



Bereavement and Learning Disabilities: A Guide for Carers



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Contents

	PAGE
Information about Learning Disabilities and Grief.	
Uncertain how to help	3
Supporting someone to grieve	4
Ritual and ceremony	5
Expect the unexpected	6
Timing is everything	6
Bereavement Support Guidance*	
Book 1—Information about death	9
Book 2—Grief and ways of coping	11

* For section 2 you will need the two booklets below:

- Bereavement: Information about death
- Bereavement: Grief and ways of coping

Information about Learning Disabilities and Grief

A death is really difficult for everyone and in modern society we perhaps deal with it less well than we did in the past, so it can be the case that we don't really know how to handle it. It is very important for us to mark the passing of a person's life in order for us to accept what has happened. Most people do find ways to do this. Grief is a natural process but some people, for various reasons, can become stuck part-way through the process.

Uncertain how to help?

Following a bereavement carers of those with learning disabilities can feel quite uncertain as to what they can expect from the person they care for.

It is tempting to look for the reactions we think of as 'normal grief reactions' such as crying or those that are consistent with our own. It is also tempting to assume that if these reactions are not present that the person is not grieving.

It can be assumed that people with learning disabilities don't really grieve because they don't really understand what has happened. However, regardless of the level of understanding **the loss is a reality** for the person. In fact, those with learning disabilities are found to have higher levels of behavioural and psychiatric issues following bereavement than the rest of the population.

A common reaction for carers is to try to hide what has happened from the person they care for, or at least shelter them from the worst of it. Many carers never discuss the subject of death with the person if it doesn't come up because it is an unpleasant subject and might upset them. If it must be discussed, carers often shy away from the words 'dead' and 'death', instead they often use euphemisms such as 'gone to sleep' or 'gone to a better place'. This can cause confusion.

It's not possible to hide the reality of death from someone forever, especially from someone who spends much of their time in learning disability environments where, due to the nature of some disabilities, they may even have to experience death more often.

It is a useful exercise, if possible, to explain death before they have to go through it.

Lack of understanding requires more honest and direct input about the subject rather than less. When death education is non-existent the loss of a loved one can be bewildering.

Did they just leave one day – does this mean they don't care about me?

Family carers may be grieving themselves and they may hide this grief and put on a brave face for the person they care for. In fact, modelling how to express grief can be helpful. By allowing them to share their pain they will not feel so isolated. It can also reassure the person that their feelings are normal. Often people with learning disabilities live in a world of smiling cheerful people who remain that way even when terrible things happen. This can be very bizarre and lonely when you feel the opposite.

Supporting someone to grieve



It can be very hard for carers to see the person they care for deeply upset. There can be a tendency to try to 'jolly them along' or distract them rather than to encourage them to express these difficult feelings. Carers may struggle most with helping the people they support express anger as they may be worried about the behavioural repercussions but there are ways to do this safely. If you are not sure ask for help, see page 14

There can be much focus on behaviour for people with learning disabilities. They can sometimes have experiences where the world is divided into good and bad, particularly for the older generation. Good behaviour is rewarded: people like you and you feel good. Occasionally, 'bad' behaviour is punished: people are upset with you and you feel bad. Many people with learning disabilities may associate bad feelings with being 'bad'. Sometimes you may find that they will not admit to feeling angry or upset as they are **not sure if these feelings are allowed**.

Even if this has not been their experience, they may struggle with expressing emotion for many reasons. Grief emotions for all of us can be complex, overlapping and very big, sometimes overwhelming.

Some people with learning disabilities can lack understanding and insight into their emotions; they can find emotions associated with death very confusing. Putting feelings into words can be difficult for everyone, but for some people with learning disabilities who have significant communication barriers, this can be far harder, maybe impossible.

When someone doesn't understand death or their emotions, can't express those emotions and those emotions aren't recognised or validated by others grief reactions may become more complicated and unrecognisable. This compounds the problem and creates a downward cycle of misunderstanding.

To reverse this it is crucial that following bereavement a person with learning disabilities is:

- Communicated with clearly that a death has occurred and what that means
- Not judged for how they grieve
- Encouraged to participate wherever possible
- Given space to express their experiences meaningfully

Ritual and ceremony

Ritual, ceremony and symbol are very powerful ways of making sense of the world for all of us, particularly when life is challenging. Death **rituals can be especially helpful to those who struggle with communication**. It can help sometimes in a way that explanation just can't. It allows people to:

- Affirm the reality of the death, mark the passing of the life, gain closure
- Acknowledge and explore feelings

However, it should not be assumed that a funeral or memorial service on its own with no further work will be sufficient. It is necessary to discover what the person understands and believes about death already and to explain how the ritual or ceremony they will experience will fit with this understanding.

A person with learning disabilities will probably need someone who can give them their full attention during this process so that they can ask any questions they might have. If a family carer is grieving themselves they may not be able to provide this support and another source of support should be called upon.

Expect the unexpected

The indicators that there is unrecognised grief present in someone with learning disabilities includes:

- Isolation / refusal to join previously enjoyed activities
- Changes in mood / behaviour / personality / eating / sleeping
- Becoming depressed / apathetic / anxious / irritable
- Losing touch with reality
- Asking odd / obvious questions
- Disbelief / mistrust and anger
- Talking of the loss leads to tears/ shouting
- Minor events causing fresh grief symptoms
- A reoccurring theme of loss, searching for lost objects / absconding
- Separation anxiety, longing, loneliness / fixations
- Challenging behaviour - self-injury / aggression
- Regression – mutism, bedwetting, soiling / smearing of faeces

Timing is everything

An uncertainty for many carers is how much to push the person to face their grief and how much to leave them alone to come to terms with it in their own time. Grief is a very personal process but it can take people with learning disabilities longer to process what has happened and their feelings. It is important they are not rushed before they are ready. However, it is also important to be aware that some people with learning disabilities can have a tendency to bottle up emotions. It can feel like a tricky balancing act.

The answer is to use watchful waiting to identify what stage of grief they might currently be experiencing. This can be done by gently prompting the person to choose mementos that remind them of the person who has died.

Unprocessed grief can be identified by a tendency to avoid things that are strongly associated with the dead person. This avoidance reduces when a person is moving to the next stage. A negative response to mementos indicates that they are not ready to investigate their feelings of grief yet. Allow some time to pass so that some of the raw pain can begin to subside and then gently prompt again to see if the reaction is different.

Be ready for when they suddenly want to talk. It can seem to come out of the blue but it might be that they have been going over it in their mind for some time.

Memory work

When they are ready it is a good idea to actively encourage the person with learning disabilities to remember the person who has died. It can be helpful to do this as a part of their life story.

It is generally useful to keep a life story book for people with learning disabilities where they can look back over pictures and other mementos of the past to preserve a sense of continuity in the face of any future changes or losses.



Memory work that is specifically related to a death can:

- Support access to memory and therefore helps to maintain important memories
- Include Information about the death to aid understanding
- Enable the processing and understanding of emotions

Memory is a strange thing. It can be fired by any of the senses. Have a think about the role that sight, sound, touch, taste and smell might play in memory for the person you care for. Maybe the person who died had a favourite food or drink and the taste or smell of these things vividly brings to mind the time spent with that person. Perhaps the person who died had a preferred activity such as walking the dog on the beach. Therefore, the feel of sand underfoot, the smell of wet dog, the sight of a particular dog, the sound of the waves and the taste of salt helps you relive the time you had with them. Think about ways of accessing these sensory memories and **get creative**.

It is crucial that during memory work it is the person who is bereaved that makes the choices about what is included no matter how strange. It must be meaningful to them, so try to notice what it is that works best for them.

Bereavement Support Guidance

There are two booklets available for people with learning disabilities who are dealing with bereavement.

- 1. Bereavement: Information about death**
- 2. Bereavement: Grief and ways of coping**

This section of the carers' guide will help you understand how to support someone to use them.

Book 1 – Information about death

This book explains all about death: why people die, what death is, what happens after death and what to expect at funerals. If the person you care for has a good understanding of death or if the funeral has already happened you may only want to work through parts of it or skip it entirely.

Try not to shy away from the content of this book. You may feel shocked by how direct it seems. Try to remember that confusion, uncertainty and falsehoods can cause their own trauma and can prevent someone processing the death. They can also lead to their own problems. If you tell the person you care for that the person who has died is sleeping they may become afraid of sleep. If you tell the person you care for that the person has gone to a better place they may wonder what is wrong with them that they have been left behind. If you tell them the person is buried but have not explained that their bodies have stopped working they may become fearful about people walking over the grass in case the dead person is hurt or become concerned by other issues that show they have not really understood. It is crucial to be very open, clear and honest even if it is something that is hard for you to do.

We will now focus on some areas of the booklet that may require some extra input from you.

About death

In the first exercise box try to note down as much as possible about what the person understands. This should give you an idea of where you need to start from. Try to draw out of them what they understand and believe about death and note down the words they use.

This will enable you later to answer any questions they may have in a way that most makes sense to them. Whilst you should not support misinformation you should also not undermine any beliefs that have helped them to process their feelings. It is important to keep your messages consistent, using the same language they use.

For the rest of the section just work steadily through each part, allowing enough time for the person to reflect and ask questions. You may need to revisit this section several times for the person to be able to digest some of the concepts.

The person

This is a very difficult part of the 'About death' section. It is very tempting to offer reassurance when the person you are caring for asks what has happened to the person who has died.

Remember that confusion may make the death more traumatic. It is OK to discuss beliefs if this is something they are interested in and have questions about. This can be a useful activity.

However, try not to *create* a belief *for* them because it will not be meaningful if they have not chosen it for themselves and doesn't relate to what they previously believed.

At the end is a reflection exercise. You should be able to see what new information they have learned when you compare it to the first exercise.

After someone dies

Again the first exercise box is for noting down as much as possible about what the person understands already.

The funeral service

You will notice that there is a purple arrow in the top right hand corner of page 15. From this point onwards you may find that the description is different from the type of service the person you care for will be attending. If the person you care for has a different religious or cultural background from the one described, please contact us on one of the numbers listed on page 14 and we will provide you with an alternative section. It is important that the person can prepare properly for the right kind of service.

It helps to rehearse what to expect from the funeral so that there are no surprises. It is also good if they can ask any questions they may have.

Use the exercise box at the end of this section to make a plan about what will happen on the day of the funeral.

If the person has already missed the service, try to think about ways they could have their own service. Think about what kind of symbolic gestures might make sense to them.



If they are upset about missing it, try to collect together any mementos of the service to help them feel more included. Maybe they could go to see the person who delivered the service or visit the place where it was held.

Book 2 – Grief and ways of coping

This book explains about the feelings (both physical and emotional), behaviours and thoughts people can experience when they have been bereaved. It then encourages the reader to identify what they are feeling, doing and thinking in response to their bereavement.

Finally, it suggests things that the reader can try to help them cope. It repeats the process of looking at feelings, behaviours and thoughts, but this time with a view to making positive changes.

There are lots of activities. Allow the person time to think about the different things they could try. You don't have to do everything in this section, let them choose what makes most sense to them.

The book asks you to come up with some ideas of your own. Give the person you support plenty of time and opportunities to add anything. You may need to revisit the book several times for them to begin to be able to think of their own ideas. It may depend on mood, what stage of grief they are in currently and what memories have returned recently.

Loss

This can be a very important issue for people with learning disabilities. For those who are supporting them through a bereavement it is useful to know that they can have an emotional box of loss. Into that box is put all of the things that have happened in their life that they didn't really understand but which made them feel bad. Change, even when it is for the better long term, is a type of loss and loss can be confusing if it is not well explained or prepared for. This box is then locked away. Over time this box can become quite complicated. The losses can get jumbled and interlinked, so a confusing unprocessed death can be the same as any of the other confusing unprocessed losses. Loss can include:

- Staff turnover / family members moving away
- Change of housemate / changes of home
- Closure of a centre
- Losing possessions/ pets
- A change to routine/ activities/ security
- Visitors ceasing to turn up / losing touch with people
- Rejections / being excluded

It can be anything that was once part of life that is no longer there. The more losses they have experienced the more vulnerable they will be when it comes to dealing with a death.

Be aware that there might be extra losses associated with the death of the person. Have a look at the things the person has written in the loss section and think about which of those things might be connected. Any changes after bereavement should be avoided if possible for at least a year as a rule of thumb.

Grief

This section requires the reader to work steadily through each part, allowing time for reflection, thinking about their own reactions and to fill out the exercises.

You may need to revisit this section several times for the person to be able to unpick and begin to understand their reactions.

Ways of coping

The 'Ways of coping' section contains suggestions about activities that may help the person you care for to begin to process their grief. There are many remembering activities. They are only suggestions, let the person think about them and decide what works best for them. It really depends on their beliefs and which stage of grief they are experiencing currently as to what will feel right for them.



It can also help to carry out a symbolic 'letting-go' ritual, such as tying a message or other item to a helium balloon and letting it go. A message or picture can also be burned or put in a bottle and sent out to sea. Try to come up with your own letting go ceremony that makes the most sense to the person you care for, their beliefs and for their relationship with the person who has died (do also consider the environment and health and safety).

Contact for help

Wirral

The contact details below are for the Community Learning Disability Teams where you can get further information. If you complete the feedback form on the next page please send it to the local team.

Tel: 0151 488 8100

Address: **Ashton House**, 26 Village Road,
OXTON, CH43 5SR

West Cheshire

Tel: 01244 397 222

Address: **Eastway**, Countess of Chester Health
Park, Liverpool Road, CHESTER, CH2 1BQ

East Cheshire

Cheshire East (South Cheshire) - Stalbridge Road Clinic

Address: 54 Stalbridge Road, Crewe, Cheshire
CW2 7LP

Tel: 01270 656 335

Cheshire East - Rosemount

Address: Chester Road, Macclesfield, Cheshire,

Trafford

Tel: 0161 912 2810

Address: **Waterside House**, Waterside, SALE,
M33 7ZF

Fill out the form below if you want to let us know what you think of this pack.

⇒ Circle the number you agree with most.

How did you feel before you used this book?

Really Good	Good	OK	Bad	Really Bad
1	2	3	4	5

How do you feel since using this book?

Really Good	Good	OK	Bad	Really Bad
1	2	3	4	5

Do you think you have learned much from this book?

Yes, Lots	Yes, Some	Maybe a Little	Not Really	No, Nothing
1	2	3	4	5

How useful have you found this book?

Really Useful	Useful	Quite Useful	Not Very	Useless
1	2	3	4	5

How easy to use did you think this book was?

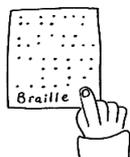
Really Easy	Easy	In-between	Hard	Really Hard
1	2	3	4	5

What did you like or find useful?

What did you dislike or think was not useful?

Is there anything you would change?

This leaflet is available in other languages or formats



For more information see www.cwp.nhs.uk.

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