

Can't we talk about something more pleasant? *

A presentation on grief

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*: Title from memoir by Roz Chast

Sharing some thoughts

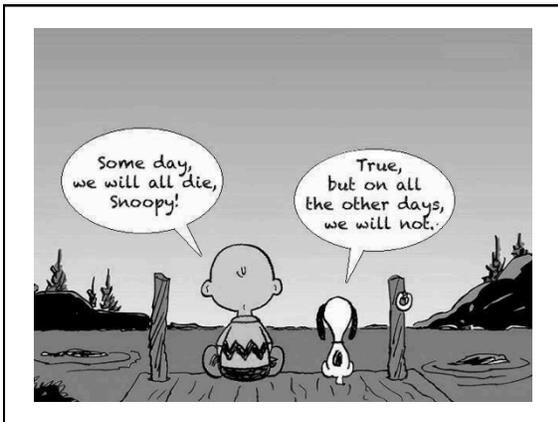
- Grief is messy
- My experience with one client
- Forming a parent professional alliance to deal with such an intimate topic
- Grief occurs in the lives of people with autism and intellectual disabilities no differently than neurotypical individuals but the expression and processing of the loss may differ

The concept of Death

- Research says: to understand death, one needs to understand:
 1. Finality
 2. Universality (death is a certainty)
 3. Causality (death occurs for many reasons)
 4. Non-functionality (functioning ends at the time of death).

Further complications

- For people with disabilities, a death may also cause secondary losses such as a move
- Communication deficits impact dealing with loss
- Skills break down under stress
- Grief is a disruption of the orderliness and predictability of one's world.
- Impulsivity and compulsivity may impact the mourning process
- There can be an increase in concerning behaviors such as aggression or self injury during grieving.



Individual differences

- Sense of time
- Understanding of metaphors or abstract concepts
- Desire to grieve alone or with others
- History of dealing with change
- Recognition and understanding of feeling states in self and others

Individual differences

- Communication skills-expressive and receptive
- Object permanence or holding things in one's head when you can't see them
- Ability to hypothesize or anticipate the future
- Cultural differences
- Religious differences

Common reactions to loss

- Fear
- Anger
- Regression
- Denial
- Disbelief (shock)
- Depression



The three most important things to do

- **Talk about it!**
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Explaining Death

- People die when their body stops working
- Dead people don't feel pain
- Dead people don't eat, go to the bathroom, etc.
- They were very, very, very, very sick
- They were very, very, very, old, injured, hurt etc.
- Religion/faith/heaven etc.
- Use very clear language – use the words dead and death

Explaining death

- When it impacts a group of individuals, it is best to tell them as a group.
- It may be helpful to compare the sick or dying person's body to theirs
- Explain that the relationship can continue but it is one sided
- Introducing the topic with less traumatic losses
- Teach about life cycle

Grief

- Grief is a reflection of love
- Can't be with the dead person, but can still talk about them, miss them, think about them
- Give permission to feel what they feel
- Grief needs to be experienced in a social context to minimize depression or grief "lodging in the self"



Things you can do before a death

- Use less emotional deaths such of as a birds, pet, distant relative, acquaintance as teaching opportunities
- Include other siblings or other relatives in the conversation
- Put together a memory bag or box
- Write a goodbye book
- Write a goodbye letter

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- Designate roles and visits to others
- Make a plan for how to explain death to your child
- Figure out and designate the person who would tell your child about your incapacitation or death
- Figure out who you would want to be with your child when he or she hears the news
- Make a plan for which of the following rituals or activities would work best for your child

Quote

**"Grief is like the ocean;
it comes on waves ebbing and flowing.
Sometimes the water is calm,
and sometimes it is overwhelming.
All we can do is learn to swim."**
Vicki Harrison

Things you can do after a death

- Rituals-wakes, funerals, shivas, etc.
- Emotional support
- Minimizing other changes – keep routines predictable
- Assurance that needs will be met
- Make the world seem as safe as possible

Things you can do continued

- Memory boxes
- Collages
- Plant a tree
- Plant a garden
- Cook and eat favorite foods
- Watch a shared favorite movie

Things you can do continued

- Make a pillow or blanket from the deceased person's clothes
- Light a candle on special days
- Wear an article of clothes or jewelry of the person
- Look at photographs
- Create a book about the person
- Let a balloon free in the air

More things to do

- Continued religious observance
- Visit places where person and deceased loved one visited to prevent dangerous searching behavior by assisting searching behavior.
- Increased supervision
- Surround the person with emotionally regulated individuals- if that is not you, find someone else
- Give choices and sense of control

More things to do

- Tell stories and share memories
- Watch home movies
- Read prewritten letters from the deceased person
- Write notes or draw pictures for the person and let them go into the air tied to a balloon
- Offer a safe and protective time and physical space for grief
- Teach coping and relaxation skills

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- Scrap books
- Social Stories
- An "I remember" poster
- Have anniversary rituals
- Encourage exercise or physical activity
- Locket or other jewelry
- Pinning something to clothing by your heart

And more

- Make links between the feelings and behaviors that express grief or loss
- Help the person put thoughts and feelings into words
- Take clues from the grieving person
- Remember that behavior is communication
- Be aware that illness may be a somatization of grief

More

- Just sit with someone and share silence
- Label feelings
- watch a video message
- Model showing sadness
- Paint a rock or stone with the person who deceased name on it.
- Stones in a fountain

More

- Provide familiar scents from the deceased person- clothing, pillow, lotions, perfumes
- Give permission for new traditions and start them
- Give reassurance that the health will heal
- Give hope that they will feel better one day
- Encourage rest and understand that grief is exhausting
- Give positive reinforcement and praise

And more

- Use a daily ritual such a coffee mug with the deceased person's face on it or their favorite cup
- Wear a button with the deceased person's face on it
- Teach and model that although it is a sad time, it is OK to have fun and be happy too

For Staff

- Agencies can designate a team of staff to be a resource on grief
- Staff training should include grief
- An assessment system can be put in place as well as individualized support plans
- Staff need avenues for their own support when helping someone with grief
- Be mindful of staff turnover as loss



And now, the things not to do

- Don't give the message that they "should not feel that way"
- Don't interpret a desire on the grieving person's part to focus on their own needs to mean that their grief is not intense
- Don't assume that a lack of reaction after the loss will mean that it was not impactful
- Don't think that when signs of grief go away, that they grieving process is over

Don't's continued

- Don't use language such as sleeping, lost or even passing away
- Don't make other changes in the grieving person's life
- Refrain from assessments

In summary

- Not possible to make it easy but can make it a little less hard
- Not a recipe since there is no such thing as one size fits all
- Preparation can prevent the last minute scrambling for what to do
- Preparation increases comfort with the topic
- Give yourself permission to deal with your own feelings of loss

In Summary continued

- Get professional help for traumatic or complicated grief. Also if reactions include behaviors such as self harm, elopement, etc.
- Make it a family affair- involve other children and extended family in the process
- Remember it is about the other person's needs and belief system, not your own
- Our hope now is that you will start making a plan instead of leaving things to chance

References

Several books and articles were used in the preparation of this presentation. The complete listing is available on the separate handout. The handout is available at this workshop or can be obtained by emailing me at dgould847@gmail.com.
