

# Autism and bereavement

## A guide for parents and carers

**At some point in our life, we will all experience loss. Loss is defined as the state of being without something that we once had. We can experience loss when someone dies, from moving house, from a change in staff or from losing a precious object for example. This information sheet is designed to provide information and advice on supporting autistic people who have experienced loss.**

### How do I know if someone is grieving?

Bereavement is defined as the time after a loss when people experience grief. There is no right or wrong way to grieve, and everyone grieves differently. Some feelings a person who is grieving might experience include:

- Numbness, a feeling of being dazed
- Overwhelming sadness
- Tiredness
- Anger
- Guilt

You might notice the following things in a person who is grieving:

- Crying
- Exhaustion
- They might have headaches, or other aches and pains
- They might have trouble sleeping
- They might lose their appetite
- Worry and anxiety
- Isolation from others

Some autistic people will experience and show some of the things described above. Others will not. This does not mean they are doing it wrong. Each individual will react to loss in a different way. Knowing the individual and knowing about how they have reacted to loss in the past, for example the loss of a pet, moving house, changing school, will help you to have an idea of how they might respond to a major bereavement.

Some individuals may show more pronounced features of autism, like increased repetitive behaviours, more sensory issues, more difficulty communicating with others, or a wish to spend more time alone. Others may not react straight away. It could take days, weeks or even months before they show any signs of grief.

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### How do I support an autistic person who is grieving?

- Use simple and direct language.
- Tell the truth, do not give unnecessary detail. Do not use imagery to explain death.
- Respect the beliefs of the individual and their family.
- Do not expect a response (crying, sadness, aggression). Do not tell them how they should respond. Instead, observe their response and work with them.
- Validate their way of grieving – let them know that it's ok to respond differently to others.
- Answer all questions honestly. It's OK to answer "I don't know". The individual may ask the same questions over and over again, and you should reply each time. Repeating the same question may be the person's way of processing the idea or dealing with the anxiety related to the change. They may also be looking for comfort from a predictable answer to a question.
- Be careful with concepts like:
  - Heaven – a person may want to visit
  - Pain – if you say the person is no longer in pain, and the autistic individual is currently experiencing pain, they may see death as a way of getting rid of the pain.
- Listen to the individual, anticipate their needs, ask them how they feel, be reassuring. It may help to explain the grieving process, without being suggestive. Bear in mind that the individual may not be able to explain how they feel or what they need. Knowing the individual well is crucial to supporting them in a time of bereavement.
- Make sure they have somewhere quiet to go if they need it.
- Some individuals may not know how to react. They might ask you how sad they should feel and whether they should cry. Some responses might be seen as inappropriate (like giggling at a funeral) but should be seen as the individual's way of coping with the situation.
- Be aware that unusual behaviour could still be due to things like pain and illness. Grief can also cause physical symptoms which should not be ignored.
- Support the individual take care of their physical body (diet, exercise, sleep).
- Encourage them to spend time on their special interests.

The feelings experienced during the grieving process are a natural part of dealing with loss. However, you should ask for help if you think that the individual you are supporting is showing signs of depression, or if the intense emotions are not going away. If you need any support, speaking to a GP is a good place to start.

The most important thing to remember is that every person is different and there is no right or wrong way to grieve. Knowing the individual and how autism affects them is crucial to providing support in difficult times.