

Supporting Autistic Youth Experiencing Grief and Loss: Tip Sheet for Caregivers



WHAT TYPES OF LOSS MIGHT CAUSE AN AUTISTIC YOUTH TO EXPERIENCE GRIEF?

Unfortunately, experiencing loss and grief is a part of life, and at one point or another, everyone experiences some type of loss. It is important to recognize that there are different types of losses, and everyone reacts to loss differently. Loss of a favorite toy, the opportunity for a routine activity, moving to a new school or home, or losing a friend, loved one, or animal companion can all cause significant sadness and grief for youth, including youth on the autism spectrum.

EMOTIONAL AND BEHAVIORAL RESPONSES TO GRIEF AND LOSS

It is important to recognize that an individuals' responses to grief and loss can vary greatly. Some may respond with anger, others may cry, some may seek out social connection, whereas others may withdraw and prefer to be alone. Additionally, experiencing grief and loss can impact youths' social, emotional, and cognitive functioning, making it difficult for them to focus and attend to instruction, interact with others, and regulate their emotional and behavioral responses.

Autistic children and adolescents may present with similar or different emotional and/or behavioral responses to grief and loss. For some autistic youth, they might express their emotions differently than expected. For example, an autistic child might laugh when experiencing grief. It is important to recognize that just because an autistic youth is responding differently than what may be expected, they are still experiencing grief and sadness.

Changes in child or adolescent behavior immediately after a stressful life event or loss should be expected. However, if changes in behavior persist several months after the event, reach out to your child's school counselor or school psychologist for additional support

Different emotional and behavioral responses
» Laughing or smiling instead of crying
Varied intensity of emotional and behavioral responses
» Having a flat affect and showing no change in emotions or behaviors
» Demonstrating significant emotional and/or behavioral responses, such as aggression or frequent crying

POTENTIAL CHALLENGES FOR AUTISTIC YOUTH EXPERIENCING GRIEF AND LOSS

It is important to recognize that when autistic youth respond differently than expected in a situation, that difference in response is influenced by the characteristics of autism and the social communication and behavioral differences experienced by the youth.

Here are some potential challenges that autistic youth facing loss and grief may experience:
<p>Understanding the emotions or feelings of others impacted by the loss</p> <ul style="list-style-type: none"> » Asking questions or making comments at times that may not be socially appropriate » Asking a parent who has just gone through a divorce why they are crying
<p>Knowing and understanding “hidden” social rules around how to respond</p> <ul style="list-style-type: none"> » Not knowing how to behave at a wake or funeral » Voicing to family members or friends at a funeral, negative, yet true, memories or qualities of the person who has died
<p>Recognizing that a change in routine due to a loss is causing sadness, anger, and/or frustration for them and that it is normal to experience those feelings</p> <ul style="list-style-type: none"> » Asking questions repeatedly about what happened to gain reassurance, especially when there is a change in routine or there are feelings of sadness, worry, and/or anger
<p>Experiencing confusion around specific aspects of the situation or loss</p> <ul style="list-style-type: none"> » Not being told developmentally appropriate information about the situation, thereby experiencing confusion and lack of understanding » Not understanding the permanency of death and thinking their loved one will eventually return

RESOURCES TO SUPPORT AUTISTIC YOUTH EXPERIENCING GRIEF AND LOSS

An introduction to social narratives for supporting autistic youth experiencing grief and loss

Social narratives are visual stories which describe various social situations, expected social behaviors, and when these behaviors should be displayed. Social narratives can be effective with autistic individuals for addressing difficulties with interfering behavior, communication, social skills, academic readiness, adaptive skills, and attention (Wong et al., 2014).

TRIAD has developed the following Grief and Loss social narrative templates for families and educators to support autistic youth experiencing the following situations:

- » death of a loved one,
- » school shooting,
- » natural disaster, and
- » parental divorce.

Before using these social narrative templates with your child, please review the next few sections that share some important tips for implementation. At the end of this resource, you will find some additional considerations and strategies for supporting autistic youth experiencing various types of grief and loss.

Implementing Grief and Loss Social Narratives

For social narratives to be effective for autistic youth, it is important that they are individualized, to the extent possible, for a youth's specific situation. Please see the following guidelines for individualizing TRIAD's Grief and Loss social narrative templates.

- » Familiarize yourself with the steps for writing social narratives by downloading the tip sheet on how to write social narratives: <https://bit.ly/49doxZY>
- » Look through the social narrative template and using the guidelines for creating social narratives (see tip sheet link above), modify the language to fit the circumstances for your student. Be sure to look at the notes section below each slide for additional instructions when individualizing the social narrative.

Social narratives work best when they include more descriptive than directive statements (two descriptive statements for every one directive statement). Descriptive statements share facts and feelings. Directive statements direct behavior or an individual's responses to situations.

- » Be sure to gather appropriate information about the relevant details of the situation before attempting to individualize the social narrative.
- » If using pictures or visuals, be sure to include pictures that are representative for your child, both in terms of developmental level and specifics of the event the social narrative is describing.
- » Make sure the level of language used in the social narrative is appropriate for your child's language level.
- » Identify any background knowledge or information your child may need to know to support their understanding of the social narrative.

ADDITIONAL CONSIDERATIONS AND RESOURCES FOR WAYS TO SUPPORT AUTISTIC YOUTH EXPERIENCING GRIEF AND LOSS

❑ Death of a Loved One

Whether a child loses a family member or a beloved pet, the death of a loved one can cause significant grief. In addition to using TRIAD's *Death of a Loved One* social narrative with your child or adolescent, here are some other considerations and resources for supporting autistic youth experiencing the death of a loved one:

Considerations and Resources for Supporting Autistic Youth Experiencing the Death of a Loved One	
Elementary-Aged Considerations:	Middle/High School-Aged Considerations:
<ul style="list-style-type: none"> » Stick to routines as often as possible, as routines provide consistency and predictability, especially during times of significant change. » Provide clear, concrete, and developmentally appropriate information about death. Using books and videos can be helpful to support understanding. » Try to make the concept of death as concrete as possible. Avoid euphemisms or phrases such as “going to sleep” or “passing away” to explain death or dying. 	<ul style="list-style-type: none"> » Check in with your adolescent often and notice changes in their behavior that may signal they are having difficulty. » Provide opportunities for your adolescent to express their feelings and thoughts in whatever way is most appropriate and comfortable for them. » Explain to your adolescent that everyone experiences grief differently and that there is no wrong way to grieve, unless it causes harm to themselves or others.

Additional resources for talking to autistic youth about the death of a loved one	
How to Talk to Your Child with Special Needs About Death (Friendship Circle)	https://bit.ly/3uzVYXC
Understanding Death and Illness and What They Teach about Life (Catherine Faherty)	https://bit.ly/49fkjqW
Bereavement and Autism Spectrum Disorders (National Autistic Society)	https://bit.ly/48ffYMT
Finding Your Own Way to Grieve: A Creative Activity Workbook for Kids and Teens on the Autism Spectrum (Karla Helbert)	https://amzn.to/49ex9zx
Autism and Grief Project	www.autismandgrief.org

❑ School Shooting

Tragic events, such as school shootings, unfortunately occur, and youth can be exposed to them directly or indirectly. Hearing about a school shooting, whether it has happened in your community or not, can cause increased anxiety and feelings of loss or grief for any individual. In addition to using TRIAD's *Experiencing a School Shooting* social narrative with your child or adolescent, below are some other considerations and resources for supporting autistic youth who have experienced or heard about a school shooting.

Considerations and Resources for Supporting Autistic Youth Who Have Experienced a School Shooting	
Elementary-Aged Considerations:	Middle/High School-Aged Considerations:
<ul style="list-style-type: none"> » Talk about the event by offering simple facts that are developmentally appropriate and avoid sharing unnecessary details. » Acknowledge their fears and let your child know they can share their feelings with you and ask you questions. » Reinforce ideas of safety and security. Share what their school and the community is doing to increase safety. 	<ul style="list-style-type: none"> » Encourage your adolescent to ask questions about the event and answer those questions directly using developmentally appropriate language. » Correct any misconceptions or inaccurate information shared by your adolescent. » Be patient with yourself and your adolescent. Recognize that the incident may impact their behavior, attention, and concentration both at home and at school. Remind your adolescent that if they have any concerns, share them with you.

Additional resources for talking to autistic youth about a school shooting	
Helping Youth After Community Trauma (National Child Traumatic Stress Network)	https://bit.ly/3SXC16f
Helping Children with Disabilities Cope with Disaster and Traumatic Events (Centers for Disease Control and Prevention)	https://bit.ly/3uw5hb0
Helping a Child with Autism Deal with Disaster (Autism Speaks)	https://bit.ly/3UEvRsT
Restoring a Sense of Safety in the Aftermath of a Mass Shooting: Tips for Parents and Professionals (Center for the Study of Traumatic Stress)	https://bit.ly/49y0CEb

❑ Natural Disaster

Natural disasters can be unpredictable and range in impact depending on your location. Often these situations can be chaotic and call for immediate action. Experiencing a natural disaster can be distressing for autistic youth who may dislike having no control over a situation that is, by nature, out of our control. In addition to using TRIAD's *Following a Natural Disaster* social narrative with your child or adolescent, here are some other considerations and resources for supporting autistic youth who have experienced a natural disaster.

Considerations and Resources for Supporting Autistic Youth Experiencing a Natural Disaster

Elementary-Aged Considerations:

- » Prepare your child ahead of time by explaining what natural disasters may commonly occur in your area and why they occur. Acknowledge that these events can feel scary even if they are natural.
- » Involve your child in creating a visual for steps to take at home in the case of a natural disaster (e.g., steps to take in case of a fire) and practice the steps together.
- » Allow your child to have access to objects (e.g., fidget toys, headphones, etc.) to help them remain calm.

Middle/High School-Aged Considerations:

- » Make sure your adolescent understands how to respond in the case of a natural disaster and ensure that these methods will make them as safe as possible.
- » Provide opportunities for your adolescent to share about the impact a natural disaster had on them. Allow them to express their feelings and thoughts in whatever way is most appropriate and comfortable for them.
- » Discuss options for your adolescent to volunteer in their community, such as cleanup or helping at shelters. This can help them gain a sense of control.

Additional resources for talking to autistic youth about natural disasters

Natural Disaster Resources (Autism Speaks)

<https://bit.ly/3SXRqDO>

Person-Centered Emergency Preparedness (P-CEP) Workbook

<https://bit.ly/48fhnmd>

□ Parental Divorce

Although there are situations in which both caregivers are still part of a child’s or adolescent’s life, divorce can bring a new kind of loss – a loss of normalcy. The amount of change to a youth’s routine will vary case by case, but it can still be difficult for autistic youth to adjust to their new “normal.” In addition to using TRIAD’s *Dealing with Divorce* social narrative with your child or adolescent, here are some other considerations and resources for supporting autistic youth dealing with parental divorce:

Considerations and Resources for Supporting Autistic Youth Dealing with Parental Divorce	
Elementary-Aged Considerations:	Middle/High School-Aged Considerations:
<ul style="list-style-type: none"> » Stick to routines as often as possible, as routines provide consistency and predictability especially during times of significant change. » Provide resources, such as picture books, that demonstrate family dynamics that mirror your own. » Assure your child that this change does not impact the relationship they have with you. Even if it takes consistent reassurance, it is important for them to understand that they will always be loved. 	<ul style="list-style-type: none"> » Limit adult conversations about the divorce to when your adolescent is not present. » Provide opportunities for your adolescent to share how they are feeling about the change in your family. Sometimes it helps to talk about big changes, such as having more living arrangements than before. » Allow your adolescent time to adjust. Recognize that this may impact your adolescent’s behavior, attention, and concentration both at home and in the classroom, depending on the nature of the divorce.

Additional resources for talking to autistic students about divorce	
Telling Your Kids You’re Getting a Divorce (Pathfinders for Autism)	https://bit.ly/42AEd73
How to Help Your Autistic Child Cope with Their Parents’ Divorce (Stages Learning)	https://bit.ly/3wfBHHf
For Teens: Dealing with Divorce (Kids Health)	https://bit.ly/48hChSa
For Kids: Coping with Divorce (Kids Health)	https://bit.ly/3Sy8M8K
Dinosaurs Divorce: A Guide for Changing Families (Laurene Krasny Brown & Marc Brown)	https://a.co/d/bNNbsBg

ADDITIONAL TRIAD RESOURCES

- Grief and Loss Overview Tip Sheet for Educators
- Grief and Loss Overview Tip Sheet for Caregivers
- Experiencing a School Shooting: Social Narrative Template
- Learning about a School Shooting: Social Narrative Template
- Following a Natural Disaster: Social Narrative Template
- Dealing with Divorce: Social Story Narrative Template
- Death of a Loved One: Social Story Narrative Template