

DEALING WITH GRIEF AND LOSS IN MY GBS JOURNEY

BY LAURA RUTHERFORD

Authorized to re-publish - Blog Post September 30, 2020

Re-published 2020 November Newsletter



Grief and loss. Two human emotional reactions we deal with in our lives. Traditionally, we relate grief and loss to losing a loved one in our lives. Or when someone faces a challenge or trauma, there is a loss and/or grief. On Sun Sept 27, 2020 I attended a webinar on dealing with grief and loss, hosted by the GBS/CIDP Organization of Canada. Initially, it was difficult to link my grief and loss as many of the examples given were related to a death of a person. Luckily halfway through I was able to try taking the tools given and adapt them to a “thing”, which would be GBS in my case.

These traumas can be small or large but impacts your life none the same. Plus, each time our reaction to these traumas can be different as one’s coping skills vary. They speak of the 5 stages of grief - Denial, Anger, Bargaining, Depression and Acceptance. It is these stages of grieving I learned about when I went to counseling in November 2009. My counselor shared with me; I had not fully grieved for my sister who had passed away 18 years by this time. I was shocked to hear this. What I have come to realize, I dealt with my grief in two ways. I went through the process superficially to the point to be able to continue moving on with my life without my sister. What I had done was bury and not dealt with my emotional attachments to the grief - my anger of why did she have to die; sadness because I no longer have a sister; and guilt of why didn’t I see the signs of a person having suicidal thoughts. Sometimes I still have those feelings but I know now how to process these thoughts so I don’t dwell on them long. I just simply acknowledge those feelings, but then go on about my day.

Through counseling, I found grieving is associated to any type of traumas one may face. Many I didn’t know would fall under the umbrella of Grief & Loss. Unbeknownst to me, I found out I needed to work through the feelings of being bullied because of my size (being obese) since I started kindergarten (age 5) all way to adulthood where I was bullied by my managers in the workplace. The traumas I faced at the age of 16 when my mom was diagnosed with Stage 3 breast cancer and 10 months last my sister Kathryn was diagnosed with osteogenic sarcoma of her humerus. We had to face as a family similarly when their cancer returned and metastasis to their spines, making it stage 4 in

their cancers. Happily, both went into remission. Even though I was 26 years old when it happened, there is grief and loss as a child of divorce. In the beginning, I felt caught in the middle between my parents while still processing my loss of Kathryn's death. It was difficult to sort out my thoughts and feelings for sure. Having it become overwhelming as I was feeling "where do I start", with so many different traumas at once. What I do know though - each of these traumas I had faced in past, have shaped my personality as well as developed the coping skills to help me face the biggest trauma - being diagnosed with Guillian-Barre Syndrome (GBS). People who have GBS/CIDP (and other GBS variants) face a major trauma (the disease) but then we have to process with the continuous different levels of grief and loss that comes with having this disease.

I am assuming people who suffer from chronic illnesses or from other autoimmune diseases go through the same process of having to deal with setbacks throughout their life. Therefore, facing repeatedly the grief and loss with each of those setbacks. The ultimate goal would be to know which coping skills to use; so, does not get stuck in a rut and vicious cycle which could lead to depression and feeling surrounded by only negativity. I know that have been so fortunate to have an awesome support of family, friends and even the staff at the facility I am living in - AgeCare-Skypointe have been encouraging too. With my GBS variant, outcome is said to have a slow and poor recovery, but my support team reminds me where I was and where I am today; they send me encouraging messages to help lift my spirits and their shoulders are ready to just let me vent and have good cry when everything gets to be too much and overwhelming. Plus, they have continued to pray for healing and to keep my faith to carry on.

I thought I would share and provide an idea of some of my traumas I have had to face these last 4 years, and I will continue to face for the rest of my life, if I do not recover more.

1. Feeling the loss and grieving of the life I once had (ie. being able-bodied)

2. The loss of my mobility (my paralysis improvements have been small). Only going from total paralysis (head to toe, eyebrows weren't even moving) to remaining a quadriplegic but the paralysis is from shoulders down. This improvement took 4 years to achieve.

3. Grieve the loss of not being able to go back to work as a Coding Coordinator for the AHS-Calgary Zone Data Collection Team in the Health Records Department of Calgary's Hospitals. I have worked in the Health Records Department since I was 16 years old as a summer student in Thunder Bay, Ontario and I never looked back. Almost



30 years! Wow! Not many people can say they stayed in one field their whole career, which they still enjoyed performing.

4. Feeling a loss of my identity, my sense of purpose. Before getting sick, I felt my work identified who I was as I didn't have a family of my own. GBS took that away from me. I feel my life is in limbo. I didn't have that confidence, that anchor any more.

5. Now that I am on Long Term Disability, who am I? What identifies me to others? What could be my purpose to "society" as a quadriplegic? (I think improving my confidence in myself will play a part in finding my identity and purpose moving forward.)

6. Grieve the loss of my independence. Being a quadriplegic, I require total care for my daily basic needs. Needing to learn that it is okay to ask for help, your family and friends want to help you. Allow them.

7. When I was able-bodied, I enjoyed travelling. Travelling to Ontario and Quebec to spent time with my family, my relatives and my friends. Of course, enjoyed travelling to different countries like England, Scotland, the Netherlands, France, Germany, Switzerland, Spain, and Italy. Plus, within Canada seeing the Cabot Trail and Cape Breton in Nova Scotia - definitely a highlight for me. Now, dealing with the loss of not being able to travel anywhere in the foreseeable future, will take time to accept.

8. I can't seem to be able to catch a break. Always seems I am dealing with something. It's exasperating needing to face it on a daily basis. Dealing with constant pain. It really does bring you to the edge and you have a meltdown. Just looking since I arrived to AgeCare-Skypointe: 2018 (nephrologist, urologist); 2019 (urologist, gynaecologist, neurologist, ophthalmologist); and 2020 (urologist, gynaecologist, dermatologist). Due continuous issues with my urinary catheter, dysfunctional uterine bleeding (DUB) and atypical cells recently found in a mole on my left back shoulder; I'll be having ongoing follow up appointments with my urologist, gynaecologist, dermatologist. Never a dull moment for me.

9. Dealing with the loss of "my normal life" occurring at diagnosis of GBS, which will be my "new normal" living as a quadriplegic. Then in 2020, Covid-19 global pandemic of a highly deadly contagious virus arrived gripping the world. At the time I type this post, in a short 7-8 months we have lost over a million people to this virus. If you have as many pre-existing conditions which increases your risk of a fatal outcome as this disease attacks more than the lungs, it's systematic - the whole body. Once again, I am having to change to another "new normal" which includes Covid-19 as this virus is here to stay.

Having gone through counseling once before working on grief and loss, I am more aware of signs when I am heading down that "rabbit hole"; therefore, able to recognize when I need to reach out to a family member, a friend or a third party (a counselor or a psychologist). As I have said in the past, if I have my 3Fs, I can basically face anything. The 3Fs - Family, Friends, Faith. Tonight, a friend posted this scripture from the book of 2 Corinthians. Another reminder that God is there to comfort us by putting people in my life to see me through my troubles. Then in turn, I am able to be there for someone else

who is going through something similar. A verse showing us the importance of “paying it forward”. For me, this concept of paying it forward is a part of my grief and loss process towards a healing in my life.

2 Corinthians 1:4 He comforts us in all our troubles so that we can comfort others. When they are troubled, we will be able to give them the same comfort that God has given us.