

**Service, Support and Success:
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***Grief:
When You Are At A Loss After A Loss***

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On the day of his mother's funeral, he wondered why she didn't visit. He hadn't been told that she had died, his family forbade the staff to mention it. They thought it would upset him. They thought that he wouldn't understand. They thought that it was best, all round, for everyone, if he was kept in ignorance. They wanted to save him from grief. But, then, he was left wondering why his mother had abandoned him, why she never called, why she never visited, why she had stopped loving him. It was only after his health severely declined as he mourned the loss of her love that he was finally told. His tears were mixed with fury, he never got to say goodbye to his mother. He never got to share his pain with his family..

Grief is painful.

Loss hurts.

The attempt to protect people with disabilities from grieving is a compassionate but mistaken gesture. We are humans. Humans love, Humans mourn the passing of those they love. No one is exempted from loss. There may be a reason beyond 'protection' why people with disabilities are kept away from the expression of grief. No one, that's *no one*, knows the right words to say to comfort someone, the right ways to be supportive of another's grief. We live in a culture that is more comfortable talking about sex than death. Avoidance seems to be the only strategy that we all agree on and that we all know doesn't work.

Despite the theories about the different stages of grief, such as the well known, 'denial, anger, bargaining, depression, and acceptance,' we have to acknowledge that the stages are just a way to try to corral and organize the chaos that grief brings into our life. We all like a list. The stages of grief are the kind of list that makes sense, except, not everyone will go through these stages, nor will the stages necessarily happen in that order. Too, there is no timeline for the grieving process. Depending entirely on the circumstances, the people involved, the closeness of the relationship and the emotional make-up of the person doing the grieving, there is simply no predicting what happens when.

Even in the midst of the chaos of grief and the emotional fall out of loss, there are a few things to keep in mind when supporting someone through their entirely unique journey. So, here are some ideas and cautions to keep in mind:

- 1) *It isn't about you.* While it is understandable that you might also be feeling grief when someone loses a family member or a friend. After all, many staff are so much a part of someone's life that they often develop their own sense of closeness with those inside an individual's personal circle. However, when you are at work, supporting someone, your job is, simply put, one of support. A situation arose in one instance where a staff was so distraught at the sudden death of the parent of someone she supported that everyone had to support the staff ... including the individual who lost her mother. It's hard to be professional in times of strong emotion, but your grief cannot overwhelm someone else's, your loss cannot rob someone of theirs. Hopefully you have your own support circle, here, you need to be the one supporting not the one supported.
- 2) *It is about you.* Given what was just said, it's OK to express an understanding of the person's loss. It's OK to acknowledge that you too cared for and will miss someone. It's OK to validate someone else's feelings by sharing a bit of your own. But it's important to be judicious in what you are sharing, enough to let the person know you 'get it' but not so much that the person is flooded with both your grief and their own.
- 3) *Respect diversity.* One young staff, upon hearing of the death of the sibling of a fellow he supported, immediately crossed himself and said a prayer. The fellow he was supporting was neither a Christian nor particularly religious. The staff was hurt and offended that the fellow he supported was hurt and offended. The damage done to their relationship that day was not repairable. People come from differing backgrounds and from differing faith communities. It is important to be incredibly respectful of cultures and traditions both, but particularly of faith. Different cultures, religions, families and individuals have different rituals and traditions when it comes to death and grief. This is very sensitive territory, as it is so easy to cause offense and appear disrespectful. It's best to be cautious in one's caring and in one's expressions of grief.
- 4) *Don't silence grief!* It is important to talk about what happened, to be open to hearing about it and to assist the person in telling the story. Many people, when grief struck need help to express themselves. If it seems that the person is struggling to find words to tell you, help them out by asking questions. 'What happened?' 'When did you find out?' 'How did they die?' 'Who told you?' Let their responses tell you when they are done. Don't turn this into an interrogation, just let them tell their story until they are done, or until they are done 'for now'.
- 5) *Don't stuff up emotion.* It's OK for people to feel sad. Often during training about feelings people with disabilities indicate that they were never allowed to talk about their sadness at the loss of a family member or friend. It's important that grief, sadness and anger be expressed in a timely fashion. Telling the person that 'he is in a better place' or

'she wouldn't want you to be sad' doesn't help. It's kind of like telling someone that what they are feeling is wrong. Sadness, like all emotions needs to be expressed and to be respected.

- 6) *Don't force chatter.* If someone doesn't want to talk about it, they don't want to talk about it. Beyond letting the person know that you are there if they need to talk about it or if they'd like to talk to someone else then you'd help them find that person, let it go. Don't force your help on someone.
- 7) *Leave taking is important.* Everyone should have the *option* to attend the funeral or the memorial ceremony. Funerals help to make the death real because you are participating in the ritual 'saying goodbye' and celebrating someone's life. Funerals, or other group rituals, are also beneficial in that they provide an opportunity for people to come together, to share their feelings and their memories. If attending the funeral is not possible, or is not chosen, then holding a personal memorial may be a good way to achieve the same benefits. This could take many forms and should be guided by a person's wishes.
- 8) *Maintain boundaries.* A person may reach out for a big hug or to crawl onto your lap, or have you lay beside them when they are crying. None of these things are acceptable. Beyond sitting with someone or giving them a side hug, it's not wise to use a lot of touch. People are particularly vulnerable during grief. Con artists use grief and the loss of boundaries that come with it, to victimize people. Show caring, show concern, but keep the regular boundaries in place.
- 9) *Save memories.* If the person would like to, help them create a memory book of pictures and souvenirs from their relationship they had had. It can be very helpful to have something to do and creating a book of memories might be a project that helps the person to talk about their loss and remember the life and the love they had shared with someone else. It also can give the person something to hold on to in the days ahead when they feel the loss more keenly.
- 10) *Seek support.* If it seems that the person might be having a lot of difficulty, beyond your capacity to help and understand. With grief, remember that there are people who have expertise in grief and grieving. Don't be afraid to seek out someone to work with and help the person deal with their loss. Grief counselors and art therapists may have tools to help with the expression of grief and with healing from loss that the individual you support might need.

Grief is proof that we have loved and have been loved. All of us, in our lives, will be honoured to grieve those we have shared our lives with. It's important to allow the feelings to be expressed in

whatever way they need to be expressed. These ten tips are just ideas as to how you may best support someone.

There are other losses that need to be mourned, however, loss of home, loss of independence, loss of a friendship, loss of a staff – loss of a dream, loss of a hope, loss of a personal expectation. Those losses will be dealt with in an article later on this year. This article is simply the beginning of a conversation about grief and loss.