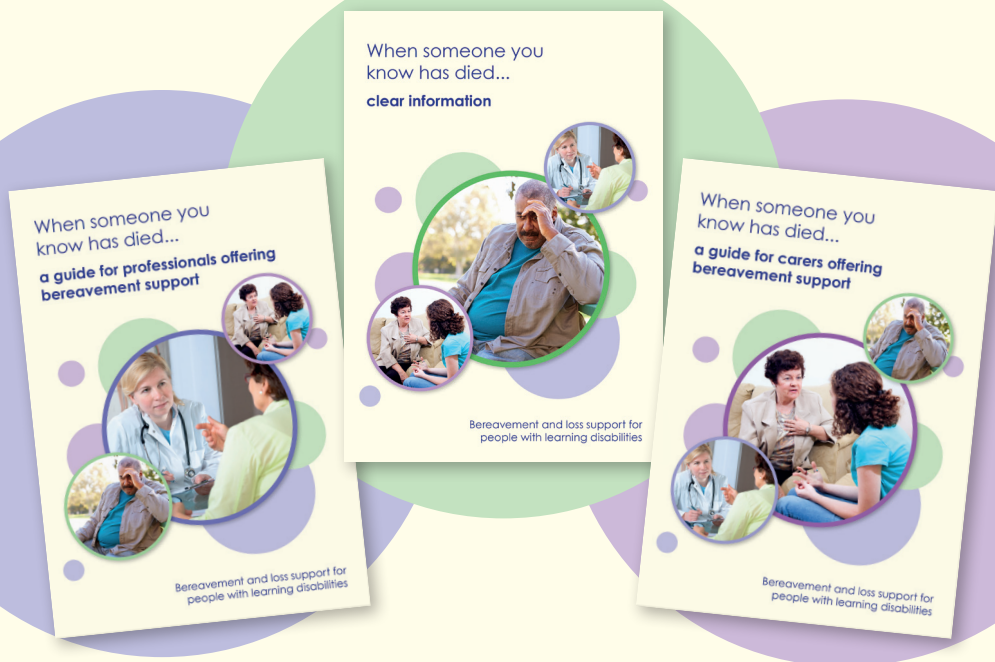


When someone you
know has died...

a guide for carers offering bereavement support



Bereavement and loss support for
people with learning disabilities



Introduction

We may all need extra support following a death. This booklet is part of a series of three entitled “When someone you know has died...”

The clear information leaflet is for bereaved people with learning disabilities. The booklets for professionals and carers offer guidance to support people with learning disabilities.

This leaflet was written to help you as a carer to offer appropriate support to your bereaved relative who has a learning disability.

Everyone deals with death in his or her own way and carers should be guided by what the person needs at this sensitive time. However, carers should never assume what these needs might be, and talking with the bereaved person in a way that they can understand is crucial and fundamental to appropriate support.

Explaining about death

Death is a difficult concept to explain, so sometimes we avoid even trying to define it. You could try initially asking the person what they think death means. Dealing with death is often hard because we like to protect the ones we love from the pain of grief. Sometimes the circumstances around the death may be hard to talk about and difficult to explain or understand. But everyone has the right to know about the death of someone close to them, and to be told the truth about the death in a way that they can understand. This may not be easy, particularly if you as a carer are grieving too.

When explaining about death, use clear language that the person can understand and plain words such as death and dying to avoid confusion. You may need to use picture books to explain (for example) what happens at funerals. You can use euphemisms that the person may be familiar with (for example, gone to heaven) but always accompany these with the word 'death' or 'died'. For example 'Grandpa has gone to heaven because he died...'

*Grandpa has
gone to heaven
because he died...*



Some people may have difficulties remembering things and may need to have the same information consistently repeated over a period of time. It's important to use the same language and phrases to avoid confusion, to reinforce what is being said, and promote understanding.

Think about how the person might want to be involved in the funeral and explore this with them. Meaningful involvement can include helping to choose hymns, carrying the coffin and travelling in the hearse. Talking this through with people will help them to say what they really want to do. Being involved can help to affirm the reality of the death and help them reflect afterwards on how they were able to commemorate their loved one.



Ways of responding to death

Loss can mean different things to different people and can affect people in many different ways. Some people may react in ways that we do not expect, for example, they may not react at all to the news but this does not mean that they will not grieve later. It may take time (sometimes months, even years) for some individuals to accept the reality and finality of the death and that they will never see the person alive again. Following the death of someone close, people may behave differently, for example they may talk, communicate or behave in a different way. Grief is a response to loss and can make people feel sad, unwell, angry or lonely. People don't always appreciate how hurtful loss can be, so be watchful around the bereaved person and look for signs of distress and sadness.

Help and support

Help and support from other people can be very important, and can come from a range of different people. Bereaved people usually find the support they need from people they are familiar with and trust, so the family can be a pillar of support and comfort. However, some people may need to access additional help at this difficult time from, for example, their community nurse, local faith leader, bereavement counsellor or doctor. A person with a learning disability may need help to access these services, and advocates can help with this.

Members of the family may need to talk through their feelings too.

Other people involved with the bereaved person with a learning disability (e.g. Day Service staff) will need to know that the person has experienced a bereavement, so they can anticipate any changes in mood or behaviour and can be prepared to offer additional support.

As a carer you may find supporting a bereaved person difficult and may need to seek support for yourself from your friends, family, GP or a counselling service.

Loss and change

A death often leads to other associated losses such as loss of friends, familiarity, changes in routine and even moving house. Such losses need to be acknowledged and the bereaved person encouraged to preserve memories (e.g. photos and meaningful mementos of the person who has died; taking photos of the house they used to live in) either in a memory book or as part of life story work. These losses may occur soon after a death or develop and accumulate over time.

Involvement and choice

Everyone has the right to be involved in the rituals following a death. These can include saying goodbye to the deceased at the hospital or Chapel of Rest; going to the funeral; choosing flowers; selecting mourning clothes; or contributing to the order of service.

Everyone has a right to choose to be involved in these rituals as much or as little as they need. Being involved may help people to accept the reality of the death.



☑ Checklist

This checklist has been included to help you to consider the issues around the bereavement in a constructive way, and to help guide you through how you might involve the person with a learning disability during the aftermath of loss.

- ☐ Has the person with a learning disability been told the truth about the circumstances around the death in a way that they can understand?
- ☐ Does the person understand what he/she has been told?
- ☐ Has the person been offered the chance to participate in the rituals following the death?
- ☐ Has the person been helped to capture memories of the deceased in a method of his or her choice?
- ☐ Does the person need additional support from other professionals?
- ☐ Does the person need help to access any additional support?
- ☐ Have all relevant people been informed of the bereavement (e.g. Day Service professionals, Respite Care professionals)?



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