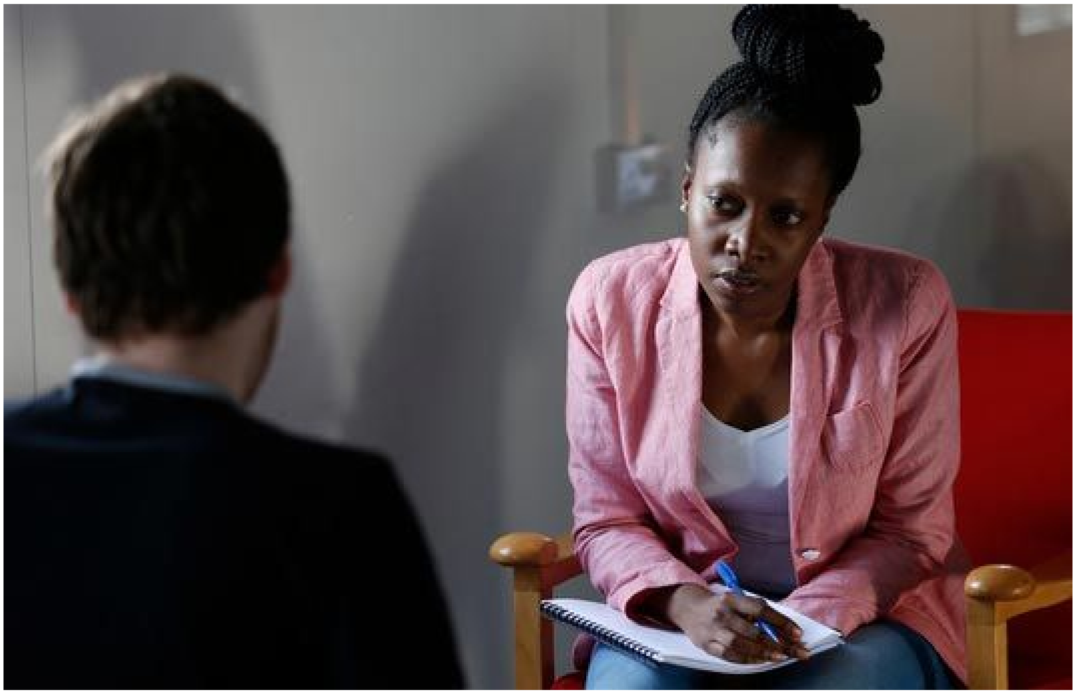
Managing Grief Better: People With Intellectual Disabilities



It is imperative that all people, including those with learning disabilities, are able to access the supports given in their culture to understand death and loss.

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Part of life is dealing with one's losses and grieving. We have social structures, support systems, teachings and rituals that help us understand and recover from significant loss. It is not uncommon for adults to feel they must protect others from these difficulties including children, elderly people and persons with disabilities. In fact, strenuous efforts are often made to protect people with intellectual disabilities from life's losses and disappointments. The harsh reality of their own and their parents' mortality is a secret they will have been judged too vulnerable to be told. Their death education has often been non-existent, so their bewilderment at the disappearance of a loved one should be no surprise. It is imperative that all people be able to access the supports given in their culture to understand death and loss. Protecting someone usually results in more problems in that grief and mourning will not be properly experienced, leading to more significant future difficulties.

In trying to understand how the needs of someone with an intellectual disability might be similar or different to yours and mine, the context in which they have lived their lives must be considered. A very typical situation, for example, is that of a middle-aged person with an intellectual disability living in a dependent relationship with ageing parents. The family is often isolated with few friends and little practical support at home. Their adult son or daughter may have a regular daytime occupation, and be accustomed to staying in a respite care home or hostel from time to time. Many adult sons and daughters with an intellectual disability play an important role in domestic affairs at home, with dependency being very much a two-way matter. When their first parent dies, they may not be told directly of the death. Nevertheless, they will be aware of their parent's absence, of sadness in the family, and of whispered conversations and concern about themselves.

While the rest of the family grieves, emergency admission to respite care or an unexpected holiday with distant relatives may be arranged for the person with an intellectual disability. Thus, the person is excluded and kept ignorant of facts that he or she needs to know. Their confusion and fear persists when other family members are coming to terms with their loss. Families comfort themselves with the hope that the person with an intellectual disability has not noticed or say, "we could not take her to the funeral - she'd be too upset," as if being at a funeral was inappropriate.

"Denial" of the loss by the person with an intellectual disability at the time is not surprising in these circumstances. The individual's ordinary routines and certainties will have been turned upside down. Prolonged searching behaviour and an increase in separation anxiety can be expected. However, angry and aggressive reactions may be delayed to such a degree that, when such behaviour does occur, no relationship to the loss is recognised.

A second scenario is seen when the surviving parent dies. The bereaved, dependent person is admitted to emergency care but never returns home. At one stroke, he or she has lost parent and confidante, home and possessions, a familiar neighbourhood and routines, and perhaps a pet. Searching for the lost parent and home is difficult unless one is able to explain one's needs and unless a new caregiver is willing to help. In my experience, most caregivers do not recognise emotional needs such as these. A loss of skills, and decreased joie de vivre may lead to inappropriate and difficult to reverse decisions about future living arrangements and opportunities.

There are other loss situations which might be experienced by a resident of a long-term institutional placement. Staff turnover, the discharge of roommates to community care, the end of weekly visits by a devoted parent - now dead - and the death of people one has lived with for many years all go unremarked.

Intellectual disability is a broad category which encompasses mild intellectual disability to profound mental retardation with multiple disabilities. The greater the handicap, the less likely the individual's grief will be recognised. Caregivers tend to ignore or misunderstand the effects of such losses. Research has shown that some people with intellectual disabilities will have a delayed understanding of the ageing process. It seems likely that the irreversibility, universality, and the inevitability of death will all be difficult concepts to understand, despite many years of experience as an adult. The capacity to integrate their experiences and to learn from them will be limited unless sensitive help is available.

It is unlikely that the attitudes of a family or of professional caregivers will change in the period between a death and the funeral. There is an important advocacy role for doctors, funeral directors, care managers and social workers who must not be afraid to challenge caregivers and support providers who make decisions to exclude the person with a disability from the full grieving process.

The following recommendations are made to assist persons with disabilities in dealing with death and loss:

POINTS FOR CAREGIVERS OF BEREAVED PEOPLE WITH INTELLECTUAL DISABILITIES

- **Be honest, include and involve**
- **Listen - be there with the bereaved person**
- **Actively seek out nonverbal rituals**
- **Respect photos and other mementos**
- **Minimise change**
- **Avoid assessment of skills**
- **Assist searching behaviour**
- **Support the observance of anniversaries**
- **Seek bereavement specialists for consultation if behavioural changes persist**

1. Be honest, include and involve
Many caregivers find themselves quite unable to be honest or to include and involve the person with a developmental disability. The person should be offered the choice of whether to attend the funeral or memorial service. If he or she is unable to choose directly because of cognitive limitations, it is usually advisable to involve the person as fully as possible in all the rituals being arranged.

2. Listen - be there
Being available to listen and provide support is essential. This must occur immediately after the death, and, most importantly, also in the weeks and months following. Understanding the permanence of death comes slowly, thus the person with a developmental disability may experience delayed grief.

3. Actively seek out nonverbal rituals
The nonverbal rituals with which most cultures surround death are helpful to many of us. They are particularly helpful to people with intellectual disabilities who cannot find solace

in the written or spoken word. Counselling picture books may be helpful in explaining what happens when someone dies.

4. Respect photos and other mementoes

In the early stages of a bereavement it is quite common to avoid pictures and possessions and places which are associated with the person who died. As time passes, such mementoes may come to be treasured. Indeed, the reduction in avoidance of such cues can provide a useful measure toward resolution of grief. People with an intellectual disability should be helped to choose some mementoes, and this choice should be offered again at a later date when some of their emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected.

5. Minimise change

It is advisable to minimise changes in routine and changes in accommodation or of caregivers at a time of grief. As a rule of thumb, we suggest major changes should be avoided for at least one year.

6. Avoid assessment

If a caregiver has died, it may seem sensible to assess an individual in order to "fit" him/her into the best service or support system. However, this can be the worst time to assess someone whose behaviour and skills may have regressed because of the emotional energy being expended on grieving.

7. Assist searching behaviour

By revisiting old haunts and going to the cemetery, caregivers can assist appropriate searching behaviour to support emotional recovery. Hoarding behaviour may suggest that more help of this kind is required. For example, the person who absconds or is found wandering may be trying to find their lost home and family. Mark was asked to leave his "group home" of eight years standing some time after the death of his grandfather from cancer, and his dog in an accident. Despite not being told of the deaths officially, he became slow and uncooperative with ordinary routines and went missing for hours on end. On the second occasion he was found in a distressed state in a wooded park. His carers asked his parents to take him away.

Anne moved to a group home after her mother's death. She went to great lengths to conceal the small possessions she took from the jackets, purses and bags of visitors to her group home. Staff knew things would have been hidden in her room and tried to make light about her behaviour. It seemed she felt cheated about something as though she was trying to make up for her own loss. The behaviour stopped after some individual counselling.

8. Support the observance of anniversaries

Anniversaries should be formally observed. Many religions have formal services a year after someone has died. This is especially helpful at the time of the anniversary of an important loss.

9. Seek specialists for consultation if behavioural changes persist
Referrals for consultation with bereavement specialists are typically made very late. It is important to make referrals, especially mental health referrals, as soon as any serious grief reactions are noted, such as aggressive behaviour, persistent irritability, mutism, loss of skills, inappropriate speech (i.e., asking "where is Dad?" all the time), self-injury, tearfulness and absconding. A recent study of the efficacy of volunteer bereavement counselling and support for people with learning disabilities found significant improvements in mental health and behaviour. On the other hand, specialists without specific experience in bereavement did not achieve the same success.

CONCLUSION

People with disabilities have a right to participate fully in the grief and mourning process and in all of society's support systems and rituals associated with these losses. Concerted effort is needed to offer death education to professionals and to parent organisations so that they may become familiar with normal grief reactions and provide proper supports. Death education can be introduced into the school and adult education curriculum for people with learning disabilities. Advice is needed to construct guidelines for special agencies to follow when a death does occur. This might include helping professional caregivers rehearse breaking the news of a death. Practical plans to avoid immediate admission to residential care are required. The importance of ensuring that the bereaved person has some mementoes of their deceased relative must be remembered and advice on the importance of nonverbal rituals at the funeral may be helpful. Bereavement counselling for people with intellectual disabilities should be made available routinely and not just when a maladaptive reaction has been recognised as grief. Both individual and group work with bereaved individuals may be helpful, particularly if nonverbal approaches, such as the use of counselling picture books, are available.

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