Loss, bereavement and learning disabilities: providing a continuum of support


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Aim and learning outcomes
The aim of this article is to enable readers to explore the concept of loss in relation to the support of bereaved people with learning disabilities. The concept of loss and its associated effects will be introduced; the challenges in working with bereaved people with learning disabilities identified; approaches to effective support explored and a model providing a broad spectrum of support presented for discussion. After reading this article, you should be able to:

- Define the concept of loss and recognise its potential, associated effects;
- Identify the key challenges inherent in supporting the bereaved person with a learning disability;
- List five practical approaches important in supporting bereaved people with a learning disability;
- Describe the various levels of support and the associated roles and skills involved in supporting the bereaved person with a learning disability.

Now do Time Out 1

Introduction
‘Loss is an integral part of the human experience. One must risk to live and achieve, but with risk there is the ever-present chance of loss or being deprived of something that provides a source of gratification. Loss is a recurring experience from the time of birth until one dies’ (Bower 1980). For people with a learning disability, although they may have experienced uncounted loss throughout their lives, many have not been actively encouraged to explore and express their grief for a variety of practical, philosophical and sometimes erroneous reasons. Despite the many changes that have evolved in recent years regarding the care of people with learning disabilities, their emotional needs are still often neglected (Arthur 2003), particularly in relation to loss, death and bereavement. By identifying the potential challenges often presented, professionals can explore a variety of approaches in an effort to support the emotional needs of this population. An understanding of the concept of loss may be the key to a genuine understanding of bereavement (Penson 1992), and thoughts around this will now be explored.

The concept of loss
According to Elders (1995) the term loss implies that one has been separated from, is unable to locate, or has had something taken from one. Some of the losses experienced are positively validated by society (such as the death of a parent) but some are not (such as abortion). Oswin asserted the importance of loss when she stated that: ‘I thought that it sometimes seems as if all our lives we are trying to cope with loss – either the fear of it, or the memory of it, or its raw immediate presence’ (2000 p21).

Hess (1980) described loss...
as being potentially of four different types: loss of body image or some aspect of self; loss of a loved one or significant other; material loss; and maturational or developmental loss. Rando (1993) cited primary loss (the loss itself) and secondary losses (a physical or psychological loss that coincides with, or develops as, a consequence of the initial loss). More recently, Machin (1998) has differentiated between developmental loss (which evolves over time and is considered as part of human development) and traumatic loss (incorporating loss through a damaged relationship; physical or mental loss through disease or disability; political or economic loss; and loss through unfulfilled ambitions). These types or categories are listed together in Table 1. Spall and Callis (1997) describe loss through unfulfilled ambitions as ‘ought’ losses; the perceived loss of things that ought to happen but probably never will, such as childlessness. While bereavement is perceived as being a distinct part of loss generally, Bruce and Schultz (2001) have specifically explored the notion of non-finite loss and grief, which they define as losses that are contingent on development; the passage of time; and on a lack of synchrony with hopes, wishes, ideals and expectations. 

**Table 1. Types of loss**

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<td>Loss of body image</td>
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<td>Loss of significant other</td>
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<td>Secondary loss</td>
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Consider the people in your care. Identify any actual and potential losses they might have had previously (or are currently experiencing). How might you describe these losses in relation to the theories of types and categories presented in Table 1? 

**Bereavement as loss**

Bereavement is the reaction to the loss of a close relationship (Raphael 1984) and ‘because of the intensity of the loss experience, the large number of people it affects, and the systematic variations with which its consequences are distributed across populations, bereavement has far-reaching implications’ (Stroebe et al 1993). Bereavement has subsequently been researched from a wide variety of professional perspectives, including anthropology, epidemiology, sociology, psychology and medicine, in order to help others to understand the certain counterintuitive reactions and complex symptomatology and to provide explanations of individual differences in grief work and outcomes (Stroebe et al 1993).

Traditional approaches to grief counselling and support include the stage models (Kubler-Ross 1969, Parkes 1996) and task models (Worden 1991), many of which have strong links to attachment theories (Bowlby 1980). Such theories have similar stages, phases or tasks and advocated that bereaved individuals needed to engage in grief work in order to resolve or accommodate the loss. Traditional models of grief have been criticised by Thompson (2002) for their lack of empirical supportive evidence and the narrowness of their approaches (e.g. ignoring the cultural and structural dimensions of social relationships).

Contemporary models adopt a more socially constructed approach (Doka 1989, Neimeyer and Anderson 2002, Klass et al 1996), alerting professionals to the complex nature of the psychological, cultural and social influences on death and bereavement (Stroebe and Schutt 1999). Doka (1989) in particular recognised that grief is partly shaped by the social context in which it is experienced, and this belief is currently receiving recognition and attention by counsellors and researchers alike.

When someone dies, survivors may respond or grieve in a variety of ways as they seek to make sense of what has happened and adjust to a different life without the deceased. Parkes (1993) described grief as an emotion of change and readjustment which (according to Worden 1991) can affect individuals in an emotional, physical, behavioural or psychological way.

**Support for loss**

Over the years, a variety of authors have sought to identify and describe grief reactions in a meaningful way in order to increase understanding of the counselling and support needs of bereaved people (Doka 1989, Klass et al 1996, Stroebe and Schutt 1999, Worden 1991). Worden described grief counselling as ‘helping people facilitate uncom- plicated, or normal, grief to a healthy completion of the tasks of grieving within a reasonable time frame’ (1991, p.37).

Fortunately, the majority of bereaved people will receive the help and support they require from within their own social support networks (Worden 1991). However, some individuals may need additional, specialist support to help them accommodate their loss and move on with their lives. Bereavement counselling may offer the constructive support that some individuals need to help them to confront and deal with their loss.
in a helpful and supportive manner. Bereavement counselling may be offered through a variety of different routes including professional services by trained doctors, psychologists or social workers; voluntary agencies; or by self-help groups (Parkes 1980). For people with learning disabilities, accessing generic counselling services may be difficult, as Conboy-Hill identified, ‘access to ordinary counselling and support services would be ideal but as yet, the practitioners within these services are not geared to our clients’ needs and the services themselves are often not free’ (1992).

**Bereavement and people with a learning disability**

Historically, carers and other professionals believed that people with learning disabilities did not grieve or respond to death, largely due to a lack of cognition or their perceived understanding of the concept of loss, death or dying. However, the Department of Health (1995) recognised that ‘Life events, such as a bereavement … may cause a person with learning disabilities to experience symptoms of stress reactions more readily than other people’ and, over the past 35 years, a variety of written sources, often anecdotal and largely incorporating oral histories and case studies (e.g. O’Nians 1993, Thurm 1989) and more recently empirical research (Hollins and Esterhuyzen 1997), have illustrated that people with learning disabilities do respond to bereavement and often do so in ways that mirror non-disabled, bereaved people (Oswin 1991).

**Challenges to offering support**

**Now do Time Out 3**

Cloistered away in institutions, many individuals have often been denied the opportunity to participate in the rituals commonly associated with death, such as sending flowers or attending the funeral, and as such have been shielded from death (Cathcart 1995, Doka 1989, Lipe-Goodson and Goebel 1983). Low expectations, stereotyping and the stigma associated with learning disability (Kitching 1987) have meant that people have often been all treated the same. Additionally, the complexity of cognitive ability, attention span and a limited emotional vocabulary (Conboy-Hill 1992) may challenge conventional approaches to bereavement counselling and support.

According to Kerr et al (1996) over 50 per cent of people with learning disabilities have significant communication impairment which may also make dealing with death and dying difficult for all those involved. Oswin recognised the role of fear as a typical reaction when addressing grief and bereavement as she explained that ‘death and grief create fears…and the combination of bereavement and people with learning difficulties…has usually been considered so fraught that problems have been swept under the carpet’ (1991, p26). More recently, Conboy-Hill (1992) has acknowledged the carers’ lack of knowledge and ignorance about death and bereavement, which sometimes resulted in, what Elliot (1996) described as, over-protectiveness.

Bereaved people often have a perceived sense of disempowerment following bereavement. For people with a learning disability this sense of disempowerment is often total, as both personal and professional carers try to protect them from the full impact of the loss (Elliot 1995). Many individuals are actively discouraged from being involved with death and dying, and are still being denied the opportunity to participate in bereavement rituals. Carers may often be uncertain about how to handle grief, because of the potential for varied reactions (Thurm 1989).

Emerson (1976) described how, following a bereavement, family and staff usually denied the event, gave inappropriate emotional responses, did not allow or facilitate any emotional responses, and did not allow appropriate time for grief work. She also found that families often displaced feelings towards the client with the family as they became ‘angry over the death or separation, become angry with the clients’ (1976). While Oswin (1981) suggested that carers were reticent about involving people with learning disabilities in death and dying because they were afraid of losing control and getting upset in front of them.

According to Oswin (1991), people with learning disabilities may also experience multiple losses as a result of bereavement. Following the death of a major carer, individuals may lose their home, familiarity, independence and sense of identity as they frequently have had to move into supervised care either temporarily or permanently. When a death can be anticipated (for example, where there has been a palliative illness) this is usually experienced as a sudden death by the person with learning disability, since he or she are rarely told in advance of the event (O’Nians 1993). Such paternalistic attitudes and over-protectiveness exclude the individual with a learning disability from being actively involved with their dying relatives and excludes them from saying their ‘goodbyes’ in any meaningful way.

Bereaved people with learning disabilities may often be denied the time or privacy required and changes in behaviour or mood may go unnoticed by carers (Oswin 1991). Kitching (1987) identified that because some individuals are not able to make their needs known, and are not involved in bereavement, this resulted in grief responses often being delayed. However, the ability of some people with learning disabilities to express their grief in a socially acceptable manner may prove difficult.

People with a learning disability have a history of segregation, marginalisation and disempowerment. Many will always require additional help and support, either from personal or professional carers and, as such, are reliant upon such carers.
to facilitate their needs. This meant reliance upon various professionals to develop care philosophies and approaches on a macro level, and reliance upon personal carers for their physical, emotional, psychological and behavioural needs from a micro perspective. Therefore, nurses are often in a strong position to support their grief.

Doka (1989) argued that the very nature of disenfranchised grief created additional problems for griefers. While removing or minimising sources of support, he suggested that for many disenfranchised grievers (such as children and people with learning disabilities) there were no coherent, well-organised or readily available support systems to help them with their grief work. Doka further asserted that responses to grief can therefore be complicated for the disenfranchised grieve.

People with learning disabilities, for a variety of both obvious and erroneous reasons, continue to be excluded from death, dying and bereavement. They are also described as having an external locus of control, dependent on others for (for example) care needs and decisions about care options, particularly involving death and bereavement. Such challenges to offering appropriate bereavement support need to be identified and addressed in order for them to be effectively overcome.

Time out 4
Reflect upon the concept of disenfranchised grief (Doka 1989, 2002). How might you feel if you were disenfranchised? Make a list of what (and who) might help.

**Disenfranchised grief**

Active exclusion from the process of death has been powerfully described by Doka (1989) as disenfranchised grief and the author views this work as being pivotal to an understanding of the lack of active involvement in the grief process. Doka described disenfranchised grief as ‘the grief that persons experience when they incur a loss that cannot be openly acknowledged, publicly mourned, or socially supported’. Initially, Doka identified three reasons for this disenfranchisement:

1. The relationship to the deceased is not recognised (where the relationship between the bereaved and the deceased is not based on recognisable kin ties);
2. The loss is not recognised (where the loss itself is not socially defined as significant);
3. The griever is not recognised (where the person is not socially defined as capable of grief) (Doka 1989).

More recently, he has added two further factors:

4. The circumstances surrounding the death (such as suicide);
5. The ways that individuals grieve (eg styles of grieving and cultural factors) (Doka 2002).

These factors often result in a lack of inclusion in any associated ritual, such as attending the funeral, which (as Doka reminds us) is often perceived as a service of the living and which is only acknowledged for those who are thought of as being legitimate mourners or grief sanctioned by society. Marginalised groups such as people with learning disability frequently do not have their grief legitimised by society, and attendance at funerals (for example) continues to be difficult for this population (Raji and Hollins 2003).

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**Support for bereaved people with learning disabilities**

People with learning disabilities do grieve, but, because of the nature of the learning disability itself (and often other associated disabilities), they may need special help in order to explore their grief. Oswin (1990) advocated major changes in social policy to respond to human needs with this client group, and offered a simple three-point plan incorporating forward planning, honesty and training. However, many of the issues for appropriately responding to bereavement centre on fundamental, practical issues to minimise the disenfranchising effects identified by Doka (1989) and serve to enfranchise the griever.

Emerson (1976) suggested that initially carers needed to recognise the occurrence of a loss; encourage emotional release and expression; expect a period of grieving and to remember the broader needs of the other family members who are also grieving. Some people with learning disabilities may require sensitive help and guidance to make informed decisions, such as whether to view the body (Cathcart 1995). Appropriate communication is crucial, and as nurses will have a pivotal role in supporting this client group, the way they communicate about death and dying will be important. Clear and concise language is required at all times (Oswin 1991) and nurses should avoid the confusing messages inherent in euphemisms (James 1995).

The normality of grief should be reinforced (before, during and after any death) to promote emotional recovery (James 1995) and individuals should be given opportunities to express feelings (Lewis 1991). Nurses should be actively looking for grief responses (Kitching 1987) and be aware of indicators for additional bereavement interventions, such as counselling (Elliot 1995). Working with bereaved people with learning disabilities may be extremely challenging as nurses address a range of attitudinal, psychological, practical and emotional issues. The nature of the learning disability itself and the complexities of cognition and limited emotional expression may shape the
way that carers help people to work through their grief. Strohmer and Prout (1994) suggested that ‘With cognitively and developmentally limited clients, it is necessary to develop direct interventions that are appropriate for the client’s language and cognitive levels. In the area of language, this necessitates consideration of vocabulary, level of complexity of questions.’

Subsequently, professional carers need to develop resources and strategies that are simple and concrete and use methods or activities other than solely words, in order to effectively access and understand the world of the bereaved individual who has a learning disability. Creative approaches (incorporating the therapeutic use of life story books, memory books, photographs, drawing, photographs, poetry and reminiscence work) are all recognised ways of helping bereaved people with learning disabilities to accommodate their grief in a constructive and recordable way (Read 1999).

Addressing simple practice issues such as enabling opportunities for individuals to attend funerals, and other associated rituals, and offering sensitive and meaningful support to enable individuals to make decisions, tempered with effective communication offered by appropriately informed carers may encourage active engagement with the bereavement experience for the individual with a learning disability and encourage ordinary grief responses. To disenfranchise such people means that they cannot be actively involved, and may not even know about the death of their loved ones, and so cannot be involved at a time when other family members are grieving.

Nurses need to identify ways of enfranchising people with learning disabilities, thus facilitating healthy grief in a constructive and consistent manner by exploring a range of therapeutic approaches. In response to this, Read (2003) developed a checklist to support positive practice in this area (see figure 2 on page 37). Designed for professional carers, this 17-point checklist (Read 2003) can be used to assess what services are available to support people with learning disability from a palliative care and bereavement perspective. The checklist asked about staff training, staff roles and responsibilities, accessibility to resources and directories, evidence of liaison with other professional groups and the availability of guidelines and audits of services related to palliative care and bereavement. The checklist could be used to assess current services, to identify service deficits and in turn be used to promote areas of professional development specifically in this area of care and support.

**Time out 5**

**A model to facilitate healthy grief work**

Not all bereaved people need specialist interventions, as many may learn to cope with their loss with the help of relatives and friends in their own social context, in keeping with the majority of society. Bereaved people with learning disability can learn to develop healthy coping strategies that will help them to deal with grief, but only if:
- they are treated with full adult status;
- their grief is acknowledged and recognised;
- they are given accurate and truthful information;
- people communicate with them in a meaningful way;
- they are actively encouraged to participate in grief and the associated grief rituals;
- they are offered continuing and appropriate support;
- carers have the knowledge, skill and understanding to appreciate their sadness and know when to seek additional, specific help from others.

Such a continuum of support involves a broad range of strategies offered at many different levels. These strategies range from general preparation before loss or death has occurred (education); portraying loss and death as natural life events (participation); consistent support after the death has occurred (facilitation); and the identification of the need for specific help (therapeutic interventions). This continuum of support is illustrated in Figure 1.

**Education:** Helping people to understand about loss, change, grief and death in formal (educational curriculum) and informal ways. This may involve:
- Educational opportunities to explore how others, and individuals themselves, respond to loss, for example using group work as an educational vehicle (Read et al 2001, Read and Papakosta-Harvey 2004);
- Openly sharing feelings and responses to loss on a day-to-day basis;
- Helping individuals to record life events using (for example) life story approaches and photographs.

**Participation:** nurturing a healthy emotional response. This can be achieved by proactive support, incorporating:
- Naturalistic opportunities to talk, explore and express feelings in a broader context, not just about sadness (for example, when watching the television);
- Developing and using a range of resources (such as those from the Books Beyond Words series, St George’s Hospital Medical School)

**Facilitation:** Reactive support following a loss or death, involving:
- Assessment of needs;
- Giving factual information;
- Offering consistent support;
- Education (person learning about grief responses and grief rituals)

![Image](535x143 to 571x197)

**Fig. 1. A model offering a continuum of bereavement support**
References


Continuing professional development

- Encouraging grief responses;
- Normalising the grief responses;
- Knowing when to refer on when appropriate.

This involves a whole host of skills from the professional carer, incorporating active listening; perception and observation skills; communicating in a meaningful way and having the knowledge base which accompany the development of these skills.

Therapeutic interventions: Referring someone for specialist help and support which may involve:
- Assessment of need (knowing when to refer on);
- Counselling;
- Psychotherapy
- Guided mourning interventions.

If individuals are actively involved in understanding about death and dying before it happens (education); are encouraged to share experiences of selves and others in naturalistic settings (participation); receive appropriate support at the point of need (facilitation); the need for more specific help such as counselling (therapeutic interventions) may be reduced. Nurses and other carers will have a pivotal role within this continuum of support model. Nurses may be involved in developing appropriate guidelines to act as a framework from which to both actually and practically facilitate the broad range of support required.

Now do Time out 6

Conclusion

This article has introduced the concept of loss in relation to the support of people with learning disabilities. It has identified the challenges involved; explored approaches to help and support; and presented a model which illustrates the continuum of support required in clinical practice. Nurses may be involved at all levels of this support, and are therefore in a unique and important position to support the person with a learning disability experiencing a loss. Dealing with death is never easy, but with appropriate help and support people with learning disabilities can learn to cope with loss and death, and will develop appropriate coping strategies that to enable them to become more resourceful at such sensitive times.
## Developing positive practice in learning disability, bereavement and palliative care (Read 2003)

The following checklist assesses what services are currently in place.

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<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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<tr>
<td>1. Have any of the staff team attended a course (preferably multidisciplinary) around death, dying or bereavement within the last two years?</td>
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<td>2. Are any of the staff team identified as taking the lead role in loss and bereavement work?</td>
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<td>3. Do you have easy access to a resource base regarding bereavement support?</td>
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<td>4. Do you have a client based recording system where pertinent information can be stored and easily retrieved?</td>
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<td>5. Do you have easy access to a resource directory regarding who, how and where to access palliative care information and support for people with learning disabilities?</td>
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<td>6. Do you have leaflets or other information regarding bereavement or palliative care that you can offer to individual, families and friends?</td>
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<td>7. Are any leaflets you have accessible to people with learning disabilities?</td>
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<td>8. Does anyone in the local palliative care network (for example, Macmillan Nurses, Marie Curie Nurses, Hospice, Clergy) liaise with the staff team?</td>
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<tr>
<td>9. Does anyone in the staff team liaise with the local palliative care network (for example, Macmillan Nurses, Marie Curie Nurses, Hospice, Clergy)?</td>
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<td>10. Do you know how to access counselling for people with learning disability in your locality?</td>
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<td>11. Do you regularly use life story approaches in a client centred, individual and personal way with people with learning disabilities?</td>
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<td>12. Does the staff team have easy access to appropriate resources (books, videos, photographs) from a loss, bereavement and palliative care perspective?</td>
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<td>13. Do you have a philosophy statement regarding learning disability, death and bereavement?</td>
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<td>14. Do you have guidelines regarding bereavement care and support?</td>
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<td>15. Do you have guidelines regarding palliative care and support?</td>
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<td>16. Do you have information and contact names and addresses of different culture, religious and ethnic groups within your locality?</td>
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<td>17. Do you have an evaluation system in place to monitor this work in a systematic and formal way?</td>
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