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

Guidance and Support

It can be difficult to discuss death and bereavement, and to help a person with autism to cope with a death. Every autistic person, and their level of understanding, is different. Just like neurotypical people, those on the spectrum will understand and adjust better if they are involved and prepared in advance as much as possible. You will need to adapt any approach or guidance for the person concerned.

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 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:

Mind blindness

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 may increase or grow more intense due to anxiety, so for example if the child/young person watches a certain TV programme quite often, this may increase. Similarly, if the child has a special interest that they like to talk about, this might also increase.

Imagination, time perception and memory

These 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.

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.

- 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. 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 or going online and letting them have a virtual tour of the venue for the funeral/cremation. 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.**

- 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.

Recognising Grief

You may not recognise the autistic person's displays of grief, but any difference in their behaviour may be an expression of their confusion and loss. These behavioural changes may occur immediately, or a long time after the death. You may notice a reoccurrence of these or other behaviours at significant dates after the death, at an anniversary, Christmas or birthdays.

There are recognised approximate stages of bereavement:

- Shock, numbness, denial.
- Despair, turmoil and acute grieving. This can include anger, guilt, anxiety, fear, panic, depression, pain, appetite disturbance, breathlessness, illness, increased need for sleep, sleeplessness, hyperactivity, nightmares, regression, loss of skills.
- Recovery, including acceptance, resolution of grief, when the bereaved can think of the deceased without pain or anger and can recall the times they had together in a positive way.

These stages may merge, and not everyone will experience all of them. Your autistic family member, or the person you are supporting, may experience confusion over why they do not see the person anymore, or anxiety about why members of the family seem to be acting differently. It is important to remember that the above stages do not necessarily go in the

order described. Fluctuating between them is normal. Response/reactions to grief and bereavement is unique to everyone. So, for example, they may experience shock, then appear to be at the point where there is an acceptance of the death.

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 memory stick with a playlist of music that the person enjoyed or videos of them, 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.

You could use a social story to explain how people become upset and cry when someone has died, and perhaps that it is okay that they have/have not cried.

Social stories and comic strip conversations can help autistic people develop greater social understanding and stay safe.

What are Social Stories?

Social stories were created by Carol Gray in 1991. They are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why.

The terms 'social story' and 'social stories' are trademarks originated and owned by Carol Gray.

Social stories can be used to:

- develop self-care skills (e.g. how to clean teeth, wash hands or get dressed), social skills (ego sharing, asking for help, saying thank you, interrupting) and academic abilities
- help someone to understand how others might behave or respond in a particular situation and this is particularly helpful when thinking about the death of somebody and what to expect from others around them
- help others understand the perspective of an autistic person and why they may respond or behave in a particular way
- help a person to cope with changes to routine and unexpected or distressing events (e.g. death, funerals, absence of teacher, moving to a new house, thunderstorms)
- provide positive feedback to a person about an area of strength or achievement in order to develop self-esteem
- create a behavioural strategy (e.g. what to do when angry, how to cope with obsessions)

How do social stories help?

Social stories present information in a literal, 'concrete' way, which may improve a person's understanding of a previously difficult or ambiguous situation or activity. The presentation and content can be adapted to meet different people's needs. They can help with sequencing (what comes next in a series of activities) and 'executive functioning' (planning and organising). By providing information about what might happen in a particular situation, and some guidelines for behaviour, you can increase structure in a person's life and thereby reduce anxiety.

Creating or using a social story can help you to understand how the autistic person perceives different situations.

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EXAMPLE

My toys

My toys belong to me. They are mine.

Many of my toys were given to me.

Some of my toys have my name on them.

I may play with my toys or share them with someone.

I have toys that are mine.

If you feel like you or a child needs support then you may also find it helpful to read stories with them which may help them to understand. Please see the book list attached which details some suggestions you may like to try. You may also find it helpful to visit the following websites which may provide you with further information:

- www.winstonswish.org
- www.cruse.org.uk
- www.childbereavementuk.org
- www.autism.org.uk
- www.youngminds.org.uk
- www.themix.org.uk
- www.seesaw.org.uk

You can also contact our Wellbeing Team for support by emailing wellbeing@havenshospices.org.uk or calling 01702 220321

Sources:
National Autistic Society
Child Bereavement UK
Google Images

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FEELINGS THERMOMETER

5	Rage, Furious	
4	Angry, Mad	
3	Frustrated, Confused, Annoyed, Sad	
2	Nervous, Worried, Anxious	
1	Happy, Calm, Satisfied, Pleased, Okay	

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FEELINGS VOLCANO