

## A DAY TO REMEMBER:

### ESTABLISHING A CHILD BEREAVEMENT SUPPORT SERVICE

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*Abstract: There is a great deal of interest in the development of bereavement services for children. This article looks at the establishment of one such service in the Highlands of Scotland offering information, peer support, emotional expression and an opportunity to remember.*

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“Children should be seen and not heard.” This conventional wisdom has had its day for the most part. However, in many instances, this saying still holds true for children in bereavement. The death of a close relative is difficult for any person to deal with but children may find it particularly so because they may be excluded from the mourning that adults engage in or they may simply not have enough information about death and its consequences to try and make sense of what has happened.

There has been a growing interest in the needs of bereaved children and young people over the past few years but there are still only a small number of projects and services offering support outwith the formal psychiatric and psychological services. The following is a description of one such service based in Inverness serving the Highlands of Scotland.

#### **Crocus Child Bereavement Support Group**

The Crocus Group got its name from a poem by titled “Believe” which speaks of the hope that comes from the advent of the spring flowers after the darkness of winter. Long before the name was thought of the idea of such a group came from the request for support by a mother whose three year old son had died of heart complications in the local paediatric ward. Nursing staff did not know what they could offer and asked for the advice of the chaplaincy. It was quickly apparent that there were no formal or informal support structures for the carers of children who had died as a result of sudden or non-cancer

deaths. After discussion with interested healthcare professionals a service of remembering was held at which bereaved carers known to ward and community staff were invited. A few weeks later a dozen carers gathered to explore the issues common to the loss of a child and these parental support meetings are still being held. There is also a Service of Remembering held each February to which families are invited.

It was apparent early on at these meetings that many carers had difficulties dealing with the siblings of the child who had died. How was the death to be explained? Was it right to have children at the funeral? How do you cope with changes in behaviour or falling behind at school? While carers felt that, in general, many of their own concerns could be addressed in different ways, they felt that their children did not have the same opportunities. Many parents did not feel competent to support their children through bereavement for fear of saying or doing the wrong thing. Nor did they always feel able to deal with their children's grief while still trying to sort out their own. Adults usually want to protect children from painful experiences but in attempting that they may leave them vulnerable to anxieties and fears.

While trying to meet the needs of these families was a laudable effort the group realised that the same difficulties would also be experienced by families where the deceased was not a child. Could something be done to tackle this? How big a problem was it? In order to determine the level of potential need

in the community a questionnaire was sent to clergy throughout the Highlands asking for an indication of the number of children that might have been affected by the death of a close family member over the previous two years.

Table 1

Number of funerals reported	1808
Number of funerals in which children were directly affected	121
Number of children affected	208

With approximately 2400 deaths per annum in Highland the questionnaire suggests there may potentially be 276 children each year able to access a child bereavement service.

Professionals from health, education and social work were also consulted and there was a general agreement that some form of bereavement support for children would be extremely beneficial. Over time several employers have seen the value of the voluntary work their staff were undertaking and have included Crocus Group work into their staff's responsibilities. Those involved in the Group's work include nurses from acute services, primary care and hospice, social workers, nursery nurses, play therapist, art therapist, chaplain and recently one parent who has undertaken some basic training in Befriending. The question that remained to be answered was what could be offered with little or no resources and only the goodwill of some dedicated volunteers drawn from several different disciplines?

### A Day to Remember

After much consultation and planning the first Day to Remember was held in October 1999. From the beginning we were clear that we were not offering any form of counselling or any kind of long term support. One day was all that we could envisage being able to deliver as a means to assist the children and their families to deal with issues of grief, loss and bereavement. The day was designed around activities intended to stimulate the child's memories of the person who had died in a supportive environment. Peer support was also viewed as a key concept of the day, at which children could see that they were not the only ones affected by a death.

Eight primary school age children were invited to attend all of who had been through a recent loss of a parent, grandparent or sibling. All of the children were known to the professionals involved which was partially a form of safety net for anxious volunteers and a means of testing the concept of the day and the activities that were used.

The feedback from carers was very positive and the children all expressed their enjoyment at the time, although no formal evaluations were carried out.

Over the course of time we have developed and refined the content of the day as we have reflected on our experience and the practicalities involved. For example, on our very first day we had an 'anger wall' which entailed the children throwing lumps of papier mache at a wall as a means of expressing some of the more deep seated emotions they might have. On one level this may have been achieved but the thankless task of scraping the remnants off the side of the building meant it has never been repeated!

### Programme for the Day

A typical Day to Remember will begin with the children and their carers being met at the door and after introductions the children begin by making a name badge. Then there are a couple of getting-to-know-you games which consist of throwing a ball to one another, culminating in the children and the volunteers saying who they had come to remember. It is important to set some ground rules for the day, such as 'it's okay to cry' and 'you don't have to talk if you don't want to.' These are gently explained by one of the volunteers and are also posted on the wall of the room. Children are invited to bring with them a special item which reminds them of the person who has died which may be anything from a photograph to a pair of glasses. Some children choose to share what the item they have brought means to them.

There are a number of creative activities such as making a collage or picture of the family before and after the death, clay modelling, and probably the most enjoyed event in each day that has been held, the memory jar. This is made up of portions of salt coloured with chalk and poured into a small bottle, each colour representing a different memory. So

green might represent the grass in the garden that dad liked to work in and blue, the colour of his eyes.

All of the items made can be taken home and used as a means of opening up channels of communication with family and friends about the person who had died.

The use of story allows for a more reflective time for the children using material written specifically for bereaved children.

Not all children are confident enough to verbalise their thoughts and feelings in a group, although they may choose to do so with one of the volunteers. In order to foster peer support we have developed a question or comment box in which children can post a card to be answered or shared before the day's end. The cards will have an opening few words which can then be completed by the child in their own words. For example, "The person who helps me most is...." Or "I feel frightened when..." These questions or comments are read out at near the end of the session and answered as honestly as is possible. It is important to say to the children that some questions even adults don't know the answer to, and that this is quite normal.

By the day's close many connections have been made both between the children and the volunteers and among the children themselves. As a closing act we gather together to form a web, by throwing a ball of wool from one person to another which creates a giant web symbolising the fact that none of us are alone. This leads on to re-connecting with carers who will be arriving to collect the children at this point. In the final act of the day each child is given a helium filled balloon with a tag attached to the string on which they are invited to write a message to their loved one. Once all are ready the balloons are taken outside to be let go at the same time. However, beware trees, gale force winds and high buildings! The adults are usually keen to find out how their child has found the day and individual volunteers can take this opportunity to talk about any issues that may have arisen.

Once the children and their carers have gone there is a time for the volunteers to debrief. This has been a most valuable time, even though most volunteers are pretty tired by this point! Any problems concerning the organisation of the day can be quickly identified

and dealt with, and observations about the children's reactions can be noted and followed up if necessary. It is also an opportunity for volunteers to express their own feelings about what they have been dealing with in a supportive atmosphere.

In the early stages of holding Days to Remember carers would simply drop off their children and collect them at the end of the day. As a result of reflecting on the issues raised by carers mentioned earlier in this article, those who accompany the children to the Day have been encouraged to meet in a different room from the children and have the opportunity to talk informally over a cup of coffee. This offers the support of the volunteers who facilitate this meeting and also that of other carers who often have faced similar problems. At the end of the day two evaluation forms are given one for the adult and one for the child and those returned are assessed at future planning meetings. One older child commented: "I didn't know why I went to the Day, but I do now. Thank you for helping me to see that I am not the only one who lost a mum."

### Referral

It has always been the policy of the Crocus Group that anyone can refer a child to the service. In practice this has meant that the majority of referrals come from health care professionals and from schools but this has not exclusively been the case.

Table 2

Designation of Referrer	Number of children
Health Visitor	14
GP	11
School	12
Community Paediatrician	4
Family	4
Social Work	9
Clergy	2
School Nurse	6
Other Community groups	2

To date 64 children have attended a Day to Remember. Approximately a third has come from Inverness with others making a two or three hour journey to attend.

Most referrals are made by phone to the service co-ordinator who can assess the suitability of the referral and if not appropriate for the Crocus Group other possibilities can be suggested.

A referral form is sent out asking for details of the child, their family, the deceased, their relationship to the child and what the child has been told about the death. Referrals made within four to six months of a death are usually deferred simply to allow for the passage of time to clarify any issues about the bereavement. However there are no other restrictions on a child being referred as the aim of the service is to offer support to all children who experience the death of a close family member.

Carers and referrers are told the date of the next Day to Remember but these dates are always contingent on there being sufficient numbers of children to be viable as a peer support event. In the event of there being too few children they are invited to attend the next Day which may be 3-4 months later.

## Funding

The Crocus Group is a registered charity and does not receive any statutory funding. In 2002 we were able to secure support for the post of Child Bereavement Co-ordinator with the assistance of the Lloyds TSB Foundation and many other generous individuals, charities and firms. This appointment has enabled the work of the Group to develop far beyond what had been possible hitherto. The Highland Health Board, Highland Council's Social Work and Education Departments have also given grants and practical support to enable the service to run as smoothly as possible. It is our intention to seek some degree of core funding for the service which would set it on a firmer financial footing although the support of the community for the project has been a major strength in its development.

## Future Developments

Several volunteers have undergone training in the Seasons for Growth programme provided by the Notre Dame Centre in Glasgow. This is a programme based on the belief that grief is normal and that children and young people need to be provided

with an opportunity to examine how grief has impacted on their lives. To date we have held one seasons course which was specifically for teenagers, a group which had always been beyond the scope of the Day to Remember. Six young people enrolled and the feedback has been very encouraging. It is our intention to offer the programme to the most recent attendees at a Day to Remember over the course of the coming year and to hold another programme for adolescents.

## Efficacy of services for bereaved children

It is difficult to say at this juncture just how effective the activities of the Crocus Group have been. There is no doubt that there is a great deal of interest from professionals in health, education, social work and voluntary groups. A day held last year to raise awareness of the Group attracted over 100 people from these sectors and demand has led to the planning of another this coming spring. That parents and carers feel that the service is important can be shown simply by the distances they are prepared to travel to attend a Day to Remember. Gauging the service from the eyes of the children is much harder. Certainly their evaluations show that they have enjoyed the day immensely. What the long term effect of bereavement support may be is yet to be determined. It is true to say that children often carry the experiences of bereavement with them well into adulthood and how they deal with subsequent losses may depend on how a significant death in early years was dealt with. Perhaps what interventions such as those offered by the Crocus Group and others may help to normalise the experience of bereavement in what remains a death denying society.

## References

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