An evaluation of a hospice memorial service



Fran Duncan DipSW (right) Principal Social Worker

Roy Findlayson MA (centre) Chaplain

Patsy Wilson MA BACPAcc (left)

Children and Young People's Counsellor

Marie Curie Centre, Newcastleupon-Tyne, UK

The memorial service is becoming more common, alongside the

funeral, as a formalised ritual to remember the dead and give thanks for them, their life and activities. Recognising a need for this led the chaplain and social work team of our hospice to set up a quarterly memorial service, an 'Occasion of Remembrance and Thanksgiving'. However, we wanted to know whether this event met the expectations and needs of those who attended, and so we carried out an evaluation.

Today the majority of deaths in Britain occur in hospital but those with complex specialist needs may be referred to a hospice where they will receive more holistic, specialist palliative care from a multidisciplinary team. The holistic care embraces the family and carers of the dying person and continues after the patient's death. Bereavement care is seen as an integral part of specialist palliative care which, as well as focusing on the physical problems, also tackles psychological, social and spiritual needs.

Rituals surrounding death, dying and bereavement became less formal during the last century, but it is recognised that some form of ceremony helps to affirm the reality of a death and ease people in their grief¹. In recent times there has been a spontaneous public response in the UK when famous people have died, such as Princess Diana, Jill Dando and the Queen Mother. There is an increasing acceptance that the bereaved need to remember and celebrate the life of the deceased in order to make sense of what has happened. The ritualised framework of a memorial service offers a recognised cultural and social structure in which to express feelings and

thoughts through song, poetry, prayer and meditation, in a safe, controlled environment. Bringing together bereaved people to share thoughts and feelings can foster a

EDITOR'S NOTE

Returning to the place where a loved person has died can be an ordeal. It can also be a turning point in the process of grieving. Rituals of remembrance linked with social gatherings provide support to bereaved people, an opportunity for them to find meaning in the death and for bereavement support services to

assess the need for further help. For all of these reasons many hospices and palliative care units now hold such services although there is variation in the timing, involvement of nursing staff and extent to which the multi-faith element is emphasised. This paper provides feedback from the Marie-Curie Centre in Newcastle-upon-Tyne and the editors would welcome comments from other services and their users. Do the two thirds of people who do not come to the services need

this kind of help? Has anyone looked at systematic bereavement risk assessments comparing those who come with those who do not? CMP spiritual and emotional release that may help them to move on in their grieving². A symbolic act of remembrance, such as lighting a candle, can evoke the life of the deceased and mark their death.

AN OCCASION OF REMEMBRANCE AND THANKSGIVING

The Marie Curie Centre in Newcastleupon-Tyne is one of two local hospices in the north east of England. It has 22 inpatient beds and a day care unit. In 1997, with around 200 deaths each year occurring in the centre, we decided to organise a quarterly memorial ceremony. This was a development of the already existing bereavement service which offered information, telephone support, befriending, counselling and a drop-in service. The aims of the memorial service are to offer the relatives and carers:

• an occasion to remember and give thanks for the deceased

• further support from the bereavement team, if wanted

• an opportunity to experience a therapeutic release of feelings in a structured, supportive environment.

There are usually 50-60 deaths every quarter, so we send out around 60-70 invitations for each service to the relatives and carers of our day-care and in-patients. To allow the initial numbness and shock after a death to pass, we felt a period of time should elapse before issuing an invitation. This, and other practical considerations such as numbers, led us to invite just those who had been bereaved between three and six months previously.

The invitations, with a tear-off slip, are sent out two or three weeks before the service. Families are encouraged to bring children. There are no restrictions on the number who may come and attendance has fluctuated from 40 to over 100. The number of those being commemorated also varies (see table on p9). We know of no significant influences to account for the varying attendance figures.

The chaplain and bereavement team run the service, offer refreshments afterwards, and regularly review the event. Although the majority of our patients and families are white and from a Christian background, it could not be assumed that the all the bereaved would be the same, and so the service format includes both Christian and secular songs, readings, sayings and prayers. The name, Occasion of Remembrance and Thanksgiving, was chosen to reflect the balance between secular and Christian influences. The Marie Curie Centre's chapel is too small for this event and so the education department of the centre was chosen as a neutral venue where we could address both the spiritual and religious needs of the bereaved.

Included in the half-hour-long service is a symbolic act of remembrance in which the names of the dead are read out and the bereaved are invited to write on a card their feelings and thoughts about the person they are commemorating. After the service, the cards are displayed for a week in the chapel and the chaplain then disposes of them. It is not possible to light candles during the service because of fire regulations.

Later, while they are being offered home-made refreshments, the relatives and carers can speak to members of the bereavement team. This includes between four and six trained volunteers, the chaplain, social workers, and the children's and young people's counsellor. There is a noticeboard and leaflets are available from local bereavement support organisations such as Cruse Bereavement Care, as well as information on the nature of bereavement. During the service the chaplain mentions our remembrance book kept in the centre's chapel, where people can visit on the anniversary of a death to view the page and spend time in the chapel or the centre's garden.

The multidisciplinary team is given a list of those to be commemorated. They are also invited to come or take part but, after the first service, they have not done so. It seems that the nurses find both the content of the service and the relatives' expectations of one-to-one contact afterwards too distressing. Also, inevitably in such a busy unit, it is difficult for the staff to remember all the relatives and carers. It may be because the bereavement team is one step removed from the clinical experience that they are more able to cope. After the mourners have left, the staff and volunteers have a debriefing where concerns about individuals can be shared and plans made to follow up those requiring further support.

THE EVALUATION

We have encouraged suggestions from staff and volunteers and, in response, made changes to the service. However, we have had no major feedback from those attending and so we decided to use a questionnaire to explore their reactions to the whole event^{3, 4, 5}. We focused on two services, as numbers fluctuate, and devised a form with ten questions requiring yes/no answers, with a space for comments. The questions covered the invitation process, the timing of the service in relation to their bereavement, the format, including Christian/secular balance, and the remembrance act involving the writing of cards. The questionnaire, together with an explanatory letter and stamped addressed envelope, was handed out as people left the service. Many were completed and returned to us on that day.

There were comments about how comforting it was to be around others in a similar situation

The table below displays statistics for all the 2001 services, with the two evaluated services in July and October highlighted. A total of 98 attended these two services; 97 questionnaires were given out and 64 (71%) were returned. Of those who had died, 29% (in-patient and day-care patients) were remembered.

Format

Of those who responded, the vast majority (98% - 100%) felt the invitation, the venue, the timing (on a Sunday at 3 pm), and the length of the service were appropriate, and 95% believed three – six months into the bereavement was about the right time to invite them to such a service. One or two mentioned that two – three months would

have been a more suitable time as by five – six months they were beginning to set aside their grief. However, we recognise bereavement to be an individual process and three – six months appears to work for the majority.

Content

On the question of **Christian/secular balance**, 92% thought this was 'about right'. A few suggested including more influences from other faiths. Generally the respondents spoke of a 'lovely service', 'right balance, right time, right place', 'comforting'. A minority suggested participation by the bereaved. Our view is that interaction and participation are inappropriate because our aim is for the service to be emotionally experiential. Client participation may be too stressful for the bereaved and also too administratively difficult for us to achieve at every service.

The **symbolic act of remembrance** (writing on the cards) was approved by 94% who found it helpful, although some commented that it was distressing, and others that they would have liked time to prepare. (Card-writing is now mentioned on our invitations). Some said 'knowing others are in the same situation is helpful' and found it 'helpful to have opportunity to reflect and remember'. It would seem that this act of remembrance and thanksgiving is valid and beneficial, a valuable part of the hospice memorial service.

Social gathering

There are no statistics on how many people stay to take refreshments. Some leave for a variety of reasons: they may be distressed and desire privacy, or have other commitments. Those who stayed enjoyed the opportunity to talk together, relax, and talk to the staff and volunteers. There were comments about how comforting it was to be around others in a similar situation. For those attending the service alone there can be a feeling of isolation and so we encourage the bereavement team to target them, both before and after the service. Some wanted to meet again with the nursing staff.

Services in 2001 January	Deaths 62	Deaths at age 55 and under	Invitations sent 59	No details available	Relatives and carers attending 93	Patients being commorated	
						25	40%
April	67	20	69	3	50	19	28%
July	58	11	50	8	49	13	22%
October	65	13	63	1	49	23	35%
TOTAL	252	60	241	15	241	80	

CONCLUSIONS

This evaluation has told us that:

1. an occasion of remembrance and thanksgiving meets a variety of needs for those who attend

 the invitation has sufficient information and is sent at a suitable time prior to the service; the tear-off slip allows us to plan the seating, service sheets and refreshments
the venue, timing and format of the service appears to address the needs of those who attend

4. the balance between the religious, spiritual and secular content appears to work5. for those that stay for refreshments, it gives the opportunity for further support through talking to staff, volunteers and one another

6. the regular review of the occasion, including feedback from the staff and volunteers who run it, ensures that we are flexible in responding to suggestions.

It is clear from the 71% of those who returned the questionnaire that this Occasion of Remembrance and Thanksgiving is positive and worthwhile. The initial contact and structured ceremony provide a safe, controlled environment, formal but intimate, in which the bereaved can experience their grief. For many perhaps the only other ritual has been the funeral, usually about a week after the death when the bereaved would be numbed and shocked. Our services may help the bereaved to move on and offer relatives and carers an opportunity to seek further support.

What is not clear is why some do not attend: in July, only 22% of the 58 deaths were remembered by the 49 who attended; in October, 35% of 65 deaths were remembered by the 49 who attended. We will continue to review and vary the content of this occasion, but we need to do a larger survey of the needs of the bereaved to ascertain from them what would be of most benefit at particular times in the first two years after a death.

References

1. Walter T. A new model of grief; bereavement and biography. *Morality* 1996; 1: 7-25. 2. McLaren J. A new understanding of grief: a counsellor's perspective. *Morality* 1998; **3**(3): 275-290.

 Foulstone S, Harvey B, Wright J, Jay M, Owen F, Cole R. Bereavement support: evaluation of a palliative care memorial service. *Palliative Medicine* 1993; **7**: 307-311.
Rawlings D, Glynn T. The development of a palliative care-led memorial service in an acute hospice setting. *International Journal* of *Palliative Nursing* 2002; **8**(1): 40-47.
Gorman A. An evaluation of a bereavement support service. *Palliative Care Today* 1995; **4**(3): 38-38.

Bereaved adult siblings

Amanda Aitken BA PGCE DipCouns Counsellor, Torbay Social Services, Devon, UK

The relationship between siblings is potentially the longest of all human relationships. Yet when a brother or sister dies, surviving siblings often sense that society does not recognise the impact of their loss. For many, this can lead to confusion, anger and unresolved grief as full permission to grieve is denied. Looking specifically at adult sibling loss, I find that the internet seems to reflect this lack of recognition with noticeably few resources for this kind of bereavement. Those that do exist however, are worth exploring.

The Sibling Connection at www.counselingstlouis.net has been created by Pleasant Gill White, a USA-based psychotherapist and bereaved sibling. On this extensive and imaginatively conceived site, she briefly considers some of the implications of sibling loss as a child, adolescent, student and adult, raising such issues as the possibility of being overprotective in adulthood, compulsive care giving, and guilt. The student section includes links to find appropriate counsellors in the USA, UK and Canada and includes personal stories submitted by site users.

The articles written by White herself vary in depth and quality. Her outline of the basic grief theories of Bowlby, Kubler-Ross and Rondo lacks detail and in 'Factors that influence sibling grief' important aspects are listed but left unexplored. Of more interest is her article 'Bibliotherapy for bereaved siblings' on the use of books as healing aids, giving details of how to use them and questions for bereaved readers to consider. She emphasises that such self-help can raise unresolved issues so emotional support is essential. White also considers some 'families' of emotions that can follow the death of a sibling, including word banks that may help clients identify their feelings and experiences.

Other articles consider the long-term effects of childhood sibling loss, its effect on family and marital relationships, the impact of the family reactions on surviving siblings, continuing bonds between living and dead siblings, and the link between creativity and healing.

Throughout White stresses the importance of learning about the grief process and comparing one's own experiences with those of others, with a brief mention of two other cultures. She recommends certain popular films, each demonstrating different aspects of the grieving process and describes fiction and non-fiction **books** for siblings, listed in age-appropriate categories (the titles link directly with Amazon). Site users can also sign up for a newsletter, which appears to be free, providing site updates, articles and book reviews. There is a FAQ section and an extensive **bibliography**, **links** to other useful websites (click on Support) and a collection of **personal stories** provided by site users. Finally there is a well-used message board

which appears to offer a lot of support to bereaved visitors.

Although previously reviewed in Webwatch, the international organisation **The Compassionate Friends** (TFC), which has branches in the USA, UK, Canada and Australia, needs to be mentioned again in this context. This organisation originally focused on parents, but swiftly recognised that bereaved siblings could be 'forgotten mourners' and has consequently produced a number of excellent resources.

Go to www.compassionatefriends.org/ and click on Sibling Resources. Included here are two 'brochures'. Death of An Adult Sibling briefly examines the loss of shared family history and family roles and the strain on relationships, while When A Brother or Sister Dies is aimed at teenagers. For North American visitors, the site gives details of support groups for bereaved siblings and details of relevant conferences in the USA and Canada. There is also an internet chat room for bereaved adult siblings and teenagers, described by one user as an 'incredibly supportive environment'.

An **online forum** provides a message board on which to post comments and questions, and there is a sibling **pen pal program** for people of any age. Throughout this site there is a feeling of protection and security. For example, the forum is not a public board and, like the pen pal scheme, can only be accessed through contact with a TCF representative via the website. A **book** and **video** specifically for siblings can be ordered from the site and the **sibling newsletter**, with a special addition for the newly bereaved, is available as a free download.

Finally, Atlanta and Western Australia TCF groups have created their own sibling websites, providing some touching articles and poetry submitted by site users.

BOOKS DIRECT FROM CRUSE

SIBLING BEREAVEMENT Helping Children Cope with Loss

Ann Farrant

 $\pounds 16.99 + p \& p$ Looks at various effects of sibling bereavement on the whole family using case studies

FACING GRIEF Bereavement and the Young Adult Susan Wallbank

£10.99 + p&p For those aged around 18-25, a frank sensible look at the loss of a family member, friend or partner

Order from Cruse Bereavement Care 126 Sheen Road, Richmond TW9 1UR, UK T 020 8930 9530 email info@crusebereavementcare.org.uk