The Child Death Helpline

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THE CHILD DEATH HELPLINE was set up at Great Ormond Street Hospital (GOSH), London in 1992 to offer support after the death of a child. It was based on an existing hospital telephone support service for bereaved parents at the Alder Centre, Liverpool, UK and three years later the two merged to form a nationally available freephone service. Other paediatric hospital trusts have since shown interest in becoming affiliated partners, training and supporting volunteer bereaved parents to staff an increasingly busy and extending rota.

The helpline offers a caller-led listening service. The volunteers who work on the line are all bereaved parents who have had a child die four or more years ago. Our volunteers are not called counsellors and in our literature and training we are careful to make it clear that the help they are giving is not counselling, but rather a discussion focused on the needs of the caller with someone who has a natural sympathy with the feelings the caller is expressing.

The impact of a child's death is at the centre of our service. We are available to anyone affected by the death of a child of any age, however recently or long ago. We feel it is absolutely appropriate to hear from people who were thus bereaved decades ago, whose babies were stillborn, whose middle-aged children died, whose children died from an accident, an illness, murder, suicide, or for unknown reasons. Other relatives, friends and professionals can also contact us to talk over the many ways in which they too have been and will be affected.

Of course it is not necessary for people to have been bereaved of a child for them to be enormously helpful to those who have. However, knowing that the listener will have suffered a similar loss, people calling us to talk with an unfamiliar person, perhaps not having used a helpline before, uncertain and anxious about what our service involves, can be rapidly made to feel comfortable and confident to speak to whichever volunteer takes their call. It makes it easier for both caller and volunteer that feelings of desperation, hopelessness and helplessness which can be overwhelming and frightening are acknowledged as normal between bereaved parents. To others such feelings can, understandably, appear 'pathological', mad, or provoke the opinion that the bereaved parent should be 'getting better by now'. Though the power of our callers' emotions and experiences always touches us, as bereaved parents we can perhaps better offer a calm and sympathetic response.

The helpline is open every evening (7.00-10.00 pm), every weekday morning (10.00 am – 1.00 pm), and on Wednesday afternoons (1.00-4.00 pm), except on occasions when a child's death makes a sudden impact through the national media when we may temporarily increase our operating times. Knowing that our helpline provides a lifetime free service of support, accessible every day, can provide much strength from day to day.

Here one of our volunteers describes how she sees the value of our service.

> For me, one way of describing my grief and loss was as a journey that had to be taken at a pace I could not control. And it was a very lonely journey. If the helpline had been in existence when my sons died...I would have known there was someone there who could not walk my journey for me but could share my burden, if just for a short while, and give me the strength and belief that one day the sun would shine again. (Stephanie)

The team setup

At GOSH in London the helpline is a department of the hospital, whereas the Liverpool helpline is part of the multi-faceted bereavement service of the Alder Centre. The GOSH volunteers form part of a team with palliative care consultants, social workers and psychologists. These professionals work directly with the volunteers, as trainers, consultants or supervisors. This partnership between parents and professionals has proved to be essential in providing the best service to our callers and ensuring the best practice of the volunteers, whose emotional knowledge can be thus complemented by highly accessible multi-professional skills and experience. Interested support and financial backing from the involved hospital trusts has also been, and remains, crucial.

EDITOR'S NOTE

In my work with bereaved families, I am sometimes aware that there is a limit to how useful I can be because, however many stories I hear and however empathic I try to be, I have not actually 'been there'. There are times when people who have been bereaved do not need some fancy, sophisticated intervention, with the best evidence base, offered at a set time within office hours. Sometimes what they need is to be truly *understood at a time that suits them, and sometimes that understanding is best offered by someone who has had a very similar experience. This article describes just such a service for people bereaved by the death of a child.* DT

Training

All our volunteers receive training which is mainly devoted to practising active listening skills, concentrating particularly on the ability to perceive another person's main concerns and issues, and developing the confidence and the verbal 'tools' with which to explore these. Simulated interactions on authentic themes relating to child death and many other issues are examined in great detail – an essential part of the learning, which also provides very interesting, stimulating discussion. A system of 'second interview' after training, and a meeting with the whole group three months after embarking on duties, has been introduced and found to be a valuable vehicle for feedback.

Our developing practice

Over the years we have refined our practice in every area. For instance, we now have policies for difficult issues such as inappropriate callers, run workshops to maintain good practice and have developed a volunteer documents folder. This includes a volunteer service agreement covering all aspects of a safe, professional operation. In the last year we have also introduced a programme of biannual revalidation of volunteer skills.

Confirmation that our policies and methods are appropriate has come through important enterprises in the last few years. We were asked to support bereaved families at the Bristol Royal Infirmary Inquiry, the Brompton and Harefield Inquiry, and in conjunction with NHS Direct following the Redfern Report on Retained Organs – three major national inquiries into the treatment of children and their families. Some volunteers were themselves affected by the above events and their work face-to-face with distressed parents on these occasions was much valued.

The working environment

Learning from experience has never been so valid as during some of the times shortly after we started operating by freephone in 1995. We had to face, head on, the implications of offering a cost-free, caring service. A helpline can easily be 'brought to its knees', in the words of one of our founder members, with corresponding potential demoralisation of volunteers. This was nearly the case for the Child Death Helpline when we were the victim of a very sophisticated hoax caller following the Dunblane shootings.

A face-to-face service has a chance to screen clients before they arrive, and to discuss with referrers. A freephone helpline has to do this on the hoof by careful call-monitoring and conscientious communication within the team. Consequently, much thought has been devoted to working out the simplest and most effective methods of maintaining the remit and boundaries of the service, and to ensuring that volunteers are enabled to carry out the work they are trained for. Training in consistent methods of recognising and dispatching inappropriate callers is regularly offered. Relevant information is in place by each phone, and is quickly updated whenever perceived necessary through rigorous central call monitoring (by examination of completed call sheets and discussion with volunteers – *not* by listening in).

Communication is critical. Some of the volunteers, coordinators, supervisors and administrators that make up the team may not see each other for considerable periods, especially in the case of volunteers who only come to work evening shifts. We have found that phone, email, monthly newsletter, supervisory and workshop contact is the essential lifeblood of our colleagueship, and of our multi-professional team working.

For callers and volunteers the physical environment of the helpline and the nature of the telephone equipment have a big influence. Considerable thought and consultation went into this provision. A comfortable room, soundproofed booths, noise cancelling headsets, amplifying equipment, and an appropriate message for people phoning out of hours or when the lines are busy, have all proved to be essential features of our operation.

A positive experience

A few years into my work with the Child Death Helpline, I realised something that I had been taking for granted. This was the only place in my life, and I think in the lives of my colleagues, where talk of, and reference to, death (of our children, of any child, in all its ramifications) was an ordinary topic of conversation, taking a normal place with all other topics, where sadness and laughter coexisted side by side. Membership of the helpline team, though no light undertaking, is a positive part of all our lives. We can provide support both at times of great grief and trauma, or at any time when help is needed, giving callers the vital message that the only reason we sit at our end of the phone to receive calls is because we have 'been there' and we can listen. ●

The Child Death Helpline: tel: 0800 282 986; www.childdeathhelpline.org.uk