

Chapter 4

GRIEF SUPPORT PROGRAMMES

Referring to the Grief Support Programme at St. Helena Hospice:

"Our aim has always been twofold. First to normalize the experience of loss and grief, in spite of the associated trauma death so often brings. Second, to provide a safe and supportive environment where children and adults can meet to share their experience and seek support from their peers."

Clough, 1997, pg. 3

Bereaved children and families can be worked with not only on an individual basis, but also in groups. A number of different grief support programmes, which provide support through group work, have been set up in the UK in response to a specific need to support people who are having difficulties coping with bereavement. These programmes have different criteria for participation relating to the age of the participant, their relationship with the deceased and how the person died. Some deal only with children and families affected by the death of a parent through a serious illness such as cancer, whilst others are more encompassing and allow membership by children who have experienced both anticipated and unexpected bereavements of siblings, relatives or grandparents, as well as parents.

GRIEF SUPPORT PROGRAMME AT ST. HELENA HOSPICE, UK

St. Helena Hospice in Colchester, England, offers a grief support programme at least once a year to children and families where a parent or major caregiver (e.g. a grandparent with whom the child has been living) has died. The hospice has offered similar, although shorter, programmes for children bereaved of a grandparent, who has not been a major caregiver, and for mothers bereaved of a child.

St Helena Hospice's grief support programme for families provides each participant with an opportunity to:

- ✓ Obtain information;
- ✓ Meet others and gain peer support;
- ✓ Have their experience and emotional expression validated;
- ✓ Commemorate and let go or move on.

The current programme has evolved over the last 12 years, reflecting the palliative care environment in which the staff encounter children, and following considerable individual work with children prior to initiating the first group programme.

Work with bereaved children and families began on a small scale, with staff

offering information and advice and some limited grief support. As the number of children that workers were dealing with increased, so did the extent of the services offered. Initially the grief support programme was offered to a group of adolescents, but has now expanded significantly. Over time, the content of the current programme has also been adjusted, changed and developed to reflect what workers have learned are the most appropriate and effective activities, group sizes, age ranges, durations and structures.

To ensure that the programme meets the emotional needs of the population with whom you have contact, substantial pre-planning is absolutely essential. This chapter addresses some of the key factors that you must consider in the pre-planning and development stage, drawing on the experiences of St. Helena Hospice.

CRITERIA FOR THE PROGRAMME

As mentioned above, the main grief support programme at St. Helena Hospice is open to children and families where a parent or major caregiver has died.

In setting up a programme, decisions need to be made regarding who the programme is aimed at and the criteria for participation in the group. This is important in ensuring that the group is able to provide appropriate peer support to each other and that information sharing and communication is achieved.

STRUCTURE OF THE ST. HELENA HOSPICE PROGRAMME

"It is crucial to highlight t... that this programme has been developed specially to meet the needs of children and families whose lives have been touched by the death of someone through physical ill health. Whilst there are many similarities in grief reactions and responses it must be acknowledged that the circumstances of some death e.g. suicide and murder, may induce a troubled or complicated grief process. We would therefore suggest that this programme would not be sufficient as it stands for those bereaved in difficult circumstances."
(Clough, 1997 pg. 3)

In the programme at St. Helena Hospice, four groups are run simultaneously:

- **5-10-year-olds, primary school age**
 - Maximum of 10 participants.
 - Staff:child ratio of 1:2.
- **11-16-year-olds, teenagers who are of secondary school age**
 - Maximum 10 participants
 - Staff:child ratio of 1:3
- **16-25-year-olds, young adults who may be at college, university, further education or working**
- **Parents group**

The groups are divided by age in this way because developmental and emotional needs vary enormously between a 5-year-old, a 16-year-old and a parent.

Further, it may be very difficult for a child to express their feelings openly in front of their parent and they may benefit greatly from the hearing experiences of other children their age, in particular because it may lessen feelings of isolation.

Although the groups are divided in this way, the participants engage in many of the same activities, which can be effective for any age group. The final day culminates in the opportunity for all the groups to meet together, share in some ending activities and have a meal together before the programme ends.

WHEN SHOULD THE PROGRAMME BE OFFERED?

Where it is identified as appropriate, St. Helena Hospice invites families to the programme, who have dependent children, and with whom staff at the hospice have worked pre and post bereavement. The programme is normally offered 6-9 months following the parent's death. This gap allows sufficient time for the family to adjust to life without the parent who has died and to identify specific issues that they may need support and assistance with.

Staff at the hospice have individual contact with families prior to the group to complete relevant paperwork, to gain an understanding of the current difficulties and issues for each family member, and to prepare a participant profile for each group for group workers.

It is possible for a child to return and complete the programme again, if they have sustained another significant bereavement or loss that is impacting upon their coping and resilience or if they are experiencing a renewed period of grief. This can occur as they get older and their understanding of the death and what happened may have changed. It may then be necessary for them to re-visit the death of their parent at this time of emotional development and be availed of the support of the group.

WHERE SHOULD THE PROGRAMME TAKE PLACE?

The programme run by St. Helena Hospice begins with a residential weekend. Groups have been run without the residential component, but it was reintroduced as workers saw that the groups bonded and became more supportive of each other when it was included in the programme. Such bonding can have an immediate positive effect in terms of self esteem and team building.

However, finding accommodation that is self contained and appropriate for the work that needs to be completed with the four groups has been difficult for workers at St. Helena Hospice. In choosing a location for a residential weekend, detailed research needs to be carried out to ensure that the premises are suitable for the participants of the programme.

At times, parents and children may be anxious about being away from each other particularly following the separation experienced by a death. It is therefore important to ensure regular communication between groups is maintained by the group workers and that any difficulties are raised with the parent quickly.

Follow up groups have been held at the hospice in the evening using appropriate rooms. The same room is used for each group at each session, so that the groups can identify the space as their own.

WHAT SHOULD THE PROGRAMME INCLUDE?

The programme at St. Helena Hospice aims to provide a mixture of therapeutic and supportive work as well as space to have fun and be with others. Alongside the formal part of the groups are times to play, shout, laugh and do things that children and adults enjoy.

See Annex 5 for an example of a Grief Support Programme.

RECRUITING AND TRAINING VOLUNTEERS/STAFF

The programme at St Helena is run using experienced and qualified workers as well as trained volunteers from various backgrounds. All staff must have a current criminal record check to ensure that they are safe and appropriate to have contact with children and vulnerable populations. Group organisers verify that this has been done.

It is important that appropriately qualified professionals such as social workers, art therapists, drama therapists, counsellors and psychologists are included as group leaders to facilitate particular sessions in the programme and to coordinate each group. All workers need to have an understanding of group process and child development but this does not mean the whole programme must be staffed by professionally trained or qualified workers who are child bereavement experts. Although there needs to be a number of key personnel who take the lead responsibility, predominately the programmes are staffed by volunteers who have had sufficient training and have a good understanding of the purpose of the group.

Important factors to consider:

- ✓ That all workers - both professional and volunteers - attend a training programme of at least 6 hours covering group process, child development, child protection matters, confidentiality. During this training, they must have the opportunity themselves to engage in some of the therapeutic activities used in the programme.
- ✓ It is vital that the workers, who are a part of this programme, are aware of their own issues of loss and bereavement whether recent or historical. If they have experienced a bereavement within 6-18 months, the programme would not be suitable for them at the time. Workers need to be emotionally available to children and their experiences.
- ✓ Skills and qualities that are important are empathy, energy, commitment, creativity, sense of humour and genuine understanding.
- ✓ Workers must be provided with appropriate support, guidance and de-briefing throughout the programme.

DIFFERENT LEVELS OF INTERVENTION

Offering children and families the opportunity to participate in the grief support programme is one level of intervention. Priority for this kind of intervention are children:

- ✓ Who need peer support;
- ✓ Who may have a need to develop confidence and self esteem;
- ✓ Who may have limited social support; and
- ✓ Whose family is struggling with their bereavement and therefore needs support to move through the grief process, and where there may be communication problems between children and families.

Where individuals and families have *complex* needs, other statutory agencies will need to closely liaise with the family prior to and following the grief support programme, so that all their needs can be addressed. Such children and families may need to take a higher priority over children and families who have a strong network of support and guidance and whose bereavement and grief issues are not problematic or difficult.

When running a grief support programme such as this, it is therefore important to establish referral criteria to other agencies where families require assistance outside that which the programme can offer.

See Annex 6 which details different levels of intervention.

GRIEF SUPPORT PROGRAMMES

Points to remember:

- Grief support programmes provide participants with an opportunity to obtain information, gain peer support, have emotional expression validated, commemorate and let go.
- Pre-planning is essential when setting up a grief support programme. It may be worth considering running shorter groups initially to assess the appropriateness of group intervention as a means of support.
- You need to ensure that the programme meets the needs of the community including relevant cultural and religious factors.
- Criteria for participation in groups needs to be established so that participants are able to provide each other with appropriate peer support.
- A suitable location needs to be found for residential weekend and for follow up group sessions that are self contained and appropriately equipped. It is important that all the follow-up sessions are held in the same place.
- Ideally the programme should be offered to families between 6-9 months after the bereavement to allow for the family to adjust and identify specific issues that they may need support with. It is essential that monitoring and liaising with families referred to the programme is carried out by group leaders.
- The programme is not suitable for all children and families and staff need to meet with children and families prior to the programme to carry out an assessment.
- Although the group leaders should ideally be qualified professionals, the programme can be mainly staffed by appropriately trained volunteers.
- All workers (professionals and volunteers) should attend a training programme on bereavement and engage in some of the therapeutic activities used in the group. It is important that appropriate references and checks are carried out on people volunteering to staff the programme and it is important that issues of confidentiality, group process and child protection are covered in the training.
- Workers must be provided with appropriate support, guidance and de-briefing and this is the responsibility of the programme leaders.
- Children may re-engage with the group programme again at a different stage e.g. if they experience another significant loss or their emotional understanding has changed and they are having difficulties.

See Annex 5 for an example of a Grief Support Programme