


**Supporting Bereaved Children with Autism**

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Crossroads Hospice & Palliative Care

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Presented by Boeing 




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### Introductions

Meggie Beaudoin-Kobb, MDiv



David Stevenson, MDiv, CT



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## Disclosure Information

In the past 12 months, neither of us have had any relevant financial relationships with the manufacturers of any commercial products and/or providers of commercial services discussed in this presentation.

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## Objectives

- Define autism spectrum disorder (ASD), dispelling common myths, and looking specifically at behaviors and feelings
- Examine how grief impacts a child with autism
- Discuss practical interventions to support a child with autism who is grieving

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## Autism 101

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## What is Autism?

Autism is a neurological disorder characterized by deficits in both language and communication

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## Autism Spectrum Disorder (ASD)



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


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## An Autism Diagnosis

-  Persistent deficits in social communication and social interaction
-  Restricted, repetitive patterns of behavior, interests, or activities
-  Symptoms are present in early childhood
-  Symptoms limit or impair everyday functioning or relationship

(Tierney, 2015)

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## Common Behaviors

- Decreased eye contact
- Uneven development of skills
- Resistance to changes in routine
- Marked hyperactivity and/or extreme passivity, which may alternate
- Less demonstration of typical signs of affection
- Odd body movements or postures (flapping, spinning, etc.)

(Challman, 2015)

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## What Does That Look Like?

- Looking down instead of at someone directly when spoken to
- Not answering questions or not answering right away
- Not wanting to be touched
- Stimming (repetitive rocking, swaying, bouncing, or flapping hands)
- Walking only on toes
- Vocalizations (making noises that are not words)

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## Sensory Sensitive

Frequently, people on the autism spectrum:

- Experience sensory input more acutely
- Have an increased sensitivity to heat/cold, light/dark, textures on clothing or surfaces, sound (especially loud noises), textures in foods, strong smells
- May be easily overwhelmed or distracted

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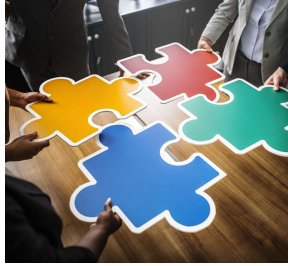
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## What Causes Autism?

- Not vaccines!
- Current scholarship suggests that certain individuals are genetically predisposed
- Environment also plays a factor, but only when in utero



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## A Sizeable Population

Centers for Disease Control (CDC): 1 in 68 children will be diagnosed with autism

Recent government survey reports even higher numbers: 1 in 45  
2% of the population = 6.5 million people in the US

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## A Brief Word on Language Choice

Person-centered language by default

***"Matt is a person with autism."***

...unless that person tells you otherwise.

***"My name is Matt, and being autistic is part of my identity."***

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## NORMAL

“**Neurotypical**” instead of normal, because normal implies that anything else is **abnormal**.



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## Verbal vs. Non-verbal

- About 1/3 of people with ASD don't use words to communicate
- Considered "nonverbal," which comes with some very heavy connotations about generalized ability
- Alternative: "people who use words" and "people who do not"
- So many ways to communicate; words are only one!

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## Autism in the Family

"Autism affects the entire family. A diagnosis of autism for one family member will affect the whole family system."

(Walsh, 2008)

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## Caregiver Stress is Real

- Caregiver stress that lasts a lifetime
- Nearly ½ of those diagnosed with ASD wander, leading to safety worries (CDC)
- 84% of adults with autism live with their parents (Autism Speaks)
- National shortage of specialized adult housing



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## Combat Soldier Study

Mothers of adolescents and adults with autism experience chronic stress comparable to combat soldiers and struggle with frequent fatigue and work interruptions. These moms also spend significantly more time caregiving than moms of those without disabilities.

(Seltzer, 2009)

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## Needs Unmet

"Nurses and clergy cannot assume that membership in a faith community automatically brings social support or spiritual well-being."

(Speraw, 2006)

- Experience of isolation
- Social stigmas surrounding autism

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## It's Hard...and That's Okay

Being a person with a disability can be really hard sometimes  
Being a person who is a caregiver for someone with a disability can be really hard sometimes  
All of this before we even introduce grief!  
But you're here, and your commitment to learning is a huge first step

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## How Does Grief Impact a Child Who Has Autism?

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## Grief is Individual

- Factors that affect grief:
- The person's personality
  - The relationship they had with the person they lost
  - How that person died

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## No Manual

- Information and research on autism and grief is scarce
- Even less on supports & strategies for children



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## Sharing Resources

- Previously, resources were geared toward children with intellectual and learning disabilities
- We will share our resources at the end of this presentation

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## The Most Difficult Loss



- The death of a loved one
- Triggers grief reaction
- Natural and emotional response
- Applies to loss of any kind

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## It Can Be Scary!

- Confusing
- Overwhelming
- Processing
- Understanding



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## Grief in Children

- Lack of interest
- Social withdrawal
- Fear of separation
- Anger
- Guilt
- Risk-taking behavior
- Anxiety
- Distractibility
- Trouble focusing
- Increase in challenging behaviors

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## Is it Grief or Autism?

- It's both!
- The symptoms of children who grieve are often *no different* for the child with autism who is grieving

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### However...

- Symptoms of grief and symptoms of autism often overlap
- Presents challenging questions for caregivers:
  - Is the child with autism really grieving?
  - Are they capable of grieving?
  - How do I gauge where the child is at in their grieving?

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### Exclusion From Grief

- Lack of appropriate supports
- Exclusion from rituals
- No preparation for the loss
- Perhaps not even told

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### A Different Experience

No doubt, when the death of a loved one crosses the path of a child with autism, there are challenges when it comes to processing that loss and challenges to that child's grief experiences

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### Challenges With the Abstract



ABSTRACT LANGUAGE



ABSTRACT CONCEPTS



TOO DIFFICULT TO UNDERSTAND?

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### Difficulty Connecting

- Social reciprocity...back and forth conversation
- Perspective taking...recognizing and empathizing

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### Struggling with Communication

 Expressing feelings

 If you can't voice feelings, it is hard to access help

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## Struggling with Change

- Rigidity
- Distress at disruption

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## Many Pieces to the Puzzle

- Anxiety
- Depression
- Increase in symptoms
- Increase in challenging behaviors



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## How Can We Help?

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## Interventions

1. Preparing a child for a death
2. Using concrete language
3. Keeping routines in place
4. Provide coping and calming strategies
5. The value of rituals and ceremonies
6. Memory activities
7. Ways to help express feelings

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## Preparing a Child for a Death

- Talking about death
- Doesn't just have to be at the time of death of a loved one
- Point out cemeteries
- Mention funerals
- Share memories of a pet who has died



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## Use Concrete Language

- Keep it concrete
- Avoid euphemisms
- Use the D-word...death
- Simplify

The emotional toll of this language on us while we're grieving should not be underestimated

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### Keep Routines in Place



COMFORT IN ROUTINES



KEEP AS MANY ELEMENTS  
THE SAME AS YOU CAN



GIVE PLENTY OF WARNING  
WHEN THINGS WILL BE  
DIFFERENT

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### Provide Coping and Calming Strategies

- Unique to each individual
- Deep sensory input
- Avoid known triggers
- Importance of taking breaks, for both the child and the caregiver
- Coping/calming activities

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### The Value of Rituals and Ceremonies

- Talk with clergy beforehand whenever possible
- Benefit of having time to get situated before the service
- Consider appointing one person as designated caregiver during the ceremony
- Make a list (words or pictures)

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## Memory Activities

- One they used to do with the deceased
- Visual activities
- Tangible activities
- A word on the environment and continuing bonds



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## Ways to Help Express Feelings

- Validate, validate, validate
- "It's okay to feel what you're feeling"
- Consider prompting ("I feel \_\_\_\_\_")
- Meet them where they are
- It may take time

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## About the TAPS Institute for Hope and Healing®

Launched in March 2018 through an alliance with HFA, the TAPS Institute for Hope and Healing® serves as a resource and training center, providing programs for both professionals working in the field of grief and loss and the public.



Presented by Boeing 

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## Upcoming TAPS Institute Programs

- March 5** **Love After Loss (for Women)**  
*Live Webinar, Noon-1:00 p.m. ET*  
With **Carla Stumpf-Patton**, EdD, LMHC, NCC, FT, CCTP, TAPS Suicide and Prevention and Postvention Initiatives  
And **Susan Starnes**, LCSW-C, Maryland Air National Guard
- March 7** **Introduction to Mind-Body Skills**  
*In-person workshop at TAPS Headquarters, Arlington, VA, 10:00-11:30 a.m. ET*  
Hosted in partnership with the **American Red Cross**
- March 10** **Love After Loss (for Men)**  
*Live Webinar, Noon-1:00 p.m. ET*  
With **Justin Yopp**, PhD, University of North Carolina in Chapel Hill  
And **Warren Pellegrin**, USMC veteran

Visit [taps.org/institute](https://taps.org/institute) to learn more and RSVP!

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