

Explaining death and coping with loss

Everyone will experience the death of a loved one at some point in their lives. Talking about death and dying can be difficult, and it can be hard to know how to best support someone through a loss.

It is important to recognise that everyone experiences the emotions of grief, and needs to be supported through the grieving process. For some people on the autism spectrum, the reactions they display may be delayed, their expressions of grief may differ from what is seen in neuro-typical people, and may include changes to their usual behaviour.

How to help

Here are some of the key things that parents, carers, friends and other support people in the grieving person's life can do to help. As with any person on the autism spectrum, it's best to take a very individual approach, and that the support comes from someone who knows the person well. Knowing a person's individualities and sensitivities makes it easier to work out what may be most difficult for them and how to address it (for example, it may be the lighting in a hospital room, attending a funeral and seeing others cry, or worrying about who will take them to school now).

- **Manage your own expectations:**
 - Don't expect a person on the autism spectrum to demonstrate their grief in the same way as other people.
 - Expect that they may seek solace through isolation rather than social contact.
 - Expect a general increased sensitivity for example, they may be quicker to anger than usual or sensory sensitivities may be amplified.
 - Expect a rise in pre-existing self-stimulatory behaviours (for example, rocking, tapping, flicking) or special interests, both of which can have a calming influence.
 - Don't be afraid if they show an intense interest in the subject of death, and if they seek 'the facts' surrounding a death.

- **Prepare the person on the autism spectrum as much as possible** with an understanding of death and grief. This can help reduce the anxiety that unexplained changes may produce for them when someone does die. Helping someone to understand the abstract concept of death – whilst not a necessary factor in experiencing grief – is also considered to help a person through grief and loss.
- **Explain death in concrete, practical, visual ways**, for example, through using a life-cycle approach with animals. For some people on the autism spectrum it may also be appropriate to explore situations of grief and loss when opportunities arise in everyday life – for example, when a character in a movie dies. Use visual and physical examples to illustrate what being dead means and to explain the irreversibility of death in a way appropriate to the person’s understanding.
- **Use clear, accurate, simple language** when talking about death and when answering any questions that the person on the autism spectrum might have. Avoid using metaphors and euphemisms (for example, “he went to sleep”), because a person on the autism spectrum may take literal interpretations of language, and this can result in confusion and anxiety. Consider also using visual supports to aid the person’s understanding of death and grief (for example, a social story may be appropriate in some situations). Don't be afraid of an interest in seeking 'the facts' surrounding a death.
- **Prepare others** for how the person on the autism spectrum might behave and explain they are not being rude or unfeeling and will be experiencing grief but may be expressing it differently.
- **Maintain routines as much as possible**, as this will help alleviate stress and anxiety, and will reduce the impact of any ‘secondary losses’, which are those subsequent losses that can occur as a result of the death (for example, a person who can no longer go on weekend camping trips because his father, who used to take him, has died). If routines have to change, wherever possible prepare the person on the autism spectrum.
- **Include the grieving person in the rituals surrounding death**, such as the funeral and viewing of the deceased’s body, if possible. Support their understanding of what happens in these social situations by preparing them beforehand. Give them explicit and clear information of what to expect and explain the hidden social rules directly. Visual aids can help prepare a person on the autism spectrum for proceedings, explain death/rituals surrounding death and plan/catalogue events. They can also help with understanding timelines, sequences of events and changes to routine. Calendars and charts can help prepare for hospital visits and put significant events into a wider context.
- **Prepare for participation in social events** such as church services by visiting where it will happen, taking photographs or making a video tour. Plan in advance management tactics, for example identifying who will do what and when. Also have an exit strategy planned in case events do not go as predicted.

March 2017

- **Help the grieving person to learn appropriate coping strategies** to help them through their grief. For example, developing and using a ‘feelings chart’ may help the person identify how they are feeling and what they can do when they have those feelings.
- **Ensure that the person’s usual methods of self-soothing are available** at times that are particularly likely to precipitate distress, anger or anxiety. Listening to audio recordings of the voice or favourite music of the dead person may also be familiar and comforting.
- **Therapy sessions** such as individual counselling or joining a bereavement support group can also help some people on the autism spectrum to cope with their grief and loss.

Resources

“I Have a Question about Death: A Book for Children with Autism Spectrum Disorder or Other Special Needs”, by AG Gaines AG and ME Polsky. Published by Jessica Kingsley Publishers; 2017.

Autism and loss by Rachel Forrester-Jones and Sarah Broadhurst. A complete resource including fact sheets and practical tools suitable for use with adults and children. Published by Jessica Kingsley www.jkp.com; 2007.

Finding your own way to grieve, by Karla Helbert. This is a practical and creative activity workbook for children and young people on the autism spectrum. Published by Jessica Kingsley, London and Philadelphia, 2013.

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

How people with autism grieve and how to help: an insider handbook by Deborah Lipsky, published by Jessica Kingsley, London and Philadelphia, 2013. This book gives a personal account of the author’s own experience of bereavement.

Support for the bereaved and the dying: a guide for managers and staff in services for adults on the autism spectrum by Helen Green Allison. Revised in 2014 and available through the National Autistic Society. www.autism.org.uk/products/core-nas-publications/support-for-the-bereaved-and-the-dying.aspx

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 C Faherty and GB Mesibov. Published by EDS Publications Limited, 2008.

March 2017

References

- Dodd, P., Dowling, S., & Hollins, S. (2005). A review of the emotional, psychiatric and behavioural responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(7), 537-543.
- Hume, K., Regan, T., Megronigle, L., & Rhinehalt, C. (2016). Supporting Students With Autism Spectrum Disorder Through Grief and Loss. *Teaching Exceptional Children, 48*(3), 128-136.
- Koehler, K. (2016). Supporting children and young people with Autism Spectrum Disorder through bereavement. *Bereavement Care, 35*(3), 94-101.
- McEvoy, J., MacHale, R., & Tierney, E. (2012). Concepts of death and perceptions of bereavement in adults with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(2), 191-203.
- Meeusen-van de Kerkhof, R., van Bommel, H., van de Wouw, W., & Maaskant, M. (2006). Perceptions of death and management of grief in people with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities, 3*(2), 95-104.
- Read, S., & Elliott, D. (2007). Exploring a continuum of support for bereaved people with intellectual disabilities: A strategic approach. *Journal of Intellectual Disabilities, 11*(2), 167-181.
- Read, S., Frost, I., Messenger, N., & Oates, S. (1999). Bereavement counselling and support for people with a learning disability: Identifying issues and exploring possibilities. *British Journal of Learning Disabilities, 27*, 99-104.
- Ryan, K., Guerin, S., Dodd, P., & McEvoy, J. (2010). Exploring the experiences of people with intellectual disabilities when service users die. *British Journal of Learning Disabilities, 39*, 259-265.
- Sormanti, M., & Ballan, M. (2011). Strengthening grief support for children with developmental disabilities. *School Psychology International, 32*(2), 179-193.