

Campion House
Green Street
Kidderminster DY10 1JL
Telephone 01562 723010

enquiries@bild.org.uk
www.bild.org.uk

Loss, Bereavement & Death

Introduction:

This factsheet looks at some of the ways a parent or carer can help a person with a learning disability to understand and cope with loss, bereavement and death.

Description:

Introduction

In the past, people with a learning disability were not always told about the death of family or friends, because it was often thought they would not understand. This is not the case and someone with a learning disability will grieve in the same way as anyone else. However there are few bereavement counselling services for people with a learning disability and many people do not fully understand or appreciate the particular needs that the person may have.

Will the person with a learning disability understand?

- It is important that a person-centred approach is adopted in order to help the person feel valued. They should be helped to understand in their own time the part death plays in the natural experience of all our lives.
- The person may ask and repeat questions which might make you think that they don't understand. It is more likely that this is part of the process of coming to terms with the death of someone they knew and loved.
- Repeated explanations at a level appropriate to the person should help them to understand. Gently check understanding and answer all questions truthfully. This may be a lengthy process, and you will need to be patient and sensitive.

What is Grief?

- The person is likely to experience all the normal responses to grief, going through the stages as follows:
 - a) shock or disbelief, mood swings, loss of concentration, sadness,
 - b) denial or anger
 - c) growing awareness
 - d) acceptance
- The person may appear withdrawn or do things that seem odd or out of place.
- A person who cannot express themselves verbally may display some of the following while they are grieving: clinging – not wanting to sleep alone, reluctance to go out, uncharacteristic incontinence, self-injury, destructive behaviour, restlessness, aches and pains (often muscular or abdominal), changes in sleep patterns, change in appetite (or loss of appetite), apathy or tiredness, minor illness or clumsiness and accidents. These may all be symptoms of underlying grief.

What can I do when a death has happened?

- Explain simply what has happened. Make allowances for the person's level of understanding and distress.
- Explain that when death happens the body has stopped working and nobody can mend it.
- Explain that the dead person can feel no pain.
- Remember that explanations can be taken literally. For example, if a person with a learning disability is told that "Dad is in heaven now" and then taken to the cemetery they may believe the cemetery is in heaven.
- If the person wants to view the body this may aid understanding. However they should not be forced to as it may be a frightening experience.
- Enable the person to participate in arrangements for the funeral if they wish. For example, choosing some flowers or music or helping prepare food for visitors after the funeral.

- Explain what happens at a funeral and/or cremation and what their role is e.g. travelling in the car behind the cortege, singing the hymns.
- Give appropriate support throughout the funeral.
- Encourage the person to talk about the person who has died and about their feelings .
- Listen and show empathy.
- Include the person in all discussions and preparations so that they do not feel marginalised, confused or rejected.

After the death

- People with learning disabilities have often been given fewer opportunities to find out about death and bereavement and so may take longer to resolve their grief.
- Encourage the person to talk about their loss to other carers and friends such as at day centres and clubs.
- A drama group or occupational therapy group using artwork may help the person to come to terms with loss or bereavement. Some people like to make a “memories album” using pictures or magazine cuttings which remind them of the dead person. Visits to the grave or memorial garden can also be very helpful.
- A piece of clothing or familiar object from the dead person may help someone with a sensory disability to come to terms with their loss.
- Sometimes people may express their grief to someone outside the family. You may think the person seems unconcerned about the bereavement but in fact might have spoken to someone else about it. Try not to feel upset or unwanted. It is important to let everyone deal with their grief in a way which is right for them.

Approver:
BILD

Author:
Jenny Pearce
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