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Special Education Service Agency Newsletter



In This Issue:

Letter from the Editor

Helping Your Student with Cognitive Impairments or Multiple Disabilities Deal with Grief and Loss

Helping Your Student with Vision Impairment Deal with Grief and Loss Helping Your Student with Autism Spectrum Disorder Deal with Grief Measuring the Impact of Grief Grief and Loss Library Resources

NEW! SESA Online Forum!

Letter from the Editor Jennifer Schroeder, SESA Multiple Disability Specialist

Dealing with grief and loss is something that is challenging for all of us. It can be especially hard for young children and people with disabilities because they do not always understand what is happening. This is true whether the loss is of a pet, a family member, or if a good friend moves away. When we look at loss, it is not always because someone has died. Your students may experience grief because someone or something that they love is no longer physically present or because a relationship has changed.

It is important that we help our students, no matter what their disability, to make sense of their feelings and emotions when this happens. For many students, just having the vocabulary to talk about how they feel can be helpful. Others may need things broken down into much more concrete terms, or may require frequent discussions about their loss and about what they can do in order to move past it. No matter what a person's cognitive, academic, social, medical, or emotional ability is, they will feel grief and loss at some point in their life. Having the necessary tools to handle it, as well as having people in their lives that recognize the behaviors that might manifest, can make a world of difference in how our students process their individual feelings.

Jennifer Schroeder

Helping Your Student with Cognitive Impairments or Multiple Disabilities Deal with Grief and Loss Julie Burger and Meriah Cory, SESA Multiple Disability Specialists

Grief and loss can be hard to deal with; it can be scary to think and talk about. Grief is a subject that our society does not easily talk about and people often feel embarrassed by the emotions and behaviors that can come up while someone is working through the grieving process. It is even harder to deal with when a person does not have a reliable communication system or when the grieving process is not explained. Many times, our students do not understand why they are having so many hard and scary emotions.

It is important to talk with the person about what has happened and be direct, but compassionate. Make sure to meet the person where they are at (both cognitively and emotionally) and use language that is meaningful and understandable.

Work with the person to build their communication so that they have a way to express what they are feeling and talk about the loss.

Always remember that everyone deals with loss differently, so not everything is going to work for everyone. Watch and listen to the person you are working with and then take into consideration some of these pointers:

Be Honest: Talk about what happened in language your student understands; do not use idioms that might be hard to understand.

Listen: Teach communication, verbal, gestures, signs and then take the time to really listen.

Prepare: Read social stories or other books that can illustrate what may come next, such as funerals, burials, or being separated from a loved one.

Respect Photos and Other Mementos: Even if they are upsetting, do not just remove these items. **Minimize Change:** Routines are great and while one needs to be sensitive, continuing with basic routines can be a comfort.

Avoid Assessment of Skills: During the initial grief, do not focus on the student's academics. Allow the student to work on familiar and comfortable activities and build back up.

Support the Observance of Anniversaries: Even though reminders can be hard and may bring up some unwanted behaviors, they should not be avoided.

Finally, a couple of great resources on grief:

<u>Supporting People with Disabilities Coping with Grief and Loss</u>

<u>5 Children's Books that Deal with Death, Loss, and Grief</u>

Helping Your Student with Vision Impairment Deal with Grief and Loss Angel Black, SESA Vision Impairment Specialist

When dealing with loss and grief, children with low vision and/or blindness deal with their feelings much like everyone else. The steps to help these students cope may include: teaching them that death is a natural part of life, being completely honest about what has happened, not delaying in sharing with the child about the death, answering their questions, and teaching the child to cherish the memories of the person they have lost. For a child with blindness/low vision this may be difficult, especially if they are not able to see a photo album or pictures of their loved one. But there is a way to help them save their memories. Help them create a tactual memory book.

- 1. If possible, use laminated paper that can be bound or kept together with rings. Or, heavy fabric that can be sewn together.
- 2. Gather items that represent the loved one, and/or items that actually belonged to that person. For example, a necklace, a piece of fabric or button from a favorite shirt, create a snowflake out of a pipe cleaner for the person who loved snow, a puzzle piece to represent a person who loved putting puzzle's together, add a favorite poem or song written in Braille or large print, cut an apple tree out of sandpaper and add felt apples for the person who loved sitting under an apple tree to read a good book. The only limitation is your imagination.
- 3. Glue all items with hot glue to your book surface.
- 4. Give the memory book a name.

Encourage the child to sit and "look" at their memory book when they find themselves missing their loved one or when they just want to take a walk down memory lane.

Helping Your Student with Autism Spectrum Disorder Deal with Grief

Samantha Weiland, SESA Autism Specialist

Students with autism may have different perceptions on social standards, however they will still experience grief over a lost one in their lifetime. It is important to recognize that individuals with autism will go through the stage of grief. Hiding the fact that someone has passed away or saying that the person is "resting" is not beneficial because it can create confusion and possibly anger for individuals with autism. Each individual with autism will respond differently during the grieving process whether they increase in self-stimulating behavior, increase in sensory overload, may appear overly calm, become increasingly angry, display typical behaviors, or even display new behaviors.

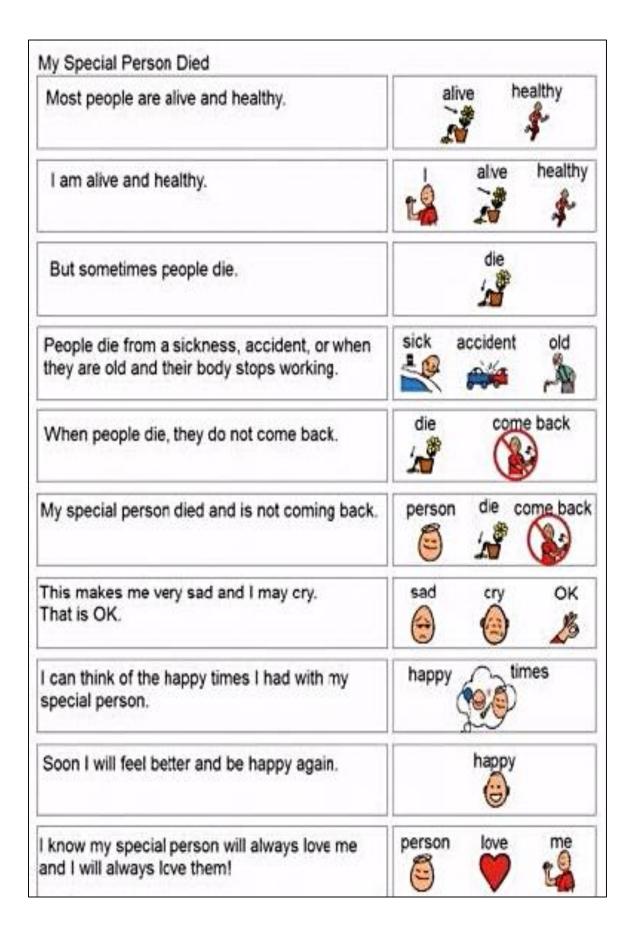
Strategies:

- Reassure the student based on their developmental level with concise concrete words. Do not use phrases like, "They have gone to a better place", etc.
- Continue daily routine to keep predictability, remember students with autism have difficulty with change. The student will already be experiencing change with the loss of a loved one. The daily routine will provide a source of comfort and stability for the individual.
- Provide the individual with concrete videos and/or books about death that are developmentally appropriate. For example: I Miss You: A First Look at Death by Pat Thomas
- Social stories that provide visuals related to death. For example, showing a picture of the
 deceased individual, the place that the funeral services take place, the emotions people will
 feel when grieving.

For additional resources on individuals dealing with loss and grief:

<u>Supporting Individuals on the Autism Spectrum Coping with Grief and Loss Bereavement and Grief Resources</u>

<u>Parent Tips: Death and Grieving</u>



Measuring the Impact of Grief Lyon Johnson, SESA Emotional Disability Specialist

Feelings of grief can surface for a variety of reasons, including loss of loved ones, friends or acquaintances, and other major life transitions (e.g., divorce, moving, etc.). It is important to recognize what are "typical" expressions of grief for different ages and what is something more (see SESA Library for grief resources). As adults reading this article, we might be able to define what grief means for us (e.g., inward thinking, emotional pain, sadness, etc.), but a student's reactions to loss are expressed often quite differently depending on the age. How one expresses grief can be influenced by a number of factors. Grief can be a very challenging life experience for anyone, but especially for younger students who have less life experience dealing with loss. Young children might experience increased anxiety, which manifests itself in regressive behaviors and decreased verbalization. Elementary age children express grief differently, but common symptoms include: Guilt, depression, attention/concentration problems, irritability, and changes in eating or sleeping patterns. Behaviorally, elementary students may verbalize bodily aches and pains (with no known causes), socially withdrawal, or engage in disruptive and even aggressive behavior. Middle and high school aged students could experience the same symptoms of grief, but also demonstrate other problematic behaviors, including avoidance behaviors, high absenteeism, peer problems, and high risk behaviors, such as substance abuse (NASP, 2015). The combination of age and life experience certainly impact how grief is expressed.

So, what can be done when a student experiences a developmental, physical, or an emotional/behavioral disability experiences grief? It is important to be mindful of how the disability typically impacted the student prior to the event leading to loss and grief. Experiencing loss is certainly a significant "setting event," which can make ongoing problem behavior worse and result in grief responses as described above. In Issue #2 of the SESA Newsletter, I wrote an article that described the steps in creating a function-based intervention plan and then how to monitor student progress. This approach certainly applies. If you are concerned about the impact of grief on a student's well-being and learning, a helpful first approach is to define and then develop a way to measure the behavior over time. The objective is to measure the behaviors that are associated with the recent impact of grief (e.g., low academic engagement, decreased work production, not joining peers, absenteeism, etc.). Hopefully, implementing positive behavior supports and interventions will result in a decrease in maladaptive behaviors and an increase in pro-social or adaptive coping behaviors over time. At SESA, the students we serve should have specific plans to monitor progress toward IEP goals and objectives (e.g., communication, social, behavioral or academic). If progress monitoring measures are sensitive to change, then graphing student behavior on a line graph, may help determine if the symptoms of grieving are adversely impacting the student progress. Such progress monitoring data can also be extremely helpful to health professionals working with students and families. Hopefully, this article expands the readers understanding of how the impact of grief responses on students can be monitored and addressed from a behavioral perspective.

Grief and Loss Library Resources Anne Freitag, SESA Librarian

For more information on any of the titles listed below or questions about the SESA Lending Library, please contact:

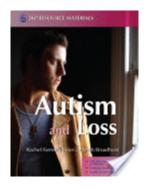
Anne Freitag, SESA Librarian.



After a Loved One Dies - How Children Grieve: and how parents and other adults can support them / by David J. Schonfeld and Marcia Quackenbush. New York Life Foundation, c2009.

Description: The death of a loved one is difficult for everyone. Children feel the loss strongly. Parents are coping with their own grief. If a parent dies, the surviving parent faces the new responsibility of caring for the

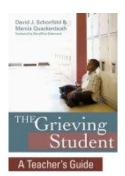
children alone. Grandparents, aunts, uncles, and family friends are affected, too. Also available <u>online</u>.



Autism and Loss / Rachel Forrester-Jones and Sarah Broadhurst. Jessica Kingsley Publishers, 2007.

Description: "People with autism often experience difficulty in understanding and expressing their emotions and react to losses in different ways or in ways that carers do not understand. In order to provide effective support, carers need to have the understanding, the skills and appropriate resources to work through these emotional reactions with them. Autism and Loss is a complete resource that covers a variety of kinds of loss, including bereavement, loss of friends or staff,

loss of home or possessions and loss of health. Rooted in the latest research on loss and autism, yet written in an accessible style, the resource includes a wealth of factsheets and practical tools that provide formal and informal carers with authoritative, tried and tested guidance."--Publisher's website.



The Grieving Student : A Teacher's Guide / by David J. Schonfeld and Marcia Quackenbush. Paul H. Brookes Pub. Co., c2010.

Description: This volume is a guide for teaches who must deal with children who are experiencing grief and loss, illuminating the classroom issues that grieving may trigger. Educators will get the real-world tips, strategies, and insights they need to explain the major concepts of death in age-appropriate ways; respond constructively to children's common feelings and behaviors after a death; initiate and maintain positive, helpful communication; learn what to say and what not to say when a child or family is grieving; use simple

commemorative activities at school to help students cope with their feelings; address children's responses to different causes of death, including suicide, illness, and violence; help a child who is "stuck" in a difficult phase of grief; provide ongoing assistance when triggers of grief renew a child's sense of loss; and notify and support students after a death that affects the whole school community.



How People with Autism Grieve, and How to Help: An Insider Handbook / Deborah Lipsky. Jessica Kingsley Publishers, 2013.

Description: The book is an honest, first-hand account of how people with autism deal with the loss of someone in their life. It explores how people with autism feel and express the loss and how they come to terms with their grief, offering practical advice to parents and carers on how best to support someone with autism during these difficult times.

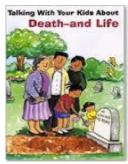


Grief is Like a Snowflake / by Julia Cook ; illustrated by Anita DuFalla. National Center for Youth Issues, [2012], c2011.

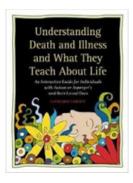
Description: A story for children. There is also an idea and activity book for parents, teachers and others to gain a better understanding of what grief is, how to personalize it, and how to endure it. The activities are practical, easy to implement and meaningful.



Sad Isn't Bad: When Someone You Love Dies / written by Michaelene Mundy; illustrated by R.W. Alley. One Caring Place, Abbey Press, c1998. Description: Teaches children fourteen reassuring lessons about grief, explaining, for example, that crying and mixed-up feelings are okay, and features illustrations of a young elf going through the same process as the young reader.



Talking with Your Kids About Death--and Life: For Parents / [Lisa O. Engelhardt, Lyn Sontag]. One Caring Place, Abbey Press, c1997. Description: Discusses how to disclose information about life, death and dying with children.



Understanding Death and Illness and What They Teach About Life: An Interactive Guide for Individuals with Autism or Asperger's And Their Loved Ones / Catherine Faherty. Future Horizons Inc., c2008.

Description: Guidance for family members and professionals for difficult but necessary conversations children and adults with autism or Asperger's syndrome. Offering detailed, concrete explanations of illness and injury, recuperating and healing, dying, life after death, losing a pet, rituals and traditions and more issues.

NEW! SESA Forum

Join the Discussion!

SESA's new online forum allows you to register and join in discussions regarding our program services and disability specific topics. Ask questions and search answers! Let's chat today! http://forum.sesa.org/

