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**Loss and Bereavement**

Some important things to consider when talking to or supporting an autistic individual when a family member or someone significant to them has died.

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| 1 | **Remember** this could be their first experience of death and they may be totally unprepared as to what to do, how to respond or recognise and manage their feelings. Some autistic people describe physical and sensory reactions initially and delayed emotional responses. Make no assumptions or as few as possible! |
| 2 | Explain what death means using clear, unambiguous language. Avoid using expressions like “passed away” or “gone away to a better place”. You will need to consider the age and understanding of the autistic person or child.  [Carol Gray - Gray’s Guide to Loss, Learning and Children with ASD](https://carolgraysocialstories.com/wp-content/uploads/2015/10/Spring-2003-ISSUE.pdf)  [Pathfinders, PFA Tips, Death and Grieving](https://pathfindersforautism.org/wp-content/uploads/2019/07/Death-and-Grieving.pdf) |
| 3 | Explain what is going to happen next. If it has not been possible for the autistic person to see the person as they were dying, it could be helpful for them to see the body to confirm that the person is not living and breathing and is dead. The Funeral Director could help with this. |
| 4 | Explain about the funeral – cremation or burial and check if they wish to attend or not. Again the Funeral Director can also help with this and you could support your explanations with pictures and other information such as social stories.  [Purple Ella, Autism and Bereavement](https://www.purpleella.com/2018/03/01/autism-and-bereavement/)  [National Autistic Society (NAS) Website](https://www.autism.org.uk/advice-and-guidance/topics/mental-health/bereavement) |
| 5 | Be mindful of the person’s religious beliefs and cultural values and other customs. Talk about these – the funeral service, the “wake” and the buffet or meal after the funeral. This should help to support understanding and resolve confusion or conflicts. |
| 6 | Be mindful of any practical or other consequences from this death e.g. financial worries and try to help resolve these. |
| 7 | Support the autistic person to identify how they are feeling and explain how grief can affect people physically and emotionally. Explain that individuals can experience grief and loss in different ways and some people need a long time to recover. It could be helpful to support this with a social story or some additional information and resources.    Emma Reardon’s article - My Father’s Death |
| 8 | Sometimes when people die, people talk about the person who has died in very glowing positive terms and do not mention any negative aspects. An autistic person could challenge this by speaking honestly and you may need to explain this social convention “of speaking well of the dead” and other social conventions surrounding death and grieving. |
| 9 | You could also support the autistic person by helping them to prepare a memory box, book or poster of the person who has died if they would like to do this. They may wish to remember in a different way. |
| 10 | Life has changed, help the autistic person plan for the future as realistically and positively as possible. |

**And remember** - Bereavements and loss take their toll on all of us. This is a time to take extra care and look after yourself whether you are supporting someone who is grieving or you are also grieving.

Try to eat as healthily as possible, take regular exercise such as a daily walk, get enough sleep and plan time for relaxation and meeting and talking with others (virtually or face to face).

**Be kind to yourselves and seek additional support if you think you need this.**

**Anne Marie McKigney**

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