

uses the present tense the possibility that such usage might create misunderstandings for children or for people who are not acquainted with the facts of the death. BC

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#### References

1. Rosenblatt PC. Parent grief: Narratives of loss and relationship. Philadelphia, USA: Brunner/Mazel, 2000.
2. Rosenblatt PC. Help your marriage survive the death of a child. Philadelphia, USA: Temple University Press, 2000.
3. Parkes CM. Bereavement: Studies of grief in adult life. London, UK, New York, USA: Penguin, 1972, chapters 4, 5.
4. Klass D. The deceased child in the psychic and social worlds of bereaved parents during the resolution of grief. In Klass D, Silverman R, Nickman S (eds). Continuing Bonds: New Understandings of Grief. Washington, DC, USA: Taylor & Francis, 1996.
5. Klass D. The spiritual life of bereaved parents. Philadelphia, USA: Brunner/Mazel, 1999.
6. Riches G, Dawson P. Lost children, living memories: The role of photographs in processes of grief and adjustment among bereaved parents. *Death Studies* 1998; 22: 121-140.
7. Rosenblatt PC, Meyer CJ. Imagined interactions and the family. *Family Relations* 1986; 35: 319-324.
8. Rosenblatt PC, Walsh RP, Jackson DA. Grief and mourning in cross-cultural perspective. New Haven, CT, USA: Human Relations Area Files Press, 1976.

#### FORTHCOMING EVENTS

**St Christopher's Hospice study days.** 2001, London, UK. **Conducting funerals and caring for the bereaved.** 22 Feb. **'How I work with bereaved families'.** Talk by Judy Hildebrand. 22 March. **Young people facing bereavement.** 6 April 2001. London, UK. Contact Maggie Johnson, St Christopher's Hospice, 51-59 Lawrie Road, London SE26 6DZ. ☎ 020 8778 9295.

**Practitioners working with bereaved couples.** 2001. London, UK. Workshops on: 26 January, 16 February, 9 March. Details from Sheila McAuliffe, Tavistock Marital Studies Institute, 120 Belsize Lane, London NW3 5BA. ☎ 020 7435 7111.

**Child Bereavement Trust workshops.** 2001. London and Buckinghamshire, UK. **Supporting parents when their baby or child dies.** 5 Feb, 12 March, 9 April, 14 May, 4 June, 2 July, 10 September. **Understanding children and young people's needs in loss and grief in the community.** 30 July, 19 September. **Responding to the trauma of a child's sudden death.** 22 March, 18 October. **Coping with post-traumatic stress.** 14 June. **Sponsored one-day courses on children, young people, loss, death and grief** (no fee except £10.00 for materials). Details from CBT, Aston House, The High Street, High Wycombe, Bucks HP14 3AG, UK. ☎ 01494 446648.

# Internet support for bereaved people

**David Martin** BA MA PhD  
Professor of Psychology  
Tennessee State University, Nashville, TN, USA



**Most bereavement counsellors respect the value that support groups can have and will be interested in the growing number of internet bereavement groups now available worldwide. While there seems little doubt that internet**

**support is helpful for some people and has huge potential, it is important to understand how the various kinds of groups operate and to be aware that many are run without a professional facilitator.**

Some of the gains reported by participants in face-to-face groups have included a deep awareness that they are not alone, realising that what they are experiencing is normal, feeling deeply understood, and having the chance to talk about their grief journey. Exchanging informal, typed messages can ease the isolation of grieving in a similar way, and we owe a debt of gratitude to those who have pioneered extending support groups to cyberspace. Some of these innovators have been professionals but others have been bereaved people themselves, reaching out to others. In some cases people have provided support groups at considerable financial cost to themselves.

However, many of the websites offering support are not run by professionals and even if a professional has developed the site, the actual contact with participants will be through volunteers. Usually, these will have received some training and often the comments of the volunteers/monitors/hosts are insightful, understanding and helpful, as are many of the comments of other group members. Frequently, though, the comments tend to offer advice or practical suggestions when it would probably have been more therapeutic to be supportive and understanding.

Little research has been done to examine how helpful such support is and under what conditions it is most effective. We do not know if it is as effective as meeting face to face in a group. The support of an internet group is more like that of peer

group, such as Compassionate Friends (a self-help organisation for bereaved parents) than that of a group led by a professional.

Why would individuals want to participate in such groups on the internet? There are probably as many reasons as there are individuals participating. Some may live in an area where normal support groups are simply not available, or be confined to the house. Others may want to have contact with other bereaved individuals frequently – perhaps every day. The flexibility of internet support groups is an attraction for many who can, for example, enjoy the option of posting or reading messages late at night.

#### EMAIL GROUPS

A good way to explore internet support is to use a means of communication which

#### EDITOR'S NOTE

Whether we like it or not, the web is a fact of life which we cannot ignore and is rapidly becoming one of the first places where people with problems and a computer look for information and support. If you enter the word 'bereavement' into any of the common search engines, you will be overwhelmed by the huge numbers of sites which attempt to respond to this need. Future articles in *Bereavement Care* will take a critical look at some of these.

In this article David Martin describes the main types of help that are available and introduces us to the language which we must learn if we are to make sense of this new field.

may already be familiar – email. Support groups accessed by email go by such names as Email Support Group, Mailing List and Listserv, and work in a very simple way. You tell the provider (one is described below) that you would like your email address added to the list and you then receive, regularly, email messages that bereaved individuals have written to the email server. There might be a minimal charge for this but usually it is possible to participate for a limited period on a free basis.

If an email group has a large number of members who write frequently, there might be many emails every day – I have been a member of some groups where I have received as many as 100 emails in a single day. Members of smaller groups may only receive a few emails twice a week. An email support group for all bereaved parents would involve much more volume, for example, than a group for those whose child had died of suicide.

Members of large and active email groups may find that their mailboxes become so full of messages, especially if they have not been checked for a few days, that it can be difficult to sort through mail and identify correspondence from friends, family and work. This problem can be solved by having a program that allows emails to be sorted into files, or by arranging to have an email address specifically for support groups. If you adopt this last solution, it may be best to use an address that conveys limited information and protects anonymity; as you get more familiar with members, you can choose to convey more information about yourself.

Another problem with email groups is that the messages arrive unsorted, with the resulting hodgepodge including recently written primary messages and responses to primary messages written up several days ago. The brief subject headings convey very little information. However, as you spend a longer time in the group, you will probably form bonds with certain members and give highest priority to reading emails from these people.

There is usually about a 24-hour delay between the time that messages are sent in and the time they are sent out to the members. There may then be another 24-hour or more delay before individuals have the opportunity to make a response to the communication, and these time lags can be a problem.

As a member of an internet group, one is usually expected to participate actively as a form of good 'netiquette.' However, it is certainly reasonable for a bereaved

individual to just read others' messages for a while before getting involved in sending any and, of course, just 'listening' to others can, in itself, be very helpful and supportive.

**Griefnet.org** has over 35 email support groups. There are groups for bereaved parents, children, siblings, friends, survivors of suicide and others, as well as for children and teenagers. In order to see the wide range available, you simply click the "Join" button, making the long list of groups and their descriptions available for perusal. (There is another step before you actually become a member of any of the groups.) Sometimes it is helpful to become a member of two or more groups: one might be a large, frequently-used group, like a general group for all bereaved individuals; the second might be a lower-volume group specific to your unique loss.

### MESSAGE BOARDS

These are known by such names as Message Board, Bulletin Board, Newsgroup and Usenet Group. At **Death-dying.com**, you will find several message boards. All of the messages are posted at the website.

Message boards offer several advantages. First, the messages are categorised and arranged in a very efficient way. It is easy to see which are the original messages and which are posted in response, and easy to scroll through the messages and identify the ones you wish to read. A person's email box never becomes stuffed full because messages only enter the computer's memory when downloaded. Messages are usually posted on a message board within minutes and this means that feedback often arrives in minutes, rather than days as in an email group.

**Alt.support.grief** is perhaps the most widely used message board in the bereavement field. It can be complicated to reach this site. One way is to go to **deja.com** and register, then enter **alt.support.grief** in the search field. Once at the site, it should be bookmarked (or listed in your 'Favourites' category) for easy access in the future. It is worth the effort to reach this site because it can be supportive just to see the hundreds of messages from bereaved individuals that arrive here on a daily basis.

### CHAT GROUPS

This is the name usually given to real time groups. Members enter these groups at the same time and communicate with each other by typing messages. The chat group is the closest experience to meeting others face to face: you can give and receive instant feedback. However, there are some

disadvantages. Messages tend to be very short. Several conversations might be going on at the same time among members. Some members might be talking one-to-one while others are addressing the entire group and it can be a little disconcerting to express deep emotions in the midst of this. As time goes on, most individuals become more comfortable with the situation.

It is often more difficult to become a member of a chat group than an email group or message board. For example, some chat groups are only for AOL users while others require that the computer have the proper software like Java, IRC or Parachat.

**Groww.org** has over 20 chat groups, called chat rooms, some opening 24 hours a day and others meeting at specified times. In the 24-hour groups, there is usually someone present at all times. There are groups for bereaved parents, spouses, suicide survivors, caregivers, and many others, and chat rooms for seniors as well as teenagers and pre-teens.

When you enter a chat group for the first time, you can experience considerable anxiety. New members will usually become the centre of attention with existing members wanting to welcome them and find out about their grief situation. You usually have the option of enjoying lots of 'hugs' - cyberhugs look like this: (((((((((( Your Name ))))))))). Some individuals would probably like to have a bit of time to observe the group before interacting and they can simply type the message that this is their first time in the group and that they want to observe for a few minutes before interacting.

### SUPERVISION AND OUTCOME

Volunteers help to make the internet support experience a positive one. Email groups and message boards will usually have a monitor who scans the messages to spot someone who needs a response from them. Certain words like 'help' will alert the monitor that a response is needed. Monitors are also looking for situations where members may be sending or getting responses that are not helpful. However, for a number of reasons, a substantial period of time often lapses before monitors make appropriate interventions. Chat rooms are usually 'hosted' by a volunteer who is performing a similar service. An attempt is made to prevent 'spam' (junk email) and stop internet predators from sending messages, but no method is 100% successful. The possibility always exists that a person might pour their heart out in

a message only to have someone respond that 'your loved one was a drunken bum and doesn't deserve to be grieved.' An internet predator might pretend to be a known group member and say outrageous things. Hopefully, we can forewarn individuals and minimise damage if this happens.

#### INTERNET GROUP ADDRESSES

The following is a list of a few of the internet support groups. These have sufficient members and activity to offer the best chance of positive interaction for bereaved people.

- alt.support.grief** – message board
- compassionatefriends.org** – chat groups
- death-dying.com** – message boards
- fortnet.org/widownet/** – email groups, message boards, chat groups
- griefnet.org** – email groups
- groww.org** – chat groups
- juliesplace.com** – email groups, message boards (for teens and children who are bereaved siblings)
- petloss.com** – one of the best support sites on the web (companion animal loss)
- webhealing.com** – message boards (called message index and found on 'discussions' page) BC

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#### LETTER TO THE EDITOR

Dear Editor

As a bereavement worker and a regular reader of your excellent magazine, I would like to congratulate you on the article, 'A response to the death of a pupil'. I am a school governor of thirty years' experience, and Vice Chair of the Gone Forever project which works with adults who are involved with children and young people who have been bereaved. We have for some years campaigned for teachers to be trained in issues surrounding bereavement and loss in their initial teacher training. We firmly believe that if a grieving child is handled sensitively during its school life, the effects of loss may be lessened. We come across so much unsympathetic handling and resultant problems in our work at the Gone Forever project.

Any help you can offer at this crucial time when the Initial Teaching Training Syllabus is being reviewed would be most welcome. I have already drawn the attention of the Secretary of State for Education and Employment, David Blunkett and Lead Officer on the Review, Hugh Baldry, to the article.

Keep up the good work.

**JILL MOORE**

Vice Chair, Gone Forever Project  
School of Education, 23 Collegiate Crescent  
Collegiate College Campus  
Sheffield S10 2BP

# Researching the bereaved

## An investigator's experience (part 1)



**Magi Sque** PhD BSc RN DipNEd RNT

*Lecturer in Oncology and Palliative Care  
European Institute Health and Medical Sciences,  
University of Surrey, Guildford, Surrey, UK*

**This article looks at the process of interviewing bereaved relatives of organ donors and the potentially painful nature of such research. The sensitivity of the topic made access to relatives difficult, while a central concern was the impact of the investigation and the possible threat that it posed to the participants and myself. I found that my background and personal approach influenced my interactions with the interviewees and the course of the research work.**

**E**very year, of the 700,000 individuals who die in the UK, only approximately 900 will become 'major organ donors'.<sup>1</sup> The relatively small number of donating families and their anonymity mean that little is understood about the experience of having a relative in a critical care situation that ends in donation. The purpose of this study was to elicit an understanding of the nature and meaning of the organ donation process for relatives of 'major organ' donors. I carried out audiotaped, narrative interviews with 24 donor relatives. As most research could be regarded as sensitive to some party involved, I believe there is a special point to be made with researching topics that are expected to be both physically and mentally distressing for the individuals involved.

There is another matter that must be made to contextualise the potentially painful nature of the interviews I conducted. Within the context of bereavement, donor relatives are at high risk of aberrant bereavement outcomes because the tragic and sudden nature of donors' deaths may be difficult for families to reconcile, especially as donors are relatively young and previously healthy. Families are necessarily approached about organ donation when their grief may be all-encompassing and when thinking and concentration is a problem. However, if donation is to take place, families need to make a number of decisions on behalf of

their deceased relative. These decisions may be problematic because they concern an operation on another's body, yet the time to debate the issues is constrained.

Relatives are asked to accept a nonstereotypical death (brainstem death) as death. The implications of brainstem death transcend the usual experience of the lay individual. Potential donors maintained on a ventilator may not look dead and often have no external manifestations of injury; they tend to be unscathed, resting, warm and florid, and their chest moves as if they are breathing. They may even move occasionally in other ways if a spinal reflex is activated. Their time of death becomes an arbitrary decision made by the attending physicians. Not only are relatives asked to accept this situation as death, but they are asked to agree to the removal of the very vital organs that would normally maintain life.

#### EDITOR'S NOTE

The importance of carrying out systematic studies of bereavement in all its forms cannot be over-estimated but ethical and practical considerations need to be taken into account in all our plans. Magi Sque has chosen an unusually difficult topic, the grief of people after organ donation. She shows how the many obstacles to research in this field can be overcome.