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Good grief: Supporting people through the grieving process

By: Amanda Gee

When I think about grief, I think about all the people I have lost in my life, all the people who I have loved or cared for who have died. It's a long list. I am sad that they are gone, but I also feel privileged that I had the opportunity to know them, to have had a relationship with them, to have loved or cared for them, to have shared experiences with them. I'm sure that we can all reflect on this and feel the same. To be human, to care about people, means that we will also grieve.

When I thought about writing this, I thought about Dave Hingsburger, who was my mentor and clinical director for many years, and about the article that we wrote for the journal many years ago about supporting people through grief. I have learned a lot since then, I have grieved a lot too, and I have grieved him, but it felt right to come back to this now, as grief never ends, and people need support.

It sounds weird to say, to write, but I have a passion for grief, a passion for grief work, and especially in supporting grief in individuals with intellectual disabilities. People with intellectual disabilities have been left out of the conversation too many times and for far too long. They have not been told about death and have not been included in funerals or other grief and mourning rituals. This has left so many individuals unable to process these major losses. I believe that people need to be included, they need to be involved, they need to be allowed to grieve and mourn, and feel all the feelings.

Death happens in this field, death happens everywhere, to everyone. It is one sure certainty in life. In places where you have people with complex disabilities and needs, and aging populations, death can happen more frequently. With death, there is grief. I have heard grief described as the love and caring left over after someone dies, and I think that's a good description of grief after death. In my work in many different places, I have seen grief supported well, and I have seen grief not supported at all. It's not easy, it's hard, and it can be awkward and heart breaking. Sometimes, we as direct support professionals want to avoid it because it reminds us of the grief we have experienced ourselves. The aim of this article is to help you to support grief well.

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Talking about death

Let's start with how to talk about death when it happens. When talking about death, it is important to use proper words such as dead and died. We seem to like to lessen the blow when talking about death – we say, 'passed away,' 'is resting now,' 'went to sleep,' and while that sounds 'nicer,' it is confusing. It is important to stick to concrete words and to use plain language when talking about death, i.e., 'They are dead,' 'They died.'

I also believe that we need to normalize death to a degree. Death is a part of life and, when we normalize it, we make it more manageable in some ways. Death will never be easy but knowing about death before you have to experience someone close to you dying can help.

Telling about death

If you have to tell someone that a person in their life has died, there are ways to do this more effectively. We don't always have control of how someone finds out but, if we do, we can do it in a kinder and gentler way. It is best to have someone find out from someone they know well, or with someone they know well such as a family member or a familiar staff. Try to have it happen in a space where they are comfortable to cry, to talk, to ask questions. Remember to use those concrete words. Sit down with them if you can, remember your boundaries – we aren't going in for a bear hug here – but sitting with someone and being present with them can be very comforting. If someone is looking for that physical comfort, a side hug may be given.

To a group

If telling a group about a death, it depends on the size of the group. With a small group, you could tell them all together, with a larger group, such as at a workplace, you could circulate through the group talking to people. One of the best ways to do this is to bring a picture or pictures of the individual around to show when talking to people about the death – this helps to clarify who and what. Staff get to share and grieve with clients this way, memories and stories can be shared, and it can help with the processing.

Sharing grief

Talking about grief is shown to reduce the intensity of grief. Sharing grief allows for people to share stories, to cry, to laugh, and to feel connected. This is a great way for people to process what happened and those initial feelings. It is also a good way for staff to share feelings with the individuals they support. We do need to remember to keep it professional and to maintain boundaries, but it's ok for staff to acknowledge their sadness as well. This also helps to normalize the experience and the feelings involved.

If an individual doesn't communicate traditionally, don't be silent about the loss and the grief. Share pictures with them, help to put words to their feelings, and acknowledge their pain as well. Take cues from the individual to see if they need some extra support.

Meet people where they are

Everyone grieves differently and at their own pace. When someone experiences a loss and is grieving, you need to meet them where they are at, and you need to check in with them and see what they need from you. Be ready to be present in silence, to reminisce, to hold the tissue box, whatever the individual needs from you in the moment.

Allow for all the emotions

I always say, '**all feelings are valid.**' When people are grieving, they can experience the full range of emotions. They can laugh, they can cry, and they can scream. Grief is an emotional roller coaster, and we need to make space for people to feel all those feelings. When grieving, we can experience intense sadness, relief, guilt, anger, silliness, and the list goes on. Sometimes, people don't seem to be experiencing any emotions. This is all normal.

The most important thing is to let them feel their feelings. One time, I was supporting a client after the death of her mother, and she was crying, and her support staff told her not to cry. In the moment, I know the staff was worried about the client and didn't want her to feel so sad, but of course she was going to cry, her mother had just died! Crying is a normal, healthy grief response. So let them cry and bring the tissue, let them be angry and acknowledge that emotion, let them laugh and share the fun memories. The best thing to do is to name it – 'I know it's really sad, I'm here for you,' or 'I see that you are feeling angry about this, do you want to talk about it?' or 'I hear that you are blaming yourself, it's not your fault.'

Death of a pet

I wanted to include the death of a pet in here, as I encountered this with a client recently for the first time. I have had many pets die and, as many of us know, the death of a pet can be devastating. But some people don't recognize this as a major loss, or as a loss that can affect a person with a disability as well. A pet can feel like as big of a loss as a family member. This death must be acknowledged as well if the client is grieving. For the individual I was supporting, we talked about the death of her dog, she mourned, she showed me pictures, and we were able to print out a picture for her to keep in a frame in her room. Through this, we were able to honour her feelings and also honour her pet.

Grieving someone else's loss

I often encounter someone who is mourning someone else's loss. They may be quite upset, but the person who died is someone they didn't even know. Maybe it's someone's roommate's friend, or a co-worker's family member whom they had never met. Grief reminds us of grief, and someone else's grief can bring all those feelings right to the surface again. The sadness may seem misplaced, or even selfish, as it doesn't have anything to do with the individual, but the grief can be real, those feelings are real. The individual still needs support. It's ok to acknowledge that it's a sad situation, and that grief doesn't fully go away.

Other losses

In thinking about grief and loss, I think it is important to consider the other losses that people grieve in their lives. Death is not the only thing that can bring on grief. Other losses can include having to move from the family home, other moves, loss of independence or ability, the end of a relationship. These feelings should not be dismissed, they should be acknowledged and processed like other grief.

Creative ways to acknowledge grief

When someone dies, we hope that we can participate in the funeral or other grief rituals that will happen, but that isn't always possible. There are lots of other creative ways we can help individuals during grief. If photos are available, they can help give someone something to hold onto during and after grief. A photo can be printed and framed, or a memory book can be made, or even just being able to hold a photo and carry it around with you for a bit can be helpful.

A memory box is another idea that could be helpful in a home or day program where staff and clients could write or draw memories of the person who has died as a means to remember and acknowledge them. A photo frame with a large mat could also be used for people to write around and then frame a picture of that person.

If possible, a tree or plant could be planted for the deceased to remember them at their program or home, or a plaque could be put on a bench in the yard. This would give people a place to visit to remember the person who died.

You could get out the art supplies and invite people to make art or cards to process feelings. The artwork could be shared or kept private, and the cards could be addressed to the deceased, or shared with family of the deceased.

Seek help

Grief doesn't have a specific timeline, and most people progress through the grieving process naturally and without abnormal difficulties. If someone seems to be experiencing complicated grief – grief that is very long lasting and is not reducing in intensity – it may be time to seek professional counselling therapy for the individual you support.

Conclusion

Grief is hard and supporting people through grief can be challenging but, when it comes down to it, just being there, really being there and actively listening are the best things you can do to help someone through it. DSPs wear many hats and grief supporter will be one of them at some point. Just do your best, remember your language and boundaries, and hopefully these tips will help guide you.

And don't forget to take care of yourself too.

About the author

Amanda Gee, BFA, RCAT, RCT (she/her) has been working with individuals with intellectual disabilities and dual diagnosis for the past 22 years in many different capacities. Amanda is an artist and an art therapist, and she lives and works in Mi'kma'ki, also known as Nova Scotia, Canada. She is the client support and education specialist at DASC (Dartmouth Adult Services Center), a registered counseling therapist at Lifemark Physiotherapy, a registered Canadian art therapist, a registered counseling therapist, and also specializes in helping people through grief and loss through the lifespan. Amanda believes in a holistic approach to therapy, incorporating many different modalities into her work, and considering the whole person and system in treatment.

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