

When someone dies.. A support booklet

A resource for family, carers and health professionals who are supporting someone with a learning disability through a bereavement.

This booklet has been created for families, carers and health professionals. It provides useful information and practical strategies that may be helpful when you are supporting a person with a learning disability through a bereavement.

This leaflet is accompanied by an Easy Read leaflet which has been developed to support discussions about bereavement.

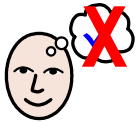
Please refer to:

When someone dies - An easy read leaflet to help to support people with learning disabilities through a bereavement

Things that are important to remember

- People with learning disabilities experience grief like anyone else.
- Each person with a learning disability will grieve in their own way.
- Some people may feel that withholding information about death from a person with a learning disability can minimise anxiety, however, generally, this is not helpful.
- Having a learning disability does not mean that a person cannot be affected by, understand, or deal with a bereavement.
- Most people with a learning disability will progress normally through the grieving process.
- Delayed reactions to grief are common within the learning disabled population. Whilst some people may appear to cope well at the time of the loss, they may experience difficulties in the weeks, months or even years after the death.
- The person's communication skills will have a significant impact on their ability to understand what has happened and on their ability to express their thoughts, feelings and opinions.

The relationship between Communication skills and bereavement



Most people with a learning disability will have some form of communication difficulty.



Some people with a learning disability have difficulty understanding spoken language. Many will have difficulty understanding large pieces of information as well as unfamiliar words and concepts.



Some people with a learning disability may be able to talk about their emotions using speech, signs or symbols.



People with limited expressive communication skill may rely on non verbal means of communication including a change in behaviour to express how they are feeling.

Some people who have a more severe learning disability may respond mainly to the absence of the person and to the change in their routine.



It is important to understand the communication needs and abilities of the person you are supporting as this will help you support them more effectively. 3

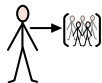
Ways to support a person with a learning disability through a bereavement.

Talk



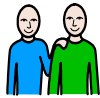
- Use words that are easily understood.
- Use words to describe the death in a concrete way e.g. 'they have died' rather than 'they have gone to a better place'.
- Talk about the person who has died. This gives the person the opportunity to understand that loss has happened and that it is OK to talk about it.
- Talk about what is happening e.g. the funeral process.
- Answer any questions as concisely as possible.
- Use the booklet 'When someone dies - An easy read leaflet to help to support people with learning disabilities through a bereavement.'

Involve



- Involve the person in the process e.g. choosing flowers, choosing what they can wear to the funeral.
- Try to let the person make their own decisions about what **they** want to do e.g. viewing the body, attending or not attending the funeral.
- Let the person decide whether they want to keep any particular items to remember the person by.

Reassure



- Reassure the person that it is OK to cry and to have a range of emotions including sadness, anger and fear.
- Do not assume that you know how the person will be feeling. Listen rather than try to fix it. They need to work through the process themselves.
- Be patient, make time to be available and listen.
- Reassure the person with a learning disability that the death was not their fault.

Encourage



- Encourage routine activities. Routines provide a sense of stability at emotional times.
- Keep reminders of the person who has died present around the house e.g. photographs or a few belongings.
- Encourage the person to take time and relax somewhere comfortable.
- Support and encourage the person to remember and talk about their loved one on special occasions like birthdays and Christmas.
- Support the person to move forward by encouraging them to explore new activities.
- Support and encourage the person to visit the grave or a special place of remembrance if they want to.

If you feel the person is not coping with their loss or that their grief is very prolonged, you should speak to their G.P. or social worker to consider whether additional support services may be of benefit.

When supporting someone with a learning disability through a bereavement-

Do

- Use simple concrete language to discuss what has happened.
- Be patient - make yourself available to listen or help.
- Acknowledge their loss and say you are sorry about what has happened.
- Allow them to express their pain and unhappiness.
- Reassure them that they are not to blame.
- Encourage them to be patient and do not expect too much of them.
- Take the lead from the person, if they don't want to talk that is ok!

Don't

- Avoid the person because you are uncomfortable - this can cause them more pain.
- Tell them what to do or how to feel.
- Change the subject when the loss is mentioned.
- Point out that they should be grateful to have other things in their lives.
- Don't assume that everyone needs help. Some people will cope with the grieving process with minimal support.

