

Primary & Secondary Losses

By Janelle Breese Biagioni

Two famous quotes come to mind as I write this article. The first is from Gertrude Stein's 1913 poem, *Sacred Emily*: "A rose is a rose is a rose." The other is from Shakespeare's *Romeo & Juliet* play: "A rose by any other name would smell as sweet." Both quotes imply that no matter what you choose to call a rose, it is still a rose.

"A loss is a loss is a loss," sounds logical and on the surface could be perceived as making sense. Gertrude Stein's theory was that the word *rose* invokes an image so no matter what you call it, it remains a rose; therefore, this implies that the word *loss* invokes an image and would still be a loss no matter what other word is used to describe it. In my opinion, this theory is not relevant to loss, especially loss associated with brain injury. When this viewpoint is applied to loss after brain injury it perpetuates the false perception and expectation encountered by survivors and families, which is: You look like the same family; therefore, you should behave like the same family. We all know how blatantly inaccurate that is.

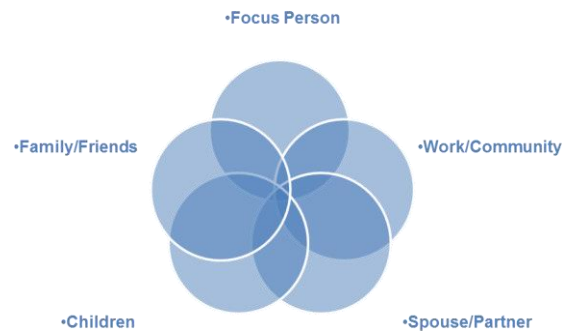
Far too many people have been left wounded for years because of the assumption that a loss is something you get over, dismiss, or set aside. A cookie-cutter approach was often used to determine how long one should suffer. In other words, six months has passed so you and your life should be back to normal now. Or there are specific phases or stages to go through in a particular order and if the person did not pass through them as scripted then he or she is not grieving correctly – yet again, a completely inaccurate postulation.

Unique Aspects of Loss

Loss is heartbreaking. That's the extent of any similarity from one kind of loss to another. Each loss brings its own unique aspects to consider. The loss of a job, although often devastating financially, is arguably much different than the death of a loved one. The death of a loved one leaves scars etched on our hearts, yet the loss experience of a person who has been sexually, mentally and/or physically abused is equally or more devastating for them. The death of an aged grandparent vs. the death of a child brings vastly different experiences for the ones left behind. Yet, undeniably, each loss is significant in the lives of those experiencing it and requires time, energy and patience to heal from.

One of the most difficult elements of grief is how to unravel the layers and work through each level adequately. For starters, it is overwhelming. Moreover, the general thought is that a loss is a *single event*. When people are provided the tools and support required to examine their sorrow, they discover that there is the main loss or event (i.e. death) and other losses spinning off the original event (i.e. loss of relationship).

Primary & Secondary Losses



The diagram above depicts how our lives connect and overlap with others. The focus person, or in this case, the survivor of brain injury touches many lives: spouse/partner, family/friends, children, and work/community. When something happens to the focus person, good or bad, it has impact on those he or she is connected to.

The following summarizes some Primary & Secondary Losses following a brain injury and how it impacts the focus person:

Primary Loss: physical › **Secondary Loss:** ability to walk, talk, see, smell, taste etc.

Primary Loss: cognitive › **Secondary Loss:** ability to make decisions, control emotions, to be organized or initiate activity, or to enjoy the things that use to give them pleasure etc.

Primary Loss: vocation › **Secondary Loss:** lifestyle (finances, home, activities, and comforts)

Primary Loss: relationships › **Secondary Loss:** self-esteem, connections, social capital, intimacy etc.

Primary Loss: independence › **Secondary Loss:** ability to drive or to live on their own, and/or make their own decisions.

The above is a sampling of primary and secondary losses one may experience. There are more.

One Loss = Multiple Losses

A primary loss results in secondary loss for everyone. In essence one loss escalates to multiple losses. The challenge then for the person becomes: What/who are they grieving? Are they attempting to grieve all the losses at once or are they stuck on one more than the other?

Here is how it may look for the person living with a brain injury: he or she is not able to return to work and his or her earning capacity is limited to a small disability pension. Because the survivor's earning capacity is limited, the secondary loss is a loss of lifestyle. The person may no longer be able to live in the home they had and is now dependent on food banks. Even going to a movie becomes an extreme luxury.

How a Primary Loss for One Results in Secondary Losses for Others

Following the above example, the secondary loss of lifestyle will also affect others in the family. For instance, due to financial constraints, a child may no longer be able to participate in activities such as sports or hobbies. These changes result in losses for the child.

Here is another example. If the husband cannot return to work and his wife leaves her job to keep up with caregiving duties, the family goes from being a double income family to only one person bringing in money. In this situation, the earnings come from a disability pension for the husband and will not be enough to support a family. The entire household is impacted by this. As well, the wife not only faces a significant change in her marital relationship, but she also experiences additional losses with departing from her job. These include leaving behind her co-workers, and perhaps her dreams and goals and often her sense of identity.

Whose work is it to do?

Each person needs to do his or her own work. No one else can do it. What is the work? It is feeling, talking, examining, reflecting and determining next steps. It is about letting go, forgiving and moving forward.

A major challenge is that the natural unpaid supports we have with our family members are also those suffering and working to resolve their own losses. It becomes critical then that family members have the opportunity to do this work separately. For example, a family of four (mom, dad and two kids) each have their own fears, sadness, anger, frustration and resentments. It is heartbreaking to say that *“you no longer feel like a wife anymore”* or that *“I am mad at daddy for getting hurt.”* Although they may not understand how to cope with these feelings, it is imperative they have opportunity to say how they feel and what they are going through without fear of hurting or feeling disloyal to another in the family. Individual support is critical to helping each person release their feelings and reconcile their losses. Unfortunately, this is often not available.

We can help people to survive trauma and tragedy in life and to return to a sense of joy and happiness but we **MUST** provide them with the support and services needed for however long they need it. There is no way to the other side, except to go through the process.

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