facilitator and the group? When and how do people disclose this? Do they still feel welcome to attend? How do you support people who are upset by this news? What

if someone wants to bring the baby to show the group or to attend while breastfeeding? Subsequent pregnancy is an extremely frequent occurrence but one that can cause upset and distress and needs careful consideration. In Child Bereavement UK's experience, discussing this as a possibility right at the start of the group and discussing how this might be managed can help mitigate some of the challenges.

Parents can be in a situation where they are blaming/initiating proceedings against a hospital/doctor etc, and looking for support from both the facilitator and the group. Have you considered how you will handle this personally to remain supportive yet objective in your response?

Couples attending a group can be supportive but it also brings the couple relationship into the group. Have you considered how you will manage disagreements or differing views between the couple in the group?

Groups can be extremely helpful in building a sense of shared

What parents have said about attending groups

"Thank you for this group; I don't think I would have coped without it since losing my lovely son. Some friends and family just don't try to understand what you are going through - as much as none of us want to be here, we all understand each other".

- W, bereaved mother

"At the end I felt "lighter". As if some of the weight of grief had been lifted by being shared".

 Attendee at bereavement support group "It was a comfort to be amongst people who all knew exactly how we felt and what we are going through, could empathise fully and share their own experiences and allowed us to share our own thoughts and emotions".

 Bereaved couple K & A after attending their first support group.

"Being around people that understand, being able to talk openly and frankly about your child without people looking away, and just being able to cry without fear of judgement has been immensely liberating".

- B, bereaved father

experience but can also highlight situations where parents can compare, for example what they were offered around the time of death (hair/hand prints or not).

Are you a bereaved parent yourself? How much of yourself will you share? Have you considered what you might personally find challenging in the group? If you have not had this experience how will you respond if asked about this is the group?

Suggested resources

Marina Oppenheimer (2016) Bereavement support groups: a guide for clinicians and non-clinicians. CreateSpace Independent Publishing Platform

Harriet Sarnoff Schiff (1977) The Bereaved Parent. New York, Crown Publishers.

Catherine Seigal (2017) Bereaved Parents and Their Continuing Bonds. London, Jessica Kingsley Publishers

Peter Standord (ed) (2011) The Death of a Child. London: Continuum

Child Bereavement UK has a variety of resources for bereaved parents and those supporting them, and provides training courses including 'Facilitating Bereavement Support Groups' and 'When a Child Dies – Supporting Parents and Families' www.childbereavementuk.org



General Data Protection Regulation (GDPR) (2019)

If personal data (e.g. name, telephone number, email address etc.) is collected and stored, the legal requirements of the GDPR (2019) has to be complied with. Where there is no umbrella or host organisation to take responsibility for this, the group coordinator can contact the Information Commissioner for advice by calling their Helpline **0303 123 1113**. (DBS Checks: Working with Adults in the Charity Sector, March 2019).

Public Liability Insurance & Public Indemnity Insurance

Public Liability Insurance is usually required (advice can be accessed from all major insurance companies) if groups are not covered by the tenancy agreement at a venue. Professional Indemnity Insurance is essential for professionals who are acting as facilitators, in either a voluntary or paid capacity. All professional bodies will require this compliance for their registered members who are in practice, although an

umbrella or host organisation is normally responsible for providing this cover. Self-employed professionals should provide evidence of their own Professional Indemnity Insurance.

Safeguarding

An umbrella or host organisation will be able to provide access to Safeguarding advice, or have a named person who acts as their Safeguarding lead. Independent groups may need to actively source independent Safeguarding advice and support. It is advisable that all facilitators and coordinators of support groups undertake basic Safeguarding training in order to recognise risk and know how to report concerns (this can be through online resources, generally available at low cost through a Local Authority).

Disclosure & Barring Service (DBS)

A standard check through the <u>Disclosure & Barring Service</u> (<u>DBS</u>) is required for volunteers and professionals who deliver a "regulated activity" where children or vulnerable adults may attend. These checks should

be updated once every three years. A "regulated activity" is hard to define and unlikely to apply to a group that may only meet on an irregular basis or is wholly independent of an umbrella or host organisation.

However, most support groups are delivered on a weekly or monthly basis, facilitated by either volunteers or professionals, who are in a position of leadership within the group whether they are qualified professionals or not.

Therefore, DBS checks for facilitators are strongly advised. In addition, these checks are normally required under tenancy agreements with church halls and similar venues under their own Safeguarding policies for activities that could be defined as "regulated". If there is no umbrella or host organisation, a coordinator should be nominated to ensure that DBS checks are monitored and kept up-to-date. There is no charge levied by the Disclosure & Barring Service for volunteers working for a Registered charity.

The Equality Act 2010

It would not be possible to restrict access to a support group to a vulnerable adult under the Equality Act (2010) unless the individual is known to present a risk of significant harm to others in the group. The Equality Act 2010 has to be complied with to ensure that all services (including bereavement support groups) are delivered without discrimination or prejudice. It is unlikely that support group coordinators and facilitators would have access to confidential information about a support group member and may not be aware that he or she is registered as a vulnerable adult with their Local Authority.

Resources

DBS Checks: Working with Adults in the Charity Sector Disclosure & Barring Service, 2019.



"A wonderful support group run by equally wonderful people. It was good to be able to talk freely and openly about our loss"



These guidelines were developed by Support After Suicide Partnership and the National Bereavement Alliance. 2019