

# Does it hurt to die?

## Bereavement work to help people with learning disabilities



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### Recognising the need for specialist educational support for bereaved people with learning disabilities, we set up a programme to help a group of eight learning disabled people come to terms with multiple or major losses. The programme, a series of ten workshops, was designed to explore a wide range of issues surrounding loss. Accounts from group members are encouraging, suggesting that the approach is worthy of further study.

It is a terrible indictment of public services, if families feel that their sons or daughters are better dead than living without parents and being the unhappy recipients of inappropriate services.<sup>1</sup>

Bereavement affects everyone but ordinarily most people deal with it, or receive services to help them do so. People with learning disabilities also face major losses in their lives, perhaps more commonly than the majority of the population. They may experience extra losses, for example, of friends, neighbours or home, if, as a result of bereavement, caring services need to be provided by strangers or they have to move to another environment. In our experience, the special needs of this group are not always recognised.

Another problem for those with learning disabilities is that often they are not made aware of what has happened to a dead relative or friend. Bicknell<sup>2</sup> and Oswin<sup>1</sup> reported that news of a death can be withheld for weeks or months, sometimes is never told at all, and that these omissions deny them the opportunity to attend the rituals associated with death, such as the funeral, that are important in the mourning process. The vital role of ritual is illustrated by the experience of a young man with severe learning disabilities who lost his mother suddenly during the night. He was admitted into emergency respite

care and did not attend the funeral. The next time he 'saw' his mother was when he was taken to see a tree planted in memory of her in a garden of remembrance. He could not understand what had happened in the gap between seeing her alive and seeing a grave that somehow had become the repository of her body.

To help people with learning disabilities who had experienced such losses, we decided it was appropriate to provide a specialist education service. O'Brien<sup>3</sup> gives a useful framework on which to base this work, involving personal investment, focused attention and learning through action.

We began by contacting the staff at a local day centre who identified a group that had lost parents, carers or significant others and had not been given the time or opportunity to explore either their feelings or knowledge on the subject of death. The staff had felt unable to help and had been unsuccessful in accessing generic services to do so. We were then formally asked to design and run a course for the group on death and dying, though resulting discussions with the staff very much informed the format of the course.

A simple, curriculum-planning model was agreed, based on four components: assessment, content, method, and evaluation. The number who could attend the course was set at eight, a good size of group for encouraging sensitive discussion,

appropriate for the number of facilitators available, and practical for the demands of the programme that was to include two external visits needing transport.

### SETTING UP THE COURSE

#### The client group

Clients needed either to be able to communicate verbally, or to have reading and writing skills. In the selection process we assessed the group members' experience and understanding of death, their attitudes to it and the time that had elapsed since their loss. We looked for the presence of factors that determine complicated grief, in particular Littlewood's social determinants<sup>4</sup>, and became all too familiar with them: many of those we talked to had experienced conspiracies of silence, socially negated losses<sup>5</sup>, unhelpful social support networks<sup>4</sup>, or even absence of the same<sup>6</sup>.

Taking into account all these factors, we were able to identify people as priorities for attendance. Prospective candidates had meetings with key workers where they were given information about the course, including content, methods of delivery, attendance dates and times. It was left to the people concerned whether or not they wished to attend.

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#### Initial concerns

One ground rule for participants was that all parents/carers should be informed about what was happening so that they could ask questions and raise any concerns. This facility was to be available for the duration of the course. Any concerns about an individual would be fed back to a named worker at the day centre who would deal with them directly, with the carer, or could refer to us for advice or clarification.

### EDITOR'S NOTE

**The needs of those with significant learning disabilities are frequently overlooked or minimised in many areas, including bereavement services. Siri and Michelle Persaud describe here the workshops they set up for this vulnerable group on bereavement and issues surrounding loss. In the next issue of *Bereavement Care*, we will be publishing a report of a recent study assessing the success of two different interventions for bereaved people with learning disabilities. MN**

At the outset we experienced problems because of a communication breakdown between managers who had agreed course content and key workers who had not had this information fed back to them. All sorts of rumours circulated, particularly about the visits to the funeral parlour and crematorium, and the day centre staff were concerned that clients would be exposed to dead bodies and embalming procedures. We had to quickly allay these fears, keep the staff fully informed about what we were doing, and reassure course attendees.

### **The format**

It was agreed with the staff, ourselves and the clients that we would run the course as a series of ten, two-hour workshops held on a regular day and time each week at the day centre. This venue was chosen firstly because the familiar surroundings would be non-threatening and allow people to opt in or out of sessions with ease should they wish to, and secondly because it gave access to key workers and friends should there be a need to talk to someone not associated with the group

## **COURSE CONTENT**

All sessions began with three important activities:

- 'I feel...' exercise Each person, the group and the group leaders, expressed how they actually felt at that particular moment. This allowed the group to be aware of how others were feeling and adapt their behaviour to suit this, and gave the leaders an indication of everyone's emotional status and any need for support.
- Listening exercise. This was essential, especially in the very large, busy and noisy environment of the day centre, because many of the clients were unused to practising this very important skill.
- Recapitulation. Going over the previous week's session allowed the leaders to find out how much information had been retained and, if necessary, revise and reinforce the remembering of important information. Later, this exercise provided an opportunity to relate previous sessions to the current one.

### **Session one**

#### **Introduction to the group**

In this first meeting the emphasis was on ground rules for the group and ice breaking exercises, developing a supportive, reassuring environment so members felt able to contribute. Course contents were outlined, and the clients were able to discuss any concerns or anxieties they felt about what they would be doing over the next ten weeks. Everyone was encouraged to disclose their

losses (should they wish to), and make clear their reason for attending. A major component of this session was preparing people to be able to listen effectively.

### **Session two**

#### **Loss and things we lose**

This began with a discussion on types of loss, eg material possessions, animals, people etc. The second part of the session concentrated on feelings linked to the experience of loss. The group members were encouraged to identify something they had lost, describe what happened, and how they felt at that time. The discussion was focused on simply describing feelings, rather than using this as a counselling method for cathartic release of emotions.

### **Session three**

#### **Mourning processes**

Here we looked at the way people behave when they are bereaved. Clients were encouraged to explore and discuss their experiences of numbness, shock and disbelief, denial and avoidance, anger and guilt, and acceptance and resolution<sup>7-10</sup>. We focused on three perspectives within the mourning process<sup>11</sup>:

- physical sensations in the body, eg a dry mouth, feeling nauseated, sweating
- emotions (feelings inside us), eg sadness, worry, confusion
- behaviour (things we actually might do), eg searching, crying, restlessness.

### **Session four**

#### **Feelings**

Watching a video helped the group to realise that other people suffer losses and show their feelings in their behaviour. This was to demonstrate that it is 'OK to cry', and that people should not be inhibited in expressing their feelings when they are bereaved.

### **Session five**

#### **The funeral parlour**

The purpose of visiting a funeral parlour was to make the group aware of the processes that take place after a death. The directors showed us around their premises, taking time to explain everything and answer questions. Actually being there made this an authentic experience and, we believe, created a more permanent impression than a classroom description.

### **Session six**

#### **The crematorium and cemetery**

This second visit gave the group an opportunity to learn where people go when they die. Exploring the different types of graves and methods of disposal of a body, the clients were able to relate back to the work in session five. They were also able to see

graves at different stages (from one being freshly dug to a mature grave), how graves are looked after, and how others had remembered their dead loved ones. This trip gave the group members the chance to demystify death by involving them physically and cognitively in the practicalities surrounding it. They could also fill in the gaps in their own experiences, since in many instances they would not have been involved in the funeral process.

### **Session seven**

#### **Cultural aspects of death and dying**

We thought it appropriate to raise the group's awareness of the UK's multicultural society and the wide variety of rituals and grieving patterns practised by people from different cultural and religious backgrounds living here.

### **Session eight**

#### **Wills**

At this point we discussed what a will is, why and how we make one, what information can be included in it, and what happens if someone dies intestate. A common misconception held by most people on the course, and also by the staff, was that a will should only be made by those who have something of material value to leave, ignoring the importance of a will as a testimony of last wishes.

### **Session nine**

#### **Feelings of anger**

Although previous sessions had focused on the factual elements of death and dying, we had been exploring the emotional aspects of bereavement at the same time. However, in this session we concentrated on anger, looking at what it is, why people get angry, how it manifests itself, and if it is wrong to be angry. We used a practical exercise and a discussion, encouraging expression of feelings. We scheduled this session towards the end of the programme because by this time members had built up comfortable relationships within the group and toward the facilitators, and so were communicating much more freely. As the course progressed, group members had been continually making references to their own losses and the situations that they now found themselves in because of them. They expressed a wish collectively to be able to explore their feelings in more depth.

### **Session ten**

#### **Evaluation and presentation of certificates**

To evaluate the course, each client was interviewed privately using a prepared list of questions. This method was chosen, as indirect observation of the group had shown that some individuals tended to

dominate and lead responses that did not necessarily reflect personal opinions. A certificate of attendance for the course was distributed to all group members.

## OUTCOMES

The evaluation went very well, resulting in a range of different responses to our questions. There were two outstanding examples of the success of the course. One was a client who started the course sitting outside the perimeter of the group. He could not be persuaded to join in, physically or conversationally, though he did agree to listen. He also refused to go on the first visit, to the funeral parlour, scared of what he might see. Gradually over the ten weeks his chair moved closer to the group as he began to participate, and he came on the second visit of his own free will. During evaluation he commented that he had enjoyed the course and felt better as a result of talking about his loss.

A second person who had been very unwilling to talk about his bereavement stood up whilst visiting the funeral parlour, announcing that he had something to say. For the first time in 18 months he told everyone that his mother had died and that she had a gravestone like the examples we were being shown. Apparently when he went home, he discussed the session with his father. His father then rang the day centre, was able to talk to the staff (who had been forewarned of this development) and acknowledge that he too needed to come to terms with his own grief and help his son.

Other examples of success included a young woman who felt empowered to confront her parents for not informing her of her grandparents' death. This confrontation allowed her to come to terms with her anger and she was then able to talk openly with her parents about her feelings. Another young woman had been told various stories about death and, as a result, had a fear that her grandmother would come to haunt her. This fear was alleviated by being given correct, factual information about death processes, and by the visits to the funeral parlour.

An unexpected benefit of the workshops was that one of the support helpers who had never had a major loss to deal with in her own life told us that she had found the whole experience very educational. She felt that she was now better equipped to deal with any impending loss.

## CONCLUSION

Designing, organising and running this series of workshops has been an invaluable

experience for us as well for as the day centre staff. Much has been learnt from the people who have been helped, but more importantly the process has made the staff question their own attitudes, perceptions and beliefs about death, dying and learning disabled people. One question has emerged clearly concerning society's attitude towards death and helping people with learning disabilities: are there perceptions here that need to be challenged and changed?


We experienced much apathy and uncertainty from care staff about what services might be willing and able to help with the course, but in practice the input and support of the funeral directors were most useful. The directors had no objection to spending time talking to the group, showing them around their premises, explaining what happens after a death, communicating in a variety of ways with compassion and respect. They also willingly spent time with us finding out what were the specific needs of the group, and then using this information to tailor their presentation to suit them.

More work needs to be done in designing flexible care packages that fit into service constraints and effectively meet the needs of very vulnerable people. After a carer dies, in the majority of cases the first response of a service agency is to provide the care the dependent person now needs by moving them away to an alien environment. Because of the constraints on the various service providers, it is common for the bereavement to become lost within bureaucracy, and for the bereaved person's needs in this area not to be recognised or met, as well as being 'down played'.

Another issue which arose from the workshops concerns the pressure on those who have learning disabilities to hide their anger or distress: they must act appropriately at all times and not cause a fuss or make a scene in public. In one session when we were encouraging group members to express anger about their losses by throwing wet sponges at a wall, they looked at one another in amazement when they first heard the instructions. Their problem was not lack of understanding: it was the thought of doing something 'bad' or 'inappropriate' that caused their apprehension. Only after a demonstration did they feel able to take part and then, in fact, ask for another go. This gave all the staff concerned a very strong message about the amount of control exerted over learning disabled people, control that is not necessarily recognised or monitored.

As a consequence of the success of this

first workshop, there has been a second at another day centre, and a further one is planned. The need for this specialist service has been recognised and a rolling programme of workshops is to be available to all service users in the area.

A UK Department of Health document, *Learning Disability: Meeting Needs Through Targeting Skills*<sup>13</sup>, explores the integral part that staff working with people with learning disabilities have to play in promoting the health of their charges. This must include recognising the fundamental importance of dealing with the loss and bereavement that this group, like most people, will have to confront at one time or another in their lives. Clearly more rigorous measurement of outcomes is needed than has been reported here, before any single method of bereavement education could be advocated. Such an assessment might look at which teaching strategies best achieve a healthy adjustment to loss. 

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