

Brain Injury and Grief: Fact or Fiction?

by Janelle Breese Biagioni

Grief is most often associated with death. While it is true that the death of a loved one (family member, friend, or pet) and, at times, the death of people we do not know (Sandy Hook Elementary shooting) will catapult us into the grief journey, death is not the only cause of grief. Although death is an important reason, there are other losses in life that we also need to grieve. These too are life-changing and will solicit the same grief responses as death does.

Society has slowly recognized significant life events as also being a source of sorrow and cause for grief. Events such as divorce and separation, transitional losses (moving to a new community or job loss), and developmental losses (children leaving home) are also ways in which we experience feelings of sadness, depression, hopelessness, and sorrow. To heal from these experiences and to move forward in life, we must grieve and mourn.

Furthermore, with the advancement of technology and medicine, people tend to live longer; however, many are compromised with chronic illness, such as diabetes or heart disease. While these are often manageable, it is not unusual to experience some level of loss as a result. It could be that people are no longer able to work in the same capacity, or they may have a substantial change in lifestyle, or how they view themselves in society becomes grossly skewed, and therefore they begin to grieve. Then we have what I identify as *extraordinary grief* resulting from a disease such as Alzheimer's or a catastrophic injury such as a brain injury. This kind of grief is profound. People must grieve who they were, and the family also grieves the person who is no longer there, albeit physically present. Sadly, I think society as a whole is only beginning to understand how profound this type of grief is.

In 1969, Dr. Elisabeth Kübler Ross published a revolutionary model of grief in her book *On Death and Dying*. These five stages, commonly referred to as DABDA, are denial, anger, bargaining, depression, and acceptance. The flaw was not in her model. It was in society's interpretation of it. It was believed that people had to go through all five stages and in the order given, or they were grieving wrong. Let me tell you: the only wrong way to grieve is to *not* grieve. Prior to Kübler Ross' death in 2004, she explained the model was not meant to be a list of "absolutes" that one had to do in any specific order to heal, but that it was a list of potential grief responses a person may experience. I have come to learn, both personally and professionally, that the list of responses is far more expansive. Dr. Alan Wolfelt's Companioning Model identifies potential grief responses as shock, numbness, disbelief, disorganization, confusion, searching, anxiety, panic, fear, physiological changes, explosive emotions, guilt and regret, loss, emptiness, sadness, relief and release, and finally, reconciliation and healing.

The grief journey is complex. It is a process and not an event. It is not time specific, nor is it orderly and predictable. Moreover, the process is fraught with "crazy-making" stuff. It is a lonely path. It feels like nobody understands what you are going through. That is true. No one can truly

understand how another person feels; however, those who have walked this journey never forget what they felt or experienced. They can be a tremendous source of strength and courage to you.

I mentioned earlier that the only wrong way to grieve is *not* to grieve. In addition to that, it is important to remember that grieving is not the end to the means. It is only the beginning! I say this because grieving is about how we feel on the inside due to what has happened in our life. If one is allowed to truly feel—to grieve, this will lead to mourning. Mourning is the process of taking those feelings from the inside to the outside. It is giving expression to how we feel. This may be done in a variety of ways, such as funerals, talking, writing, art, and music. Wolfelt describes it like this: “Mourning is grief gone public.” The only way to move through or reconcile and mourn feelings of grief is to find a safe and comfortable way to express those feelings. This applies to all types of loss, including those associated with brain injury.

Understanding the grief journey and its connection with brain injury is important for survivors, family members, friends, and professionals alike. It’s important because if you do not acknowledge the losses that arise from having a brain injury, it will be difficult—if not impossible—to move forward in life. This is true for people who are living with the outcome of a brain injury, and it is true for those in relationship with them, including spouse, children, family, and friends. And it is especially true for the professionals involved because it is our responsibility to help facilitate the process of grieving and mourning for these individuals and their families. As stated, the process is chaotic. Add to it that the loss is the “death-like” experience of a person no longer resembling who he or she was prior to being injured, and the crazy-making is exacerbated.

In my work I have discovered several reasons that interfere with the grief journey following a brain injury. They are:

- 1) Society’s incomplete list of loss and an unrealistic timeline to grieve and mourn.

Society accepts the need to grieve and publicly mourn the physical death of a loved one, but there is little understanding of the need to grieve the “death of a personality” when the person is alive. The person may have physical and/or cognitive limitations; however, those individuals and their family living with such profound change are often left reeling in unfair comments like, “It could have been worse.”

There is no timeline to grieve and mourn. Unfortunately, society operates on the thought that people need only “three days bereavement leave” and/or that in a few months everything and everyone will be back to normal. It doesn’t work that way for both physical and non-physical deaths. Remember this: It isn’t time that heals all, but rather what we do with the time that heals us.

- 2) There are layers and layers of loss experienced by survivors of brain injury and by each person connected to them.

The layers of loss following a brain injury and the uniqueness in the realm of grieving are overwhelming for many. To adequately grieve these layers of loss, it requires those involved to explore and determine what the primary and secondary losses of the brain injury are and how this impacts them. This applies to both the survivor and to their loved ones. Once the layers are identified, then people can begin to work through their feelings.

Reflect on the life losses that have you have experienced, including brain injury. Do you feel that you were able to fully acknowledge the grief that resulted from your loss? Do you feel that others understood or supported you in grieving (feeling) and mourning (giving expression to those feelings) following loss?

Loss associated with brain injury could be physical and/or cognitive, but there may also be additional losses in relationships, lifestyle, employment, and in the person's sense of self. Each loss requires reflection, expression, and acknowledgment so the person can heal and accept their new life.

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