

TEC Podcast #5 “Supporting Students with Autism Spectrum Disorder Through Grief and Loss,” by Kara Hume, Tara Regan, Laura Megronigle, and Charlene Rhinehalt, *TEACHING Exceptional Children*, 48(3), pp. 128–136.

Lorraine Sobson: Welcome to this *TEACHING Exceptional Children* podcast. I'm Lorraine Sobson, Publications Manager for the Council for Exceptional Children. Today I'm speaking with Kara Hume, a scientist at the Frank Porter Graham Child Development Institute and Associate Professor in the School of Education at the University of North Carolina–Chapel Hill.

Kara is a co-author—with Tara Regan, Laura Megronigle, and Charlene Rhinehalt—of a recent article in TEC entitled "Supporting Students with Autism Spectrum Disorder Through Grief and Loss." Kara, thanks for joining me!

Kara Hume: Thank you so much for having me.

Lorraine Sobson: We all experience and express grief differently. How and why might expressions of grief by students with autism spectrum disorder or developmental disabilities differ from typically developing students who do not have disabilities?

Kara Hume: Well, grieving is an individualized process, and there's certainly not one appropriate way to grieve, but there are some more typical social conventions related to grief such as crying together with loved ones or friends, hugging, generally sad facial expressions, talking about more somber topics for a certain period of time—and those may not necessarily be demonstrated by some students with autism.

Individuals with autism may not join in a group expression of sadness or grief like hugging their friends and classmates, or they may actually appear happy or laugh, or they might talk about topics that others might find inappropriate, because of a death, a new video game or something that seems kind of lighthearted.

There are a few reasons why the grief or the expression of grief might look different for students with autism. There might be more difficulty in identifying and talking about emotion words or emotions, and students with autism often have more difficulty recognizing and understanding the emotions of others, and then have challenges sometimes of mirroring those emotions back.

Also, we see in times of stress or anxiety that all of us may react unpredictably. We might laugh or we might smile when something sad happens. That is often exacerbated for students with autism who might struggle with receptive or expressive communication, but it's really important to know that these responses don't mean that the students with autism are not grieving or lack emotion. These responses might just be signs of unease or overwhelm.

You might also see some behavioral changes that happen during periods of grief. This might include changes in sleeping or eating, more agitation or more irritability—these are actually very similar across individuals with and without developmental disabilities, but you may not hear from the student with autism about what's happening and why. They may not be able to express that in the same way others can.

What may be unique also to a student with autism is that you might see an increase in repetitive behavior during this time, so students might get more stuck in repetitive patterns of behavior, things like a student that is featured in this article got stuck buttoning and unbuttoning his pants. That was something that was more intense and more frequent and more often after he experienced a loss in the classroom. That may be unique, too, for students with autism.

Lorraine Sobson: In your article, you describe a team approach for supporting students through their grief. Can you tell us a little bit about the composition of the team and what their responsibilities are?

Kara Hume: During a time of grief and loss, that is really a time for all hands on deck. An all-hands-on-deck approach is what I would call it, so really bringing in additional staff who know the students well is most helpful, and this could include related service providers like speech–language pathologists or an occupational therapist, a special ed administrator from the school building like a department chair, an autism specialist, or people like the school counselor or school psychologist. If there are paraprofessionals that are connected to the classroom, they are really critical team members. Schools often may want to bring in someone from the district office to provide an extra set of hands.

There are a number of important responsibilities for this team. The first is often letting the family know of the loss or the event and deciding how the students will learn about the event, whether the families will tell them or whether the school staff will let the students know, and how that will be done; and then really the team needs to focus on helping to stabilize and staff the classroom.

If the loss is a teacher or a staff member in the classroom, [it is important to make] sure that there is still a structure and a flow to the school day. Then additional personnel can provide some support to students to help them process their loss.

The team is also really charged with creating opportunities across the next few weeks and even across the school year so that the students are able to express their grief as well as staff members and other students across the school.

Lorraine Sobson: That outlines the team and the responsibilities. I'd like to talk about the strategies that you outline in the article. One thing that you discuss is that concrete language is an important factor when discussing grief with students who have ASD. Could you provide examples of useful concrete phrases as well as abstract phrases that might cause confusion?

Kara Hume: Yes. Students with autism may have difficulty understanding abstract descriptions of death or loss, so it's really best to use more concrete terms. These could include "He died"; "We will not see him again at school anymore"; or "Her body stopped working, and she will not be coming back to our school." These phrases might sound blunt or insensitive but can really help our students on the spectrum better understand the loss and the permanency of the loss.

Abstract phrases like "She's in a better place" or "She passed away" may not be as clear. For example, if we use the phrase "She is in a better place," I've heard of students who've responded, "Well, why don't we go to that place and find her?" Or if we're using the term "lost", that can be abstract like, "We lost him last night," might confuse an individual on the spectrum who might insist on going to find him. So we propose using very concrete language that helps the students know exactly what happened in age-appropriate terms, and that the loss—if it is in fact permanent, that it is permanent.

Lorraine Sobson: How can using social narratives help students with ASD understand the events around the loss and their own feelings about it?

Kara Hume: Social narratives can help support a student with autism's receptive language, or their understanding of a situation. It's often helpful to provide information in multiple formats. In addition to telling the student about the loss or the event, consider giving information in a visual format as well. A social narrative is really just a story that helps to clarify a social situation and give the student some possible responses. These can be made quite easily with text, photos, or technology like PowerPoint, and using a social narrative to help a student with autism navigate through the procedures and the social expectations associated with a death or a loss can be really helpful.

They can also be used to help an individual wade through maybe some new emotions that they're feeling and they may not understand, and also to give some idea of what to do when feeling those emotions like sad or overwhelmed.

Lorraine Sobson: The social narrative can help them understand sort of the process, their expectations and responses. One of the other points that you raise is that students with ASD have varying communication skills, too. What are some ways to help students express their grief?

Kara Hume: There are so many forms of expression that can be used from just talking about their grief with a staff member they trust, to drawing pictures, writing cards or stories, creating a memory book by simply cutting out and gluing photos.

For students who are minimally verbal or nonverbal, grief can be expressed through an augmentative communication device, movement like dance or yoga, art, creating memorial video or a PowerPoint or music. There are many options, but staff will likely need to set up these opportunities for students, as they may not initiate communication about this or initiate even a need to express this grief in multiple

formats, but we know that having the opportunity to express grief in a variety of ways is beneficial for our students.

Lorraine Sobson: One of the ways people respond sometimes in the immediate aftermath of a loss is to abandon their routines, because “business as usual” feels trivial or stressful. How might this differ for individuals with ASD? And how should teachers balance or meld the need for routine with the need to grieve?

Kara Hume: It definitely does feel hard to prioritize a spelling test when a key staff member has died, so it is natural early on that some routines are going to change or adjust. For our students with autism coping with a loss, if we then add coping with lots of additional changes in routine, that can really increase the intensity of the situation especially if the routine changes include things like canceling favorite activities or having more open-ended or unstructured activities or just kind of sitting around talking about or hearing about that loss. That can make the whole situation more difficult.

Whenever possible, keep the routines the same, but embed opportunities for students and staff to process that grief within the routine. For example, instead of canceling art class, use art class as an opportunity to create something in honor of someone who has died, or during language arts read about a favorite location, or write about the student's favorite field trip they took with their friend or staff member who has died.

Routines can be comforting and can remain something that the students with autism can count on during a time of turmoil. You may also find that within routine, that might actually better allow the students with autism an opportunity to express their feelings of grief or sadness.

Lorraine Sobson: Coping and calming skills are also important for students with ASD especially in times of loss. How can teachers introduce or reinforce these to aid a grieving student?

Kara Hume: Ideally, students with autism will have regular opportunities for instruction on and practice of coping and calming skills so that when a situation does arise, like a time of grief or loss, that they can access those skills; they have those skills already in their repertoire. This could be asking for a specific activity that is calming, like a walk or getting a drink of water, listening to music, taking a break, or doing some deep breathing exercises; or access to a preferred staff member or an activity.

If they have these coping and calming skills as part of their regular routine before the loss, then during this period of loss, the student may need more opportunity to access those activities.

If there are students who have not yet learned a coping or calming routine or don't have activities that they're familiar with, it's very important to take some time to teach those calming and coping strategies. The ideal would be to teach those during

a time of day when the students are not very upset or anxious. That's typically not an opportune time to teach new things.

First, the team at the school will need to determine what activities are calming for the students, then teach them how to access those activities during the day, and teach them how to return to their regular instruction after engaging in those calming and coping activities, or helping them know how to embed them within their regular instruction. Early on it might be necessary to schedule calming or coping breaks at multiple times across the day, and then down the road the staff can introduce and then teach a self-management plan so a student can track their grief responses and their feelings, and then identify when calming strategies are needed.

One thing to keep in mind is that we may want to give our students during a period of grief lots of "down time" as a way to calm or to process their feelings, but what you might see is that an extended period of down time may not be helpful for our students on the autism spectrum. In fact, getting back to their routine ... may be more calming, so really trying to find a balance [between] access to calming and coping activities but not long extended periods of unstructured downtime.

Lorraine Sobson: Because students come from a diverse set of faith traditions, how should teachers handle the spiritual aspect of death when discussing it with students?

Kara Hume: I would really recommend letting families handle the spiritual side and avoid having conversations about spiritual or religious beliefs around death and what happens next. Instead, I would help students to know that when they are missing someone, they can think of special or specific memories, they can look at pictures from a memory book you've created in the classroom, they can go to a favorite place that reminds them of who they're missing, or hold a specific memento. They can do those things in an effort to feel closer to who they're missing. That idea of connecting to a person who is gone through pictures and memories and mementos is really a universal idea and has less to do with a specific kind of religious or faith idea. That's what I would emphasize in the classroom.

Lorraine Sobson: Some rituals surrounding grief could be overwhelming or confusing for students with ASD. Should they be included in rituals such as school memorial services?

Kara Hume: Yes. Essentially, yes. It seems that our initial instinct is to say no, that some memorials or rituals may be too much for the student, they might feel uncomfortable, so we exclude them in an effort to be helpful. Really, rituals related to grief and loss are integral in our culture and can be healing for people. Our goal should be to include individuals with disabilities in those rituals as much as possible. It might be that the length of the event is modified, or the student's role in the event is adjusted, but whatever can be done to facilitate full and active participation, is ideal.

For example, for a school memorial, preparing students ahead of time with a social narrative so they know what to expect, will be helpful, and potentially bringing along

an activity that helps the student to feel calm. Then, give the students a specific role during a service such as carrying flowers and putting them in a vase, or bringing in a piece of artwork that the class created, reading a poem, or playing a song.

The team might also work with the student to create a ritual in a smaller, more intimate setting, something that may not feel quite as overwhelming like planting a favorite bush outside the classroom or going to eat at a favorite restaurant, going to a game that supports a favorite team of who it is that they're missing.

Ultimately, we don't want to shield students with disabilities from these rituals or assume that the rituals aren't meaningful. Participation should definitely be the expectation.

Lorraine Sobson: This is so helpful, certainly for teachers who are working with students with autism spectrum disorder but also for schools who may have a loss and are looking for advice and strategies on how to help the student body. Thank you so much for talking with me today, Kara.

Kara Hume: Thanks so much for having me.

Lorraine Sobson: Kara's article, "Supporting Students with Autism Spectrum Disorder Through Grief and Loss," appears in Volume 48 of *TEACHING Exceptional Children*. *TEACHING Exceptional Children* is a publication of Council for Exceptional Children. To learn more about CEC, visit cec.sped.org.