

Supporting bereaved children and young people with Autistic Spectrum Difficulties (ASD)

Just like other children, those with autistic spectrum difficulties (ASD) will need their grief both recognised and understood and opportunities to express how they feel. Because of the nature of their difficulties, 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. They may have specific problems in conceptualising death and the rituals that surround it as a result of their information processing difficulties and problems in understanding hypothetical events. Other difficulties may relate to:

- **Mindblindness** - difficulties in seeing things from another's point of view, this may make it hard for them to understand others' feelings and behaviours and fail to realise others can help
- **Information processing** – have difficulties in understanding the rituals surrounding a death and in understanding the implications of a death e.g. that because someone has died, this means they will not be there at the weekend, to take them to school or be there to celebrate a birthday
- **Language and communication** – may have difficulty understanding the abstract concepts involved, unless others use clear, specific and concrete language, and may have difficulty in communicating feelings and in asking for support
- **Preoccupations** – these may become exacerbated or more intense due to anxiety
- **Imagination, time perception and memory** – may lead to a difficulty in understanding the impact of a death e.g. changes to routines and anticipating how things might be in the future and in comprehending events outside their previous experience

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. Here are a few 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. www.childbereavementuk.org/For/Shop/ForProfessionals/SchoolsInformation

Preparing for loss in advance

If it is known that the death of someone close is expected, children can be prepared in advance and in a more gradual way. The child may need to be prepared for visits to a hospice or hospital. In these circumstances it is particularly helpful if they can be forewarned of changes, for example in the ill person's appearance (how they might sound, look, feel to the touch etc) or for any other changes in everyday activities and routines that might result.

- Try to keep to normal daily routines as much as possible
- 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 and when and how e.g. of the hospice, of the taxi that will take them to school/swimming from now on

- Use calendars or other visual means, say to chart hospital visits, also including significant positive events such as visits to the park
- It can be helpful to develop rituals to mark death, such as lighting a candle when an animal dies. The same ritual can then be used when a person dies.

When a bereavement has occurred

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

- 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
- 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 e.g. comparing a dead fish with a live fish, observing flowers wilting and dying
- Prepare the child for ceremonies or rituals that they may be part of by visiting the relevant places beforehand, using photographs and drawing up an explanatory story using words and pictures that will explain what is happening. Detail what the child is expected to do, and show both 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 The Gray Centre www.thegraycenter.org/social-stories/what-are-social-stories either or the Autism Network www.autism.org.uk/Living-with-autism/Strategies-and-approaches/Social-stories-and-comic-strip-conversations.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 (e.g. 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 he is 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 the 'comic strip conversations' technique can help others understand what a child is thinking and feeling and can provide the opportunity to discuss things that the child might otherwise find difficult. This strategy can help identify misunderstandings and highlight emotions that have perhaps not been overtly expressed or that have manifest in other ways. You can find out more about how to do this on the Autism Network www.autism.org.uk/Living-with-autism/Strategies-and-approaches/Social-stories-and-comic-strip-conversations.aspx

Keeping memories alive

When someone important to a child or young person dies, memories are an important part of the grief process. The deceased may be physically gone from their lives 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 have a part to play, whether of happy times or ones 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 very emotive.
- Similarly, the deceased's favourite perfume or aftershave on a hanky can be reassuring.
- Putting together a memory box of tangible 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 keep in mind the importance of concrete reminders of the person that had died. Try to include something relating to all 5 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 deceased 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 (perfume, aftershave, toothpaste, deodorant etc)

- Listening to audio tapes of the voice or favourite music of the dead person may be familiar and comforting
- Use photographs to create a timeline to spark off memories of significant events and then build the deceased's life story

Resources

There is very little written specifically for children with autistic spectrum disorders who have been bereaved but the following may be helpful:

Books Beyond Words: When Somebody Dies by Hollins, Blackman and 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

www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1901242900.aspx

Cost £10.00

Books Beyond Words: When Mum Died, also When Dad Died by Hollins, Sireling and Webb

Both books 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. Published by the Royal College of Psychiatrists.

www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1904671039.aspx

www.rcpsych.ac.uk/publications/booksbeyondwords/bbw/1904671047.aspx

Cost £10.00

Hand in Hand

Supporting children and young people who have a learning difficulty through the experience of bereavement. A resource pack with practical ideas including a section on using symbols to explain death and funerals.

Published by SeeSaw

www.seesaw.org.uk

Cost £10.00

Death, Bereavement and Autistic Spectrum Disorders.

Available from the National Autistic Society Information Centre www.autism.org.uk/en-gb/living-with-autism/at-home/death-bereavement-and-autism-spectrum-disorders.aspx

Autism and Loss

A complete resource including fact sheets and practical tools suitable for use with adults and children. Available from Jessica Kingsley publishers www.jkp.com

Cost £29.99

SAD. by Lucy Finch

A beautifully designed creative resource, including a story, emotion stickers and a pot of memories. Only available direct from the creator, www.behance.net/lucy_finch