

PFA Tips

Death and Grieving

The loss of a loved one is difficult, and complex. We experience a mixture of emotions, we don't all share the same beliefs of what happens to us when we die, funerals may be different depending on religious and other beliefs, and it's not something we may prepare ourselves for. So how do we explain death, funerals, and loss to our children with autism?

Don't avoid talking about it. Explain it as fully as possible. Your child's misinterpretation might be worse than reality.

Provide as clear an explanation as possible about the death of a loved one, as well as multiple opportunities to talk about it. This might help your child to avoid misconceptions about the "missing person." For example, your child might think that the person they love is gone for other reasons, such as the person doesn't love the child anymore and has left her.

Use social stories to describe the viewing or funeral

Ask your child's speech therapist or teacher to help write a social story. You may want to draft a basic story to have on hand so that you are not trying to pull one together during such an emotionally trying time. The story should include significant details (e.g., what the casket will look like, what the body will look like, that people will be crying).

Teaching before loss occurs

If the opportunity presents itself (e.g., a co-worker dies), it might be a good chance to talk about death before a child must encounter the loss of someone very close to him. Let your child see your natural emotional responses. If your child is old enough and is able to handle it, consider having the child attend the wake or funeral.

Look for everyday examples

Another way to help your child understand death prior to the loss of a significant loved one is to explain that death is part of the natural cycle of life. You can use examples as

simple as finding a dead fly on your window sill, or the death of a famous person that you read about in the newspaper.

We can remember

Help your child understand that even though he will not be able to visit or speak to a loved one, it is ok to talk about the person. Give him or her multiple opportunities to talk about the person, his feelings, etc. Share some of your own thoughts and feelings, look together at pictures, and tell stories about the person. Some parents worry that their child should talk about it. Avoid creating this pressure for you or your child. It sometimes takes a long time for a child to realize their loved one is gone, so your child might want to talk about it at a much later time.

We grieve for all we love

Feelings of grief are not reserved just for people. We may experience the same sense of grief over the death of a cherished pet that we experience for the loss of a friend or family member.

Death as a concrete term

Death is a complicated concept to grasp, especially for people that have difficulty understanding abstract ideas. Try to make the concept of death as concrete as possible. You can let your child know that death means that the person can no longer breathe, walk around, eat, etc.

Begin with the illness

If a family member is terminally ill and getting worse, you may choose to begin to prepare your child for a possible death.



Avoid euphemisms

Using terms such as, "going to sleep", or "passing away" can be confusing for someone who interprets most language literally. If your belief system includes Heaven, help your child understand that Heaven is not a place that you can simply drive to (like New York). Otherwise, your child might become frustrated that his loved one is simply in a different place, but not communicating or visiting.

Everyone expresses grief differently

Explain to your child that different people will react differently when someone has died. Some people cry, some become silent, some feel the need to talk about the person, while others may choose to write about their feelings. Reassure your child that there is no set way to grieve and that she may grieve how she chooses.

Provide your child with reassurance

If someone close to your child dies, your child might become fearful that he will also lose you. He might benefit from receiving

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reasonable reassurance that you're still there to take care of him and that there are other people as well who can help. Be careful to monitor that over time, seeking reassurance does not become "compulsive or perseverative".

Avoid protecting your child "too much"

As parents, we naturally want to shield our children from things we know make them feel sad or that we believe are emotionally too difficult. If possible, include them in the funeral process. This might allow them the concrete experience that could help them grieve and give them a final chance to say goodbye.

Try to keep other aspects of life as consistent as possible

As we know, children with Autism Spectrum Disorders can have significant difficulty when their anticipated schedules change. As soon as it is possible, try to have your child resume normal activities. This can help decrease general anxiety which can compound feelings of loss.

Additional Resources

A Sample Social Story for Death and Grieving

<http://pathfindersforautism.org/wp-content/uploads/2017/01/social-story-about-death-and-grieving.pdf>

How People With Autism Grieve, and How to Help: An Insider Handbook by Deborah Lipsky

Available on Amazon

Gray's Guide to Loss, Learning, and Children with ASD by Carol Gray

<https://carolgraysocialstories.com/wp-content/uploads/2015/10/Spring-2003-ISSUE.pdf>

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

Available on Amazon

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