

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

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.

Every year, of the 700,000 individuals who die in the UK, only approximately 900 will become 'major organ donors'.¹ 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.