

Supporting bereaved children and young people with additional needs through grief

All children and young people, regardless of their circumstances, have a right to have their grief recognised, to hear the truth and to be given opportunities to express their feelings and emotions. Those with additional needs are no different but may need extra help with their understanding and ways to express feelings. Whilst we may not know exactly what a child or a young person with profound and multiple learning disabilities understands when someone significant dies, they will certainly be aware of that person's absence and of the changes in their own life that may result.

Helping children with additional needs deal with their grief may present teachers, parents and carers with specific challenges. The child's understanding may be at the level of a much younger child and they may have little sense of the permanence of death. Some children may never come to a complete understanding of the finality of death and may continue to believe that the dead person will return one day. They may long for things to be the same as they were.

Preparing for a death

If the death is expected, it can be helpful to prepare the child in advance in a gradual way. The child may need to be prepared for visits to a hospice or hospital. It helps if the child can be told about any changes they might see, such as how the ill person might look or sound or for any changes in their day to day activities and routines that might happen.

- Keep to normal daily routines as much as possible - many children and young people with learning difficulties find any change difficult to manage.
- Use clear, concrete language, avoiding euphemisms and abstract ideas.
- Explain any predicted changes in routine in advance, giving details about who will be doing what and when.
- Use pictures and photographs to explain what will happen at any visits to a hospital or hospice.

After a death

When a death has occurred, the child may need help in understanding the concept of death as well as needing opportunities to express their grief.

- Answer any questions as they arise honestly and using simple language, at a level appropriate to the child's understanding. Give enough information to answer the question, but without adding a confusing amount of detail. You may need to repeat your answer many times, so try to use consistent language and explanations.
- Use lots of examples to explain the non-reversibility of death, but in a way appropriate to the child's understanding. Where possible, use pictures and real objects. Try to take a biological approach that is practical, clear, and visual, with concrete examples, such as comparing a dead fish with a live fish, observing flowers wilting and dying. See below for some ideas on how to do this.
- Try to include the child in rituals, such as sending cards or attending the funeral or memorial service. Children with additional needs are sometimes excluded as it is challenging for the adults around them, or there may be the belief that the child won't understand what is happening. However, being included in these events can be extremely helpful for children and can aid their understanding of what is happening. There may be ways to enable their participation such as having another adult to care for them during the service or there might be parts of it that they could be present for. However, if this is not possible, make sure that they are given an opportunity to say goodbye with their own simple ceremony.

- Prepare the child for events such as funerals or memorial ceremonies. It may be helpful to visit the place where the service will take place beforehand or to make a multisensory or social story using photographs with accompanying text that will explain what will happen. See Resources section for sources of guidance about sensory and social stories.
- Explain and prepare for any changes to daily routines in advance, giving details about who will be doing what and when. It can be very reassuring for children to know who will be taking them to school or to activities if this has changed.

Communicating the Truth

It is sometimes assumed that children with additional difficulties need more protection from hearing about death and dying than other children, or that they do not have the capacity to understand. However, whilst their understanding may be that typical of a younger age, we often underestimate their abilities to cope with the tough things in life. The challenge is to find creative ways to communicate when words are sometimes not appropriate.

- It is important to acknowledge the death. To ignore what has happened suggests that this is an unimportant event and denies the existence of the person who has died.
- If using words, use the real ones, for example, 'dead' and 'dying', not euphemisms. If the child communicates using signs or symbols, ensure you have the correct vocabulary to hand.

Understanding the concept of death

All children struggle with the concept of death and its permanence. Children with learning difficulties may find this particularly hard to grasp and will benefit from simple, practical examples to illustrate the difference between dead and living things. Very visual explanations are particularly important for children with autism spectrum disorders.

Here are some ideas to help with understanding:

- Buy a bunch of flowers, put them in a vase and observe them wilt, wither, and die. Compare them to a fresh bunch of the same type. If kept, the dead flowers will illustrate that death is permanent and that the flowers do not return to life.
- Purchase a dead fish from the supermarket and compare it to a live one. Even when put into a bowl of water the dead one will not move, breath, eat or swim.
- Give the dead fish a burial that replicates as far as possible a real one. You can explain a cremation by burning leaves and mixing the resulting ashes with some earth.
- Take photographs of the above activities and put these into a book. This will act as a visual reminder for the many times when the explanation will need to be repeated.
- Use as many real-life examples as you can, such as pictures of funerals and coffins to aid understanding.
- Visiting the dead body will help with the concept of no life, but this will need careful preparation, so the child knows exactly what to expect. Feeling that the body is cold and observing no breathing or movement can aid their understanding that the body is no longer working.

Expressing their grief

Children do not need protection from the feelings and emotions associated with grief, but support to express them and reassurance that these sometimes powerful and overwhelming emotions are normal and necessary. This is even more the case for children with learning difficulties.

- Help the child to learn how to recognise different feelings both in themselves and others, as well as learning appropriate ways of expressing their feelings. You can do this by using everyday situations and events to point out different emotions in other people (for example on TV programmes, in magazines and stories) using consistent and simple language to label emotions from the child's own experiences and by using pictures.
- Remember that children will take their cue from the adults around them, so it is helpful if you can be honest about your own emotions and to sometimes shed tears if you need to, but to also reassure the child that you are OK and that your response is natural.
- Use a simple workbook such as 'When Someone Very Special Dies' by Marge Heegard (see Resources section). This can easily be adapted for various ability levels.
- Looking at photographs or watching videos of the person who has died can facilitate expressions of sadness or anger.
- Carrying a comfort object such as a small piece of warm furry blanket can be an aid in getting through difficult moments.
- Offer opportunities for safe ways to express frustration and anger, such as physical activities, music-making, or creating a 'scream box' (a box stuffed with paper and a cardboard tube to shout into). Give reassurance that it is OK to be angry.

Remembering the person who has died

When someone important to a child or young person dies, memories are an important part of the grief process. Whilst the person may be physically gone from the child's life, the emotional bond will still be there. This is particularly true when a parent or carer dies and children with additional needs often have a number of adults in caring roles, so will be affected by the death of any one of them. Memories help any child to construct a sense of who it is they are grieving for and why. It is, therefore, important to help make this happen for children with additional needs. Ways to remember a person who has died might include:

- Having a piece of fabric from an item of clothing worn by the person who has died, to carry in a pocket or made into a cushion, which can be comforting.
- Having the perfume or aftershave of the person who has died on a hanky can be reassuring.
- Put together a memory box of tangible reminders chosen by the child that are of particular relevance to them. Try to keep in mind the importance of concrete reminders of the person that has died and include something relating to all five senses.

A memory box therefore might include pictures of the person, pictures of things that person enjoyed, a small object that belonged to the person, a piece of fabric that is associated with that person (that may have a particular 'feel' to it), a CD of music that the person enjoyed or tape of them speaking, something that reminds the child of the smell of that person (such as perfume, aftershave, toothpaste or deodorant).

- Listening to audio tapes of the voice or favourite music of the person who has died may be familiar and comforting.
- Use photographs and memories of significant events to create timeline and story of that person's life.
- Keep in mind that the needs of bereaved children with additional difficulties are the same as those of any child but ensuring they receive appropriate support and understanding may require some additional thought and preparation from the adults caring for them.

Resources and further reading

There are limited resources which specifically focus on children with additional needs and it is often a case of adapting mainstream resources. The following are available from bookshops or online booksellers, unless otherwise stated.

Other Child Bereavement UK information sheets you may find helpful. Visit www.childbereavementuk.org

- *Viewing a body with a child*
- *Supporting bereaved children and young people with Autism Spectrum Disorders (ASD)*

A Special Kind of Grief: the complete guide for supporting bereavement and loss in special schools (and other SEND settings)

Sarah Helton

Set in a special school, this book has been written to help children with additional needs cope with the death of a friend.

I Have a Question About Death: a book for children with autism spectrum disorder or other special needs

Arlen Grad Gaines & Meredith Englander

When Someone Very Special Dies

Marge Heegard

This simple workbook book was designed to help children age 5+ understand and express the many feelings they have when someone special dies. To be used with an adult. Available from Amazon.

What Happens When Someone Dies?

Jenny Armstrong

Uses photographs to give a clear, simple account of what happens after someone dies. Gives clear explanations of a room in a chapel of rest, a coffin, a hearse and what a body may look like. Available from SeeSaw: www.seesaw.org.uk

Remembering Lucy:

A Story About Loss and Grief in a School

Sarah Helton

Bereavement and Loss: Supporting bereaved people With PMLD and Their Parents

A learning resource pack with helpful guidance and practical ideas for supporting children with profound and multiple learning disabilities. Includes a DVD with real-life stories.

Available from PAMIS www.pamis.org.uk

Sad

Lucy Finch

A beautifully designed creative resource, including a story, emotion stickers and a pot of memories.

Only available direct from the creator:

www.lucyannedesign.com/sad

How to make a multisensory story:

www.mencap.org.uk/blog/create-your-own-sensory-story-7-steps

How to draw up a social story:

<http://carolgraysocialstories.com/social-stories>

National Autistic Society www.autism.org.uk

Further resources and/or references are available from Child Bereavement UK, upon request.