



Grieving the Loss of Gluten

“Grief is a state of being that results from the recognition that the world that “should be” is different from the world “that is,” a world that is forever changed by a loss.”

~ Dr. Kenneth W. Matheson.

Dr. Kenneth Matheson's definition paints a very realistic picture for those that are gluten-free. Our entire world is changed forever once we go gluten-free.

I think it's safe to say that every gluten-free person has ridden an emotional roller coaster on their journey to health. People suffer for years [[6 – 10 years on average](#)]; endure numerous doctor's office visits and usually walk away with more questions than answers. Frustrating to say the least. The result of finally getting answers to the on-going health issues brings an immediate sigh of relief, almost a giddiness. *“WHEW, I finally know what's wrong with me!”*

All too quickly that euphoria dissipates. The reality of the situation rears its ugly head - *“What **am** I going eat and how am I going to handle this?”* Convenience – gone. Care-free dining – adios. The joy of family gatherings - replaced with dread and worry. Things that took little or no thought - now rivals a Mars Rover launch. Buckle up tight, this is could be a bumpy ride.

Having to go gluten-free means experiencing a massive jumble of emotions. The biggest and probably most complex is grief.

In 1969, Dr. Elisabeth Kübler-Ross shared her experiences working with over 500 terminally ill patients in her well known book “On Death and Dying”. In this book she describes her [Kübler-Ross Model](#) [more commonly known as [The Five Stages of Grief](#)].

Even though this framework was initially seen in terminally ill patients dealing with their diagnoses, it has been applied to any type of grief/loss situation – loss of a loved one, a divorce, a job, a limb, a pet, a food, an old lifestyle – any life changing event.

“Suppressed grief suffocates, it rages within the breast, and is forced to multiply its strength.” ~ Ovid

The grieving process is important and necessary when someone experiences a significant loss. It's normal, it's natural, it's healthy. It's often hard to look beyond the big black wall that stands before you. As daunting as it is, it must be dealt with. Repressing or suppressing grief is detrimental to our well-being resulting in a variety of emotional and physical symptoms (headaches, gastrointestinal problems, heart palpitations). Just as we are working towards a healthy gluten-free body, we must work on a healthy mind/emotional state as well.

Processing those thoughts, feelings and emotions is intense work, but it helps us to accept what has happened. Grieving forces us to create a “new normal” out of our loss - whatever that new normal may be. We have power to create whatever we wish!

The grief cycle of Denial – Anger – Bargaining - Depression – Acceptance (DABDA) is unique to each individual. Everyone deals with trauma in their own way. These stages are not rigid or sequential in their order. We don't always move through the cycles in the described order, nor do we always experience each and every stage. Transition between the stages can be fluid; subject to the ebb and flow of emotions. Some stages might even be revisited.

Let's take a closer look at each stage and see how it relates to the loss of our gluten-full lifestyle.



Denial – A protection mechanism. It helps us to mask the pain of reality while we figure out how to handle the loss.

“Celiac Disease? Bahhh, that doctor is wrong, just like all the others! His fancy book learnin' and medical tests – it's all bogus.”

“No, it's not gluten, it's the <insert any food besides gluten>.”

“I feel fine except for my headaches, depression, and maybe this itchy skin thing, and maybe frequent trips to the bathroom. Heck our entire family is like this – it's normal.”

Anger – After the denial wears off; reality and pain comes flooding in resulting in anger. This emotion can be directed at anything or anyone, even ourselves. Due to the years of mis-diagnoses, the medical profession often times takes the brunt of the aggression.

“Why wasn't this caught earlier? Damn doctors!”

“Gluten is in everything! What am I supposed to eat?”

“I want my old foods back. I can't have my favorite birthday cake. I can't go out with my friends. This sucks!”

“Gluten-free food is so expensive and it tastes terrible.”

Bargaining – The “What If” stage. We start asking questions of ourselves but also a higher spiritual power. We try to seek a compromise in an attempt to regain control of the situation.

“What if I only have gluten on my birthday? One piece of cake won't hurt”

“OK – just this one last cheat day...then I'll be good”

“Please God, I'll do anything – just don't take away my pizza”.

Depression – The reality of the situation is becoming even more evident. We start feel sadness, regret, fear, uncertainty. We are preparing ourselves for the “aftermath” of the things to come. We are in the early stages of accepting our new reality.

“My friends won't want to hang out with any more. I'm a social outcast”

“Everybody else gets to eat anything they want and I can't”

“My life is over, it will never be the same.”

“No one understands what I am going through.”

Acceptance – Not everyone reaches this stage. Some may not even be willing to call it “acceptance”, but a mere “willingness to move forward”. While they may sound similar, there is a difference between truly “owning it” and “just doing what it takes to get by”. When there is full acceptance, there's a sense of calm – a feeling that all will be OK.

“Well, I'm not happy about this, but I'll do it if I have to.”

“You know, this isn't bad. I'm finding GF replacements for my old favorites”

“WOW! I've been GF only two days and I feel so much better.”

“Gluten-free doesn't have to mean taste-free, crappy food. I can rock this...”.

Embracement – No, this is not one of the original stages, but others feel [myself included] this should be the sixth and final stage for those living a gluten-free lifestyle. With embracement we focus on the positives and benefits that the gluten-free lifestyle offers. We dive into our new normal head first. We advocate, educate and help others that we come in contact with.

“Going gluten-free is making me eat healthier than I ever have. I am trying and loving all sorts of new foods. So many naturally GF foods”

Embracement – continued

“People ask me to help them go gluten-free. It's great!”

“I wanted to help others, so I started a celiac/gluten-free support group in my town.”

Practical Ways to Cope in the Grieving Process

Dr. Kenneth W. Matheson

<http://ce.byu.edu/cw/fuf/archives/2003/Matheson.Ken.pdf>

- Understand and accept the dynamics and process of grieving by reading/self education or by seeking professional counsel.
- Be honest with yourself about your situation and your emotions.
- Be courageous enough to share your feelings.
- Find a sympathetic, understanding supporter or counselor who can provide feedback and input sorting out hurt, confusion, and feelings and move toward a resolution.
- Have a strong support system consisting of caring people.
- Reduce responsibilities and restricting commitments in order to minimize the stress load.
- Don't feel guilty about your grieving.
- Attempt to engage in productive, contributory activities.
- Endeavor to help to others who are grieving.

Of course I am biased, but a local support group has so much to offer when it comes to helping people deal with their new gluten-free life.

“We must embrace pain and burn it as fuel for our journey” ~ Kenji Miyazawa

My Personal Path

Just as we all react differently to gluten, we all handle the grieving process in our own way and in our own time. A while back, I was asked how I handled the process of ditching gluten. Looking back, I don't feel I went through all of the stages. Denial – I was sick and seeking answers, no denying something had to change. Anger – I was upset with the medical profession for awhile but realized I had to let that go. Bargaining – Nope, I was sick and wanted to feel better and would do anything to do so. Depression – Minor, but I attributed it to being sick, not from giving up gluten. Acceptance – I was ready to accept anything that made the problem go away. Embracement – I'm all about that!

Below you will find the things that helped me find gluten-freedom. This was my path to a “new normal” without gluten.

Faith – While it may not be popular to talk about a higher spiritual power, it was an important factor in my own journey. Through-out the entire process, I didn't know why I was going through it, but I knew there was a reason for it. Later I would discover that I was being given a passion and a purpose; what an amazing gift!

Knowledge - I tend to throw myself into things to learn about it. When I was sick, I turned to the internet searching for answers or clues. I find that the more I know about something, the less afraid I become. The less afraid of it, the better I am at figuring out how to handle it.

Creativity – Even before I had to give up gluten I liked to cook. For me cooking is a creative process, much like all the other creative processes I enjoy. I guess I like the process of creating, regardless of what or how it is being created.

With cooking I was faced with a challenge of using new [and often times unfamiliar] ingredients to create new and exciting foods as well as re-create healthier versions of old favorites. I was determined not to let gluten win this challenge. Creativity to the rescue!

Support - I was lucky when I stumbled across gluten as a possibility of my problems. I happened upon a discussion board that had a few people that really helped me figure it all out and how to deal with this. I had an online support system.

Not only did I have an online support system, I was lucky enough to have a very supportive spouse, friends and family. I don't think too many people outside of my wife fully knew what I was going through, how scared I was or how sick I really felt.

Having a support system to help you through those dark times is a tremendous advantage. They watch out for you and help guide you when you need guidance. Even though I didn't want to socialize with others, my wife was wily enough to convince me to go hang out with our friends or attend family functions. Once I got there, it did boost my spirits and made me feel better. Perhaps my wife couldn't fully understand what I was going thru [like another gluten intolerant might], but she was a sympathetic ear when I needed to vent, a shoulder to lean on when I wasn't sure I was doing the right thing. When I did need another "insider's" perspective, I had the online people in my corner.

Stepping outside - Throughout the time that I was figuring out my issues, I realized that I was gaining knowledge that could be of use to others. I could take what I was learning and help others. This allowed me to step outside of myself and my own problems.

I started by contributing to the very same online discussion boards that helped me. There were others just starting out – just as lost, dazed and confused as I was. Starting a local support group took the process to another level. It's an amazing feeling.

While it may appear that I was ignoring my own emotional state, I feel "doing for others" helped me to understand & process the feelings I was having. I quickly realized that I getting an extreme emotional boost from helping others. I consider this aspect most important for me. I found that my issues/situation was far from what others were

experiencing. I found that I was quite lucky in the grand scheme of things. Pretty soon, things were lookin' pretty good in my household.

"Grief is the process that allows us to let go of that which was and be ready for that which is to come" ~ Therese A Rando

Final Thoughts

I don't think anyone likes to experience the pain of a loss. Unfortunately it's a simple fact of life; there is no way to escape it – much like death and taxes. It's just part of the whole "Human Experience".

Grief is messy, contradictory and confusing. It gives us a way to make sense of our world and what we are experiencing. It's a way for us to regain control of our lives; it allows us to let go of our sick and unhealthy past and prepare for a better, healthier version that is waiting to be claimed.

We will run into obstacles, we may stumble and fall on our journey. No one ever said the path to gluten-freedom was easy. The important thing is that we always, always always get back up and keep moving forward. We are in control and have the keys to unlock the door to our new life.

Nuova vita! New life!

Resources used in this article:

<http://psychcentral.com/lib/2006/the-5-stages-of-loss-and-grief/>

<http://www.celiaccentral.org/ceeliac-disease-in-the-news/after-a-gluten-related-diagnosis-grieving-and-smiling-8785/rev--2/>

<http://glutenfreeeasily.com/five-stages-of-loss-of-gluten-plus-one/>

<http://heartachetohealing.com/finding-a-new-normal/>

<http://cmhc.utexas.edu/griefloss.html>

<http://www.guardian.co.uk/science/2012/nov/25/grief-mourning-psychology-customs>