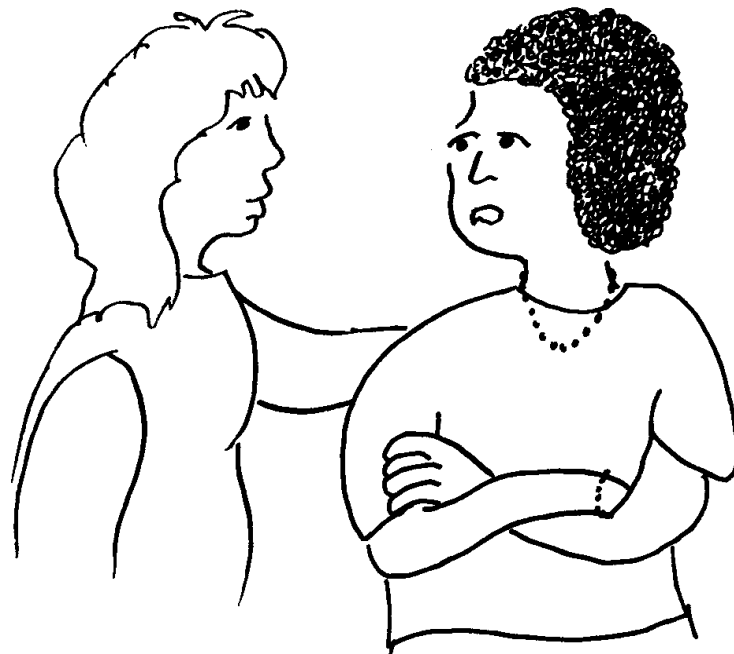


# Supporting people with a learning disability when they experience a loss or bereavement

A guide for carers



Supporting any individual who has experienced a loss or bereavement can be a difficult task for carers.

This leaflet provides some ideas to help carers think about how to support an individual with a learning disability who has experienced a bereavement or loss.

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## **How do people with a learning disability respond to a loss or bereavement?**

**“Each person with learning disabilities is an individual and will grieve as an individual” Oswin (1981).**

How people respond to a loss or bereavement can be more effectively understood when it is viewed within the emotional, cultural, social and psychological aspects of the person's life.

A number of factors may influence an individual's reaction to a loss or bereavement and this will mean that bereavement is always different. The types of areas which may affect someone's reaction to bereavement are:-

- The strength and security of the relationship e.g. how often they saw the person, what kinds of things they would do together, how well they got on together
- The intimacy of the relationship e.g. how close they were to the person, what they shared with them
- The characteristics of the relationship e.g. were they a relative, was it someone they lived with or someone they spent a lot of time with
- If the death was sudden and unexpected by the person with a learning disability. What some may see as sudden others may not e.g. was the person ill for a long time, does the bereaved person know and understand that they were ill or what was going to happen

- How the individual has reacted to previous losses e.g. what other experiences they have of loss or bereavement, what are their beliefs about loss
- Ability to express feelings and cope with stressful events
- Support from others e.g. other relatives, friends, people they may live with, other people who may also be experiencing the bereavement
- Religious/cultural background e.g. are they able to access information they may need, share their beliefs with others
- Mental Health e.g. the impact that the bereavement or loss may have on the person's mental health, if existing mental health problems, the impact this may have on experiencing grief
- Financial situation e.g. do they need help or support with managing this
- Concurrent stresses e.g. what else is happening in all areas of the person's life such as have they had to move home due to the loss, or stop seeing people who could offer them support?

## **Assumptions about loss and bereavement**

It is important not to make assumptions about how an individual responds to a bereavement or loss. Some assumptions that people can make include:

- Time takes care of everything
- It's better if others don't mention the loss
- Anger is unhelpful
- Its better not to think about it at all
- Grieving only lasts 6 months to a year

Everyone responds differently to a loss or bereavement and it is important to think about what will be helpful for each individual.

## **Understanding the idea of death**

Death can be a difficult thing for a person to understand. Understanding what death means involves knowing that:

- Death is permanent
- Death happens to everyone
- Bodily functions stop e.g. Heart stops beating
- The person who has died can no longer think, hear or feel

## **Communication**

**It is important to think about how we communicate with someone who is talking about a bereavement or loss. It may be helpful to consider:-**

- **The environment in which you talk**

Quiet, private, warm, relaxed environment

- **The layout of the room**

Easy chairs appropriately spaced, tissues being available

- **Body language**

Body language should be “attentive” but not intrusive

- **Eye contact**

Initiate and maintain fluctuating degrees of eye contact

- **Vocal qualities**

Rate of speech, pitch, loudness and tone

- **Talking face to face**

Talking face to face may be difficult for some individuals.

The person may have chosen to talk at a particular moment because you are not face to face e.g. beside you in a car, doing a job together.

- **Providing verbal and non verbal encouragement to talk**

**Verbal encouragers** could include:-

“Mmm”, “Yes”, “Tell me more”, “How do you feel about that?”

Non-verbal encouragers could include:-

*Facial Expressions*

Show concern and interest in your face.

*Body Language*

Sit at a distance and position suited to the individual.

- **Don't appear distracted**

Don't look at your watch or out of the window.

- **Touch**

Physical contact may be difficult for some individuals. Read the signs from the person and take their lead.

- **Ways of responding**

There are two main ways in which a listener can respond: accepting and non-accepting:

For example:-

*Bereaved person*, “It’s a nightmare. I’m never going to get over my mother’s death”

*Non-accepting response:-* “Come on pull yourself together.”

*Accepting response:-* “It sounds like you’re going through a very difficult time you feel like things will never get better.”

It is important to try and provide accepting responses.



## **Some recommendations and suggestions about ways to support people who have experienced a loss or bereavement.**

The following recommendations are guidelines to consider when supporting an individual. As mentioned before, everyone responds to a bereavement or loss differently and it is important to think about what will be helpful for each individual.

- Listen to and accept what the individual says.
- Give the person the opportunity to talk about the loss if they wish.
- Offer reassurance that feelings and experiences are normal.
- Being aware of practical changes that may result from the loss and offer to help.
- Give space and tolerate silences.
- Allow for individual differences.
- Provide continuing support and accept that there may be difficult times e.g. anniversary of loss, birthdays.
- Don't take anger personally as it is a normal reaction to loss.
- Accept that it is not possible to take away the pain of the loss.
- Be aware that it can be difficult to support a person who has experienced a loss. Ask for help if needed.
- Accept that the bereaved person's reaction may be different to yours.

## **Breaking the news of death**

- The news of a death should be given with honesty, gently and not hurried. It might be helpful to use simple and clear language.
- Some people may like to be physically comforted when bad news is given to them but some people may not.
- The correct language of death should be used e.g. dead, dying, died – as these words have only one meaning, unlike ‘gone to sleep’ or ‘passed on’, which may be misleading.
- News of a death should not be withheld.
- Professionals and relatives should never pretend that a dead person is still alive.

## **Going to funerals**

- People with learning disabilities should be given the same opportunities as other members of their family to go to the funeral and to be at the graveside or the crematorium.
- The person having the assistance of a professional, an advocate or a volunteer accompanying them may resolve family worries about the feasibility of a person with learning disabilities attending a funeral.
- A person with a learning disability should be given an opportunity to buy their own flowers for the funeral or to contribute in other ways requested, and appropriate help should be given in doing this.

## **Immediately after a bereavement**

- Familiar routines of care should be maintained.
- If an individual needs to go into residential care after a bereavement, the person should be able to choose to take belongings, mementoes and photographs, from home, and should have somewhere private and safe to keep them.

## **Remembering**

- The person who has died should be referred to and spoken about.
- If a person has to go into residential care after a parent dies, care should be taken not to throw away their possessions without permission: things that appear worn-out are sometimes very important.
- The bereaved person may like to have a photograph of their deceased family/friends and former home(s). This suggestion should be put to them.
- The bereaved person may like a book of memories, containing photographs, cards, letters and mementoes.
- Carers may need to offer help in buying a memorial stone for the grave, and in other physical acknowledgements of the death e.g. planting a rosebush or tree, putting an anniversary notice in the local newspaper.
- The person should be given opportunities to visit important places of remembrance e.g. grave, cemetery.
- At times of festivities the bereaved person may be more likely to miss the person who has died. It is important to think about the support they require.

## **Other forms of loss**

Individuals with learning disabilities can experience many forms of loss other than bereavement. Such loss can include moving home, moving job, loss of physical and mental abilities, death of a pet.

It is important to think about how to support the individual with these types of losses.

- If a member of staff leaves their job or another resident moves, the individual experiencing the loss should be given the opportunity to talk about his or her feelings if they wish.
- Memories of bad experiences of loss in childhood, such as early loss of parents through going into care, may be activated by later losses in adulthood such as moving into a different residential setting or a staff member leaving.
- A move of home should be carefully organised with explanations and preparation. Ample opportunity should be given to say good-bye to all known staff and other residents. The individual should be provided with the opportunity to take mementoes with them e.g. photographs, life book. If someone has left friends behind, individuals should be given the opportunity to maintain these relationships.

## **What people with learning disabilities say**

### **We want;**

- Everybody to be given the choice about whether they go to the funeral.
- Help from someone who will talk to us. Someone who will help us with practical things, like arranging the funeral and flowers, etc. This could be a member of the family, a friend or someone from the day centre or a social worker or community nurse, etc.
- To be able to remember the person who has died by having the opportunity to talk about them and by having photographs of the person.
- To be able to choose whether we want to visit the hospital or hospice, to see the ill relative before they die.
- For people to understand us if we are angry and for people to understand that we might want to be on our own for a short time.
- To be able to visit the grave.

## Support for yourself

- If you are supporting a person with learning disabilities experiencing a bereavement or loss think about the emotional impact it may have on you and the support you may want from others.
- It is important for you to acknowledge and listen to your own feelings in relation to death or loss.
- Training courses on bereavement are available for professionals working with people who have learning disabilities. Local groups such as CRUSE are also valuable links who offer information and support about bereavement.
- If you have someone in your family who has experienced a loss or bereavement you may want to seek support from family, friends or contact your local community learning disabilities team. If you are a staff member you can seek support from your line manager.

## Further information

There are many books, projects and courses available on the subject of bereavement and loss. Below are some we recommend:

Heegaard, M. (1992) The Drawing Out Feelings Series. USA: Woodland Press.

Holland, J. (2003). Supporting schools with loss: 'Lost for Words' in Hull. British Journal of Special Education, 30 (2), pp76-78.

(You can find out more about 'Lost for Words' by visiting the project and conference website:

<http://www.hullcc.gov.uk/education.lostforwords/php>)

Hollins, S. and Sireling, L. (1991). When Dad Died: working through loss with people who have learning disabilities or with children. Windsor: NFER-Nelson. There are other related titles in the Books Beyond Words series which are available at £10 each from the Royal College of Psychiatrists, 17 Belgrave Square, London SW1X 8 PG (Tel: 0171 2352351).

James, I. A. (1995). Helping People with Learning Disability to Cope with Bereavement. British Journal of Learning Disabilities, 23, pp 74-78.

Oswin, M. (1991). Am I Allowed to Cry? A Study of Bereavement amongst people who have Learning Disabilities. London: Human Horizons Series. Souvenir Press.

Worden, J.W. (1983). Grief Counselling and Grief Therapy. London: Tavistock.

If you have any queries regarding the issues raised in this leaflet, please contact the clinical psychologist in your community learning disabilities team.

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