



Dealing with Death

In the past, people with Down syndrome were denied the right to grieve because others mistakenly assumed that they had no capacity to do so. It was thought that people with Down syndrome did not experience grief, or recognise or comprehend loss. The following three real-life stories clearly show grief felt by children with DS and this adaptation of an article from the DSA of the UK (Stuart Mills, April 2002) gives more information.

Bereavement

- Bereavement literally means to be deprived by death. When experienced after the death of someone loved, bereavement is perhaps one of life's most stressful events.
- In the past people with Down syndrome would often die before their parents. Life expectancy for people with Down syndrome has increased dramatically, so now many adults with Down syndrome experience the death of their parents, who in many cases have been their main carers.
- When people with learning difficulties are bereaved, their reactions to the loss are frequently misunderstood.
- Grieving is a highly individual process and people respond to bereavement and express their grief in different ways.
- The person with learning disabilities experiences the same processes as the rest of the population.
- The grieving process for those with learning disabilities may however take longer.
- Grief may manifest itself in ways that are not instantly recognisable.
- Usually people with Down syndrome can work through their feelings about an unhappy event and come to terms with it, but will probably need help to do this.
- Bereaved people with learning disabilities may find that other people make decisions that affect their lives without any warning, or any element of personal choice or of control.

Common responses

- Whether or not they have learning disabilities, people react individually to grief.
- Most people experience at least some of the common responses to bereavement. These are summarised below:
- An initial sense of shock, numbness, disbelief and denial accompanied by one or more physical symptoms such as lack of energy, trouble in concentrating, remembering, making decisions, hyperactivity, thinking about wanting to die and a sense of unreality.
- As the early shock wears off and the impact of the reality of the death is felt, people may experience the following reactions:
- **Emotional:** Anger with the deceased or with those who it is believed could have prevented the loss. Guilt, anxiety, fear, panic, depression, despair, mood swings, irritability, crying, sadness, yearning and pining, sense of being abandoned.

- **Physical:** Symptoms such as pain, appetite disturbance, breathlessness and illness. People with learning disabilities, who are less able to express themselves verbally, may experience and exhibit increased physical symptoms of grief.
- **Behavioural:** Low vitality, need for more sleep, sleeplessness, hyperactivity, withdrawal and a lack of interest in normal activities.
- **Mental:** Confusion, hallucinations, nightmares, insecurity, searching for the deceased, poor concentration, regression and loss of skills.

Resolution

- Resolution occurs when the bereaved is able to think of the deceased without pain or anger and can recall the times they had together in a positive way.
- The journey towards resolution is not always a continuous or direct one. It may take a considerable time.
- Not everyone will experience all of the symptoms detailed above.

Depression

Sometimes grief can continue into depression and this may well show itself, in someone with a learning disability, in unexpected forms.

However, not everyone will get depressed.

Sometimes one loss can then lead on to other major changes that may result in depression.

For example, after parents have died, people with a learning disability are often moved to emergency residential care. This means that they lose their home, their familiar possessions and routines, as well as their parent and carer.

Sometimes a more serious and persistent depression develops.

This is a particular risk for people with learning disability because carers often miss the early signs of depression.

The time to get help is when any changes in behaviour or mental state persist for a lengthy period of time.

You should then seek professional help for further information.

pain, appetite disturbance, breathlessness and illness may occur

How to help

- Always give the news of a death with honesty and at a pace suited to the individual. The news of a death should not be kept from an individual in an attempt to protect him or her.
- Always use straightforward language in order to avoid misinterpretation by the person with learning disabilities. The use of terms such as 'death' and 'died' are preferable to terms such as 'passed on' or 'gone to sleep'.
- The person with learning disabilities should be given the choice as to whether or not they wish to take part in the rituals associated with death.
- If the person is unable to choose directly, it is advisable to involve the person as fully as possible.
- Non-verbal rituals may be particularly helpful to people with learning disabilities.
- It is important to allow the bereaved person to have the opportunity to choose a memento by which to remember the deceased person and to act as a focus for their feelings.
- Avoid major change at this confusing and distressing time. Many people with learning disabilities find change of any kind difficult to cope with.
- Routine can be particularly important, providing an important sense of order and structure. The person with learning disabilities may find it comforting to take refuge in their daily routines and familiar surroundings.
- Helping the bereaved person to maintain some continuity and connection with life before the bereavement is essential to recovery.
- Always give the individual with learning disabilities space and time in which to express their feelings.
- If the deceased is a family member, it may be helpful to create opportunities for the person with learning difficulties to communicate his or her feelings to someone outside of the family.
- You may wish to consider specialist bereavement counselling for the person with learning disabilities.