



‘My child is autistic and someone close to them has died. What can I do to help?’

Autistic children need their grief acknowledged and help to express their feelings.

Because of their differences with understanding and showing emotions, processing life events and social interactions and with understanding abstract ideas, they may face different challenges following a bereavement.

Autistic children may find it more difficult to see things from another’s point of view, making it hard for them to understand other people’s feelings and behaviours.

This includes not realising that others can help them with their feelings of grief.



“If you’ve met one individual with autism, you’ve met one individual with autism.”
Dr Stephen Shore, Professor of Special Education, Adelphi University, USA.

As such, it is important to take an individual approach to supporting an autistic child. Support needs to consider how the individual child learns and processes change, what they find tricky and challenging in everyday life and what they are sensitive to.

Bereavement support is best provided by someone who knows the child well and with whom the child has a trusting relationship.

What we know about how autistic people may grieve:

- They may not grieve in the way neurotypical people grieve
- They may want to be quiet and on their own
- They may not want to talk about the person who has died
- They may stim/rock/make noises to self-regulate their emotions
- Their facial expressions may not convey the emotions they’re feeling inside



Existing sensory or emotional needs may become heightened and they may also develop a high interest in death and dying, or a heightened interest in a current key area of interest. Autistic people are also more likely to struggle with the changes in routine associated with funeral rituals and life post-bereavement - so try and keep the child's routine as normal as possible.

When talking to an autistic child about a significant bereavement:

- Talk to the child in a clear honest and direct way with concrete, simple language. Use the words 'dead' and 'died'. Explain that death is permanent and that when someone has died they can never come back to life.

Avoid metaphorical language to describe death eg 'gone up into the clouds', 'is now an angel' or 'is lost'. This figurative language can be confusing for an autistic child, who may interpret things more literally.

- Talk about the facts of the situation and how sad/angry/confused people are due to the bereavement. Explain the emotions that others are likely to be experiencing and that the child may be feeling these emotions too. Visual emotion cards may help them to identify and recognise these feelings.



Helpful framework for this conversation:

“Something very sad happened and xxx died.”

“When a person dies, their body stops working.”

The child/YP needs to be told explicitly why they can't see the person anymore or they will be wondering: where have they gone? What happens to their body? Spell this out.

“People may cry because they feel sad. It is OK to be sad and cry when someone dies.”

“When I think of sad things/feel angry/feel confused, I can do things that might comfort me, such as ...”

“I will feel better over time, as I get used to the new reality without this special person. It might take weeks or months to notice that I am feeling better.”

Other ways to help

Explain to the child that different people will react differently when someone has died. Be clear that there is no right way to grieve - some people like to be quiet and alone, others cry and others like to share memories of the person.

Think about strategies you would use to prepare the child for a change in their normal schedule or to help them understand others' emotions. Eg a social story or comic strip conversation, a visual timetable or checklist, visual emotion cards, sensory breaks, fidget toys. Use these to help talk about the death of the significant person, the changes this will mean for their day-to-day life and the emotions they feel and see in other people.

These resources may be particularly helpful when preparing an autistic child for a funeral.

Autistic people may need longer to process new information, especially when it causes discomfort. So give the child time to process the information you are sharing and listen to their answers.



Be prepared...

Be prepared to answer their questions directly and honestly.

Be aware the child may need to use self-regulation strategies (eg stimming, making repetitive noises, rocking) to support their processing.

Be mindful that avoiding eye contact and/or a lack of verbal response doesn't mean the child is avoiding listening or processing the issue. Conversely, the child may talk a lot about death and incorporate this into their play/drawings. They may ask direct and specific questions about death and dying as a way of processing their bereavement.

Be aware of the child's developmental stage and specific learnings and adapt your language and resources. Bereavement can cause a child to regress emotionally - the child may present as functioning at a 'younger' level when trying to process their grief. Bereavement may also re-awaken or intensify attachment needs.



Make sure other key adults (teachers, therapists, respite care-workers, relatives) in the child's life are aware of the way the bereavement has been explained to the child and mirror this. Share copies of the resources and strategies used to support regulation.

Ensure all adults are aware the child may need enhanced access to a key adult, safe space and quiet time to support the processing of their grief.

Memories

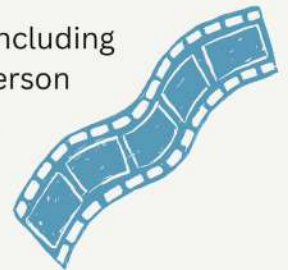
It is important the child knows they can talk about the person who has died and remember things about them. It is also important they know they don't have to talk about them and can come to this in their own time.

It may be helpful to use the child's high interest to help them make and share memories about the person who has died. For example, if a child's high interest is dinosaurs - talk about Dad's favourite dinosaur, a past trip to the dinosaur park with Dad and the dinosaur book/top-trumps/computer game the child shared with Dad.

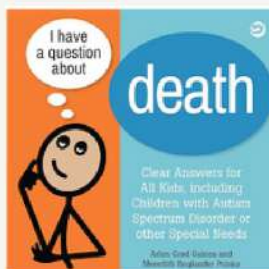


Sensory items may be particularly helpful in supporting the memory process for autistic children. These could include:

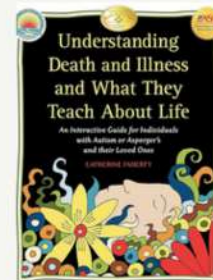
- A piece of fabric from a piece of clothing (eg a fluffy dressing gown) made into a cushion/teddy/blanket - or cut into a small square to carry in a pocket.
- Smelling the washing powder/fabric softener/perfume/aftershave of the dead person on a piece of material.
- Together with the child, creating a memory box of physical reminders, including something relating to the senses eg pictures of the person/things the person enjoyed, a meaningful object or a memory stick with a playlist of music.
- Listening to a voice recording of the person who has died.
- Photographs made into a timeline can help to stimulate memories.



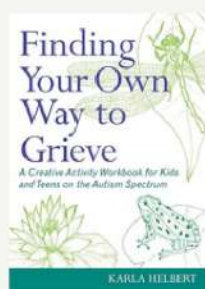
Helpful Resources



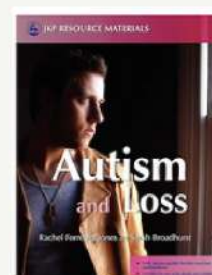
'I have a question about death: clear answers for all kids, including children with autism spectrum disorder.' By Arlen Grad Gaines and Meredith Englander Polsky



'Understanding death and illness and what they teach about life: an interactive guide for individuals with Autism or Asperger's and their loved ones.' By Catherine Faherty (Author) and Gary B Mesibov (Foreword)



'Finding your own way to grieve.'
By Karla Helbert



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