

Helping Children with Autism Understand Grief and Loss



Sarah Helton, MEd

While many people associate the word “grief” with bereavement, it relates to more than just death. We can also grieve the loss of a possession, situation, opportunity or routine. Grief affects all of us. Sadly, the grief of children with autism can often be overlooked or ignored. In this article, I will highlight how grief and loss can affect autistic children, and how we can support them.

The Cause of Grief

Children can grieve for any number of reasons. They could experience the death of a family member, friend or pet, the separation or divorce of their parents, or the loss of something that is significant to them, such as a resource, toy or belonging. They may grieve having to move house, when important people like teachers move away, or if their mother has a miscarriage or stillbirth. If a family member becomes seriously ill, or a parent is away for long periods of time due to work, military service or other reasons, children may grieve for the relationship that they used to have. They may experience grief following the death of a favorite television character or the breakup of a music group. For some children, changes in routines and significant transitions can result in grief. They want things to go back to the way they were.

Communicating Grief

Grief can be communicated in a wide range of ways. In general, we can divide such communication into four broad categories: verbal; nonverbal; augmentative and alternative; and creative.

VERBAL



If children have the verbal language skills to do so, they may express their thoughts and concerns through spoken words. They may ask questions about what has happened. However, you should be prepared for the fact that they may not express their emotions in the way you expect. Rather than saying how sad they are that cousin Charlie has died, they may instead say that they are going to miss going swimming on Thursdays as this is something they did with Charlie. They may ask questions about how and why Charlie died. Such comments and questions all show that they have thought about how Charlie's death will affect them. They need answers to these questions in order to reassure them.

Reassurance is key to supporting bereaved children. Grieving children need reassurance that the death was not their fault, and that not everyone they love is going to suddenly die.

NONVERBAL



Children with limited verbal communication skills will show their grief through nonverbal means. It is worth noting that even a child with verbal language may also communicate grief nonverbally. Grief may be expressed through changes in eating, drinking and sleeping patterns, as well as behaviors, body language, facial expressions and vocalizations.

We know our children well, and any deviation from their usual behavior could be the result of a change in their emotional state. We must not dismiss these differences or attribute them to a child's autism diagnosis. Instead, we need to notice and investigate the different behaviors that children are displaying. Are they a sign that children are struggling with the changes that have occurred in their life as a result of a bereavement or other loss? Is their internal grief being shown through these nonverbal expressions?

Think back to a loss you have experienced. How did your behavior and nonverbal communication change? Did you find yourself losing sleep, not wanting to eat or slamming doors? Why would it be any different for children with autism?

AUGMENTATIVE AND ALTERNATIVE



Some children may ask questions and communicate their grief through Augmentative and Alternative Communication (AAC). AAC covers communication that supplements or replaces speech or writing. This form of communication can only happen, however, if the vocabulary related to emotions, life, death and grief has been taught to them and included in their AAC. This vocabulary needs to be developed over time so that it is ready for them to use when they do experience grief. While these words can be added and taught to children at the time of need, it is better for them to learn these words and concepts before they are needed. For example, they can learn the words, symbols or signs for alive and dead during a science lesson about plants or when reading a story about the death of a person's pet dog.

CREATIVE



Some children communicate their grief through creative outlets. They express how they are feeling through art, music, drama and play. These are all excellent means for them to explore what has happened to them, how things have changed and how this makes them feel. Providing a grieving child with art resources and play items to express their grief can help them ask questions and share how they are feeling in a less direct and more informal manner.

How to Support Grieving Children With Autism

There are many ways that we can support children who are grieving. We can be honest with them and speak to them at their level of understanding. Try to answer their questions, however strange they may appear to you. Recognize that they are experiencing a genuine concern that needs to be addressed. Be sure to use the words dying, death and dead, rather than euphemisms, such as passed away, since the latter can confuse children. Acknowledge and validate the child's feelings, and don't try to minimize those feelings.

You can also share your own experiences of grief to help children understand what they are feeling. This allows you to be a good grief role model. In addition, recognize that children can experience grief for a wide variety of reasons. It doesn't matter what causes the grief; we need to support it in the same manner.

Think about grief as a transition. Just as we support children with autism in day-to-day transitions, such as moving from playing to getting ready for bed, the changes that occur as a result of a grief experience need to be managed in a similar way. If you know that such an event is going to happen, prepare in advance and make a plan. If it is an unexpected loss, respond to the changes as quickly as possible and keep things the same as much as you can.

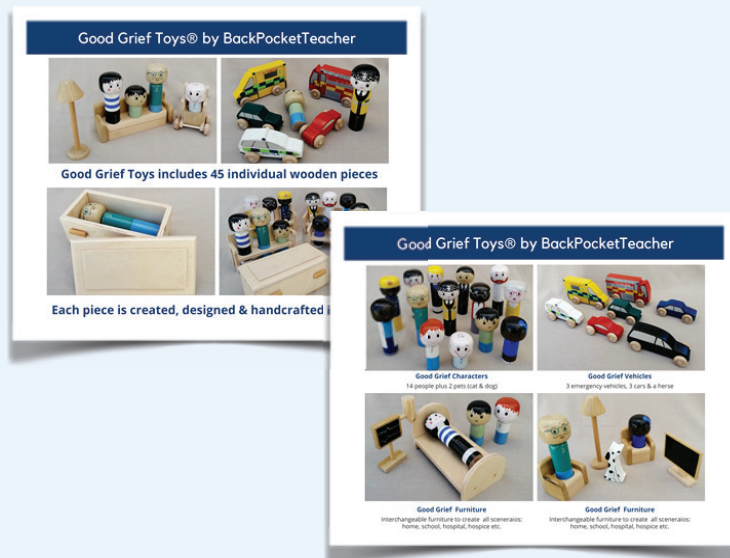
For example if the grandparents are moving away, consider all of the impacts that this will have on your children's life. If grandma always took them to school, let them know that you will now be taking them. If they worry that they'll never see grandma and granddad again, explain that they aren't leaving completely. They will still see them once a week on FaceTime, the family will visit them in their new house every summer, and their grandparents will come and stay each Christmas.

You could also support these changes by preparing a visual plan or social story for your children.

In the end, it is worth remembering that loss, bereavement and grief are a part of all of our lives. It is vital that we teach our children about these concepts as we help them develop essential life skills that they need for independent living.

Resources

Good Grief Toys® are a set of 45 individually crafted, multifunctional pieces allowing children to explore all forms of grief (death, divorce, illness, moving house, moving school, etc.). <https://backpocketteacher.co.uk/books-%26-resources>



Widgit Bereavement & Loss Symbol Resources are available at [Widgit Symbol Resources | Bereavement and Loss](#). This resource provides simple explanations supported by visual symbols - pictorial representations to aid understanding of death, bereavement and grief.



Sarah Helton, MEd, has worked in the Special Educational Needs/Disabilities (SEND) field for nearly 25 years and has an outstanding track record in a diverse range of roles (Deputy Head, Assistant Head, Teacher, Local Authority Education Officer and Educational Publisher).

She now works as BackPocketTeacher - an author, trainer and consultant in the field of child bereavement, specializing in the (sadly often overlooked) needs of bereaved children with SEND. Autumn 2020 Sarah began studying for a PhD alongside her work as BackPocketTeacher. She will be researching bereavement and SEND. Follow her studies via this website, the [BackPocketTeacher Blog](#), on Twitter [@backpocketteach](#) and Facebook [@BackPocketTeacher](#).

Sarah also works as a training facilitator for the national child bereavement charities [Winston's Wish](#) and [Child Bereavement UK](#).

Email: backpocketteacher@gmail.com
Website: www.backpocketteacher.co.uk
Twitter: [@backpocketteach](#)
Facebook: [@BackPocketTeacher](#)
LinkedIn: www.linkedin.com/in/sarah-helton/

For information only. Views, recommendations, findings and opinions are those of the author and do not necessarily reflect the opinion of Autism Advocate Parenting Magazine Inc. or anyone otherwise involved in the magazine. The magazine and others are not responsible for any errors, inaccuracies or omissions in this content. The magazine provides no guarantees, warranties, conditions or representations, and will not be liable with respect to this content. Please read our full terms [here](#).