

Supporting bereaved children and young people with Autism Spectrum Disorders (ASD)

Just like any other child, a child with autism spectrum disorders (ASD) will need their grief to be recognised and understood and to be given opportunities to express how they feel. Because of the nature of their ASD, children with ASD may not respond to the death of someone close to them in the same way as other children but this does not mean they are not grieving. This information sheet covers some of the challenges bereaved children with ASD may face, and ideas for what might help.

How ASD may affect a child or young person

Due to problems in processing information and in understanding hypothetical events, those with ASD may have specific problems in developing their own ideas about death and the rituals that surround it. Other difficulties they face may relate to:

Mindblindness - difficulties in seeing things from another's point of view. This may make it hard for them to understand other people's feelings and behaviours, including not realising that others can help.

Information processing – difficulties in understanding the rituals surrounding a death and in understanding the implications of a death. For example, that because someone has died, this means they will not be there at the weekend, to take them to school or to celebrate a birthday.

Language and communication – difficulty understanding the abstract concepts involved when someone dies, unless other people use clear, specific and concrete language. Also, difficulty in communicating feelings and in asking for support.

Preoccupations (focus on specific things) – these may increase or grow more intense due to anxiety.

Imagination, time perception and memory – may lead to difficulty in understanding the impact of a death. For example, understanding changes to routines, anticipating how things might be in the future and understanding events that they have not experienced before.

As well as suffering the loss of the person that has died, children with ASD can be further distressed by all the changes that might happen in their day-to-day lives as a result of the bereavement. Below are suggestions on how to help support children with ASD who have been bereaved. Additional ideas are given in the '*Supporting SEN Pupils*' sheet in the Child Bereavement UK *Schools' Information Pack*.

Preparing for loss in advance

If the death of someone close is expected, children or young people can be prepared in advance and in a gradual way. They may need to be prepared for visits to a hospice or hospital. It is particularly helpful if they can be told beforehand about any changes they might notice, for example in the ill person's appearance (how they might sound, look or feel to the touch) or in everyday activities and routines. You may also need to explain whether there will be medical equipment such as intravenous lines or a ventilator, and that this might be noisy.

- Keep to normal daily routines as much as possible.
- Use clear, concrete language, avoiding euphemisms and abstract ideas.
- Explain any likely changes in routine in advance, giving details about who will be doing what and when.
- Use pictures and photographs to explain what will happen and when and how. For example, pictures of the hospice, or of the taxi that will take them to school or to swimming from now on.
- Explain whether there will be medical e
- Use calendars or other visual aids, for example, to mark hospital visits, as well as significant positive events such as visits to the park.
- It can be helpful to develop rituals to mark a death, such as lighting a candle when an animal dies. The same ritual can then be used when a person dies.

When a death has happened

When someone dies, a child may need help in understanding the idea of death as well as opportunities to express their grief.

- Use simple, concrete language and avoid euphemisms such as 'lost', 'passed away' or 'gone to sleep'. You may need to explain what dead means in concrete terms - 'When someone is dead their body is no longer working and their heart has stopped. A dead body cannot move or feel anything, so there is no pain.'

- Use lots of examples to explain that death is permanent and not reversible, in a way that is appropriate to the child's understanding - 'When someone has died they can never come back to life again.' Where possible, use pictures and real objects. Try to use a biological approach that is practical, clear, and visual, with concrete examples. For example, comparing a dead fish with a live fish, or observing flowers wilting and dying, or talking about what dead means when they come across a dead bird, for example.
- Answer the child's questions as they arise – which may mean answering the same questions repeatedly. Answer simply, and honestly, and at an appropriate level for the child's understanding. Give enough information to answer the child's question, but without adding a confusing amount of detail.
- Prepare the child for ceremonies or rituals that will include them, by visiting the relevant places beforehand. It may help to use photographs and draw up an explanatory story using words and pictures to explain what will happen. Clearly explain what the child is expected to do and show what other people will be doing and saying, and what will be happening around them. For further details on how to draw up a social story visit either The Gray Centre: <http://carolgraysocialstories.com/social-stories/> or The National Autistic Society: www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx
- Help the child to learn how to recognise different feelings and emotions 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 (such as on TV programmes, in magazines and stories), by using consistent and simple language to label emotions from the child's own experiences and by using pictures. Using pictures is particularly helpful for

children with ASD, and a 'feelings thermometer' can help a child express the intensity of an emotion. You can do this by drawing a picture of a thermometer with a rating scale up the side. Encourage the child to show where they are on the scale to rate the strength of their anger/sadness/worry. Similarly, using a picture of a volcano to illustrate anger and how it sometimes 'boils over' can be helpful. Using a 'comic strip conversations' technique can help others understand what a child with ASD is thinking and feeling and can provide the opportunity to discuss things that the child might otherwise find difficult. This can help identify misunderstandings and highlight emotions that have perhaps not been openly expressed, or that have shown in other ways. You can find out more about how to do this on the National Autistic Society website: www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx

Keeping memories alive

When someone important to a child or young person dies, memories are an important part of the grief process. The person may be physically gone from the child's life, but the emotional bond will still be there. This is particularly true when a parent or main carer dies. Memories help any child to construct a sense of who it is they are grieving for and why. All memories have a part to play, whether of happy times or times that were not so good.

- A piece of fabric, from an item of clothing worn by the person who has died, carried in a pocket or made into a cushion, can be comforting.
- Similarly, smelling the favourite perfume or aftershave of the dead person on a hanky can be reassuring.
- Putting together a memory box of physical reminders, chosen by the child. This can help give some insight into factors and events that are key to the relationship with the dead person. Try to include something relating to all five senses. A memory box, therefore, might include pictures of the person and 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 a tape recording of them speaking, and 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 dead person may be familiar and comforting.
- Using photographs can help to create a timeline to spark off memories of significant events, and then build a life story of the person.

Resources and further reading

There are limited resources written specifically for bereaved children with autism spectrum disorders, but the following may be helpful and are available from bookshops or online booksellers, unless otherwise stated.

I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs

Gaines & Englander Polsky

Uses straightforward text and clear illustrations to explain what death means specifically to children ages 5-11 with ASD and other special needs.

Books Beyond Words: When Somebody Dies

Hollins, Blackman & Dowling

Using pictures, the book tells the story of Mary who is very upset when someone she loves dies. John also loses someone he is close to and is shown learning to cope better with life. Published by the Royal College of Psychiatrists (2003)

www.booksbeyondwords.co.uk

Books Beyond Words: When Mum Died Books beyond words: When Dad Died

Hollins, Sireling & Webb

Books that take an honest and straightforward approach to death and grief in the family. The pictures illustrate the death of a parent in a simple but moving way.

www.booksbeyondwords.co.uk

Sad Lucy Finch

A beautifully designed creative resource, including a story, emotion stickers and a pot of memories. Only available direct from: www.lucyanndesign.com/sad

Death, Bereavement & Autistic Spectrum Disorders

www.autism.org.uk/about/family-life/bereavement.aspx

Resources suggested by The National Autistic Society.

Finding Your Own Way to Grieve: A Creative Activity Workbook for Kids and Teens on the Autism Spectrum

Karla Helbert

A practical and informative workbook to encourage the constructive expression of grief through discussion, personal reflection and creativity.

Understanding Death and Illness and What They Teach about Life: An Interactive Guide for Individuals with Autism or Asperger's and Their Loved Ones

Catherine Faherty

Offers detailed, concrete explanations of illness, dying and related issues, in the form of questions a person might ask, followed by some possible answers. Each section continues with a communication checklist to facilitate open discussion about the issues raised in a clear and accessible way.

Autism and Loss

Rachel Forrester-Jones & Sarah Broadhurst

A complete resource about all aspects of loss including fact sheets and practical tools suitable for use with adults and children.

www.booksbeyondwords.co.uk

How People with Autism Grieve and How to Help: An Insider Handbook

Deborah Lipsky

The author's personal view on how she dealt with the death of someone close, and gives an insight on how people with autism might best cope with the death of someone in their life.

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