



Credit to 'The boy, the mole, the fox and the horse' by Charlie Mackesy (2019).

Supporting Children with Autism to Manage Death, Loss and Grief; A Guide for Parents, Carers & Educational Settings

Birmingham Educational Psychology Team has created this guidance to advise how to best manage bereavement, loss and grief for children with autism during the COVID-19 pandemic. This document should be read alongside the "Managing Death, Loss and Grief" guidelines produced by the Birmingham Educational Psychology Team.

It covers why children with autism may understand grief and loss differently as well as some information on how to support children and young people.

Managing your own needs and emotions



'Put on your own oxygen mask as well as helping your children with theirs'.

In order to support children, it is important that you consider your own support, especially if you are experiencing the death of a close family member. A bereaved family might be isolated together, and although at times this can be a support, at other times tensions and resentments could be magnified making it difficult for everyone to help each other. For more information about managing your own grief please refer to the "Managing Death, Loss and Grief" guidance.

Grief and loss in children and young people with autism

Children and young people with autism may understand and react to loss and grief in different ways; for example, they may experience difficulty regulating their emotions and appear disinterested, angry or may laugh uncontrollably. How children react will be individual to them and does not mean that they are not grieving, more specific strategies may be needed to support the child to manage their bereavement, loss and grief. Further reasons why children and young people with autism may need more specific support strategies following a death include:

- **Change:** death can bring change to a person's life; for example, daily routines can be disrupted. This is something that children with autism may struggle to cope with, and could need extra support when adapting to this change.
- **Understanding emotions:** grief can manifest differently for everyone; some individuals may demonstrate feelings and behaviours which differ from those experienced by the child. The child may require support from adults to understand and interpret the emotions of others as well as their own.
- **Seeking support:** death can bring up feelings and emotions which may be unfamiliar to the child. As a result, they may struggle to regulate these emotions and behaviours. Children with autism can need extra support in knowing how and when to seek support from others.



Supporting children and young people with autism

There is no perfect way, solution or strategy to help children cope with grief. Each family will be different, and each death or loss can be different each time for each child, depending on the situation.

What is important, and makes the difference is open communication, normalising of emotions, and being there and present for your children. Grieving children need support and presence more than advice.

When speaking to children and young people about death and loss, try to:

Think about when would be an appropriate time and who would be best placed to have this conversation with the child.

Use clear, concrete language and avoid the use of euphemisms. Stick to the facts and answer questions honestly. It is ok to say I don't know.

Clearly explain key terminology. Some of the terms around death can be ambiguous. For example, gone to heaven. A child may interpret this as meaning the person has gone somewhere and may expect them to return.

Allow adequate time for the child to process and respond to the information. However, don't expect an answer or response.

Help your child to recognise different emotions and feelings by acknowledging their emotions and validating these feelings. Support your child to display emotions in an appropriate manner where possible.

Try to stick to routines where possible. If a routine will be disrupted, try to give your child prior warning and clearly explain what will happen.

Tools to support your conversations

- Visual pictures expressing different emotions (feeling faces) can be used to support your child to display and understand their emotions and the emotions of others.
- Social stories and comic strip conversations can be used as an effective way of explaining death to your child as well as describing social rituals, such as funerals or ceremonies.

Ideas of activities to support children with autism experiencing bereavement

- Creating a multisensory memory box of reminders of the person who has died. This could include photographs, materials, songs, and items with an associated smell such as perfume.
- Using plants to create a visual life cycle to help your child understand death. Ensuring clear explanations accompany each stage of the visual life cycle.
- Creating a feelings thermometer to help your child to recognise the intensity of their feelings.
- Where children are experiencing emotional dysregulation more frequently or intensely because of the bereavement, it could be helpful to plan and allow time for activities that are calming and have a regulating effect for them, such as preferred sensory toys and physical activities.

Some conversation starters to help you talk about what happened could be:

I have something sad to say; X has died...

Today I am feeling sad because of X dying, how are you feeling?
(using the feeling faces)

It seems like you've had a hard day. I wonder if you are feeling upset about X dying?

To help explain the permanence of death

"X is dead, this means that their body is no longer working and their heart has stopped. A dead body can't move. A dead body can't feel anything so there will be no pain. When someone has died, they can never come back to life again."

Credit to 'Child Bereavement UK' taken from

<https://www.childbereavementuk.org/supporting-a-bereaved-child-with-autism-spectrum-disorder>

Model naming your own emotions and what you are going to do to help yourself feel better, for example 'I feel sad this morning, so I am going to look at my favourite family photos.'

You may want to agree a signal with your child so that they can indicate if they want to talk about the person that has died without having to find the words.

Books to read with children about bereavement, loss and grief

Reading books together can be a useful way to think about death, loss and grief. Some suggested books are below.

- 'I Have a Question about Death: A Book for Children with Autism Spectrum Disorder Or Other Special Needs' by Arlen Grad Gaines and Meredith Englander Polsky (2017)

Useful websites

About social stories and comic strip conversations:

- National Autistic Society <https://www.autism.org.uk/about/strategies/social-stories-comic-strips.aspx>
- A collection of free social stories about death <https://www.andnextcomesl.com/2018/09/free-social-stories-about-death-and-funerals.html>
- Child Bereavement UK <https://www.childbereavementuk.org/supporting-a-bereaved-child-with-autism-spectrum-disorder>

About feeling faces and feeling thermometer:

- National Autistic Society <https://www.autism.org.uk/visualsupports>
- National Center for Pyramid Model Innovations (NCPMI) https://challengingbehavior.cbcs.usf.edu/docs/FeelingFaces_chart_template.pdf

Keep things in perspective. Although it is vital to take the necessary precautions to keep your family and loved ones healthy, REMEMBER to take a deep breath and remind yourself that most people who contract COVID-19 will only experience mild symptoms.

Written by

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Further EPS Support. If you would like any further support or guidance, Birmingham EPS are running a parent telephone consultation service, where you can book in for a 30-minute consultation with an Educational Psychologist. Please contact your school or nursery for details on how to book.