



PROJECT R

A LOSS & GRIEF JOURNAL FOR INDIVIDUALS WITH
AUTO-IMMUNE DISEASE/CHRONIC ILLNESS

VELMA MOCKETT, PHD

PROJECT RESET

RENEW YOUR SPIRIT

ENGAGE DIFFERENCE

STAY IN THE MOMENT

EXPAND YOUR BORDERS

TAKE A CHANCE ON YOU

PROJECT R
A LOSS & GRIEF JOURNAL

For Individuals With
Auto-Immune Disease & Chronic Illness

VELMA MOCKETT, PHD

“Often it is not that people are not able to cope with auto-immune disease/chronic illness, it is that they are not supported to do so in ways that matter”.

V. Mockett

COPYRIGHT

© 2018. V. Mockett, All rights reserved

No parts of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronically, photocopying, recorded, scanning, or otherwise without the permission of the author. For information and permission contact: info@blinkmentalhealth.com or vjmconsulting@gmail.com

This publication contains the opinions and ideas of its author. It is intended to provide helpful and informative material on the subjects addressed in the publication. The advice and strategies contained herein may not be suitable for your situation. You should consult a professional where appropriate.

The author specifically disclaim all responsibility for any liability, loss or risk, personal or otherwise, which incurred as a consequence, directly or indirectly, of the use and application of any of the contents of this book.

For general information on other products and services, to place an order, or for information about special discounts for bulk purchase, please contact.

Email: info@blinkmentalhealth.com

vjmconsulting@gmail.com

web: www.blink-mhs.com

DEDICATION

For SB, thanks for inspiring me to write even when I felt it pointless.

CONTENTS

Introduction: Letter to Reader

Chapter 1:	<i>Getting Started</i>	11
Chapter 2:	<i>Loss & Grief: An Overview</i>	20
Chapter 3:	<i>The Experience of Loss</i>	31
Chapter 4:	<i>The Journey of Grief</i>	41
Chapter 5:	<i>Emotional Dimension of Grief</i>	50
Chapter 6:	<i>Exploring Thinking</i>	64
Chapter 7:	<i>Exploring Behaviour</i>	76
Chapter 8:	<i>Owning yourself: A New Focus on Healing</i>	82
Chapter 9:	<i>Your Transformation</i>	128
Chapter 10	<i>Conclusion</i>	133

A LETTER TO THE READER

Dear Reader,

If you are reading this, it is likely that you are in the midst of working through your experience of being impacted by an auto-immune disease or a chronic illness and you are interested in understanding more about loss & grief in the context of your disease. Being diagnosed with an auto-immune disease, a or chronic illness is more than an emotional experience, it's an entire paradigm shift. I suppose it is safe to say that when something bad, drastic, or beyond our control happens; it disrupts our internal state and it forces us to re-evaluate our entire understanding of our 'world' and our role within it.

For me, being diagnosed with vasculitis has been quite the journey. It has been a disruption. Vasculitis has disrupted the structures of my everyday life and future plans, and as such symbolizes an ambush on my immune system, core assumptions and at times my sense of self. This has caused me to re-examine my emotional, social, spiritual, as well as my self-narrative. The experience of dealing with vasculitis and other auto-immune diseases has involved the need to change the story of my body. The story of a once healthy body is no longer relevant; the new story my body tells demands a new meaning and interpretation—one that I cannot say is always understood. Indeed, vasculitis has introduced a unique challenge to my narrative—it has changed the plot.

In the early months and years of trying to navigate this disease (*or co-exist with what I use to call my 'terrible roommate'*), processing the loss and grief took a back sit. I forgot to take a moment to process the initial loss of my health and the subsequent, or ongoing losses. Thinking back, what struck me, is that I was bugged down with the 'unwanted responsibilities'— (*E.g., Specialists appointments, medication management, energy management, canceling or postponing other commitments, and deciding among treatment options etc.*). This meant that I was on the move all the time. So, between problem solving those 'unwanted responsibility' and my work demands, I was too exhausted at the end of my work day to think about anything else but rest and sleep. Also, there were other medical issues vying for my attention as well. In a sense my situation was complex. I found myself in a peculiar position of living with multiple auto-immune diseases, so it made the balancing act more complicated. Therefore, managing loss and grief definitely was at the very back of my mental space. I placed grieving on hold for a while and compartmentalized aspects of my life. This helped me function well in two disparate worlds initially. However, as I continued to experience recurring disparity between my expectations and the reality of the constraints imposed by the disease, it became clear I need to address my psychological reactions and responses. On some level, I had accepted the fact that I had this disease, yet I felt like my sense of being, belonging and becoming was being tested like it had not been in the past. At times, I was feeling like a foreigner in my body. Thus, the need for me to address the loss and grief I was experiencing became vital. I also wanted to understand the language of my grief and I need to find a way to do that, so I began to write.

It appears that a small percentage of people with autoimmune diseases have a tendency to develop additional autoimmune diseases. For people who have more than one diagnosed autoimmune disease, it's called polyautoimmunity. The combination of three or more diagnosed autoimmune disorders in one person is called Multiple Autoimmune Syndrome (MAS). I was dealing with multiple.

Writing gave me the liberty to explore both from the outside and inside when I found it hard to express what I was thinking and feeling. A friend kept encouraging me to write and so did someone else who has played a significant role in helping me maintain perspective for the past four years. Somehow, she sensed I need to walk through grief and not around it like I was doing. She invited me to reflect about a lot of things. For a while I was stuck thinking about the things about myself I valued the most before all these symptoms started to unfold.

In retrospect, I think she was intentionally inviting me to participate in a process of reflection on the impact of the losses and how best I could cope. I believe her questions magnified the impact in meaningful ways that arose my attention to the loss and grief experience in modes that I had not anticipated or considered. For me, it brought the images and stories of my life into sharper focus. After several discussions, my writing began to open up a space for exploring, understanding and acknowledging loss and grief in 'spaces' and 'shapes' that it is not usually spoken about. I was entering a new chapter and territory in my life.

As I began this new chapter, it was critical for me to acknowledge that I was susceptible to the stresses of my losses. This highlighted for me the significance of developing something to help facilitate how I was coping with loss and grief. I realized that I needed materials and tools to help me understand my experience and relate to it in ways that mattered and would bring healing. First, it was critical that I understood all the concepts related to loss and grief (*mourning, bereavement, healing, control, and hopelessness*) and how they apply to what I was going through and more generally to auto-immune disease. I also began developing a list of questions that I thought had significant to where I was in the disease trajectory. In a sense it was a sort of phenomenological (*intentional inquiry into my life-world, lived experiences and meaning making*) research into my own experience.

I started off with these questions: **(1) What is my experience of loss? (2) What is my experience of grieving those losses? (3) how am I making sense and processing it? (4) Am I really attuned to the way things are—realistic and yielding to the way things are or unrealistically positive? (5) Am I frightened by all of this? (6) How am I envisioning my future?** These then morphed into more questions, which became a sort of questionnaire I used to help me dissect what I was feeling and thinking, as well as how I was behaving. It helped me to explore the multi-dimensions of loss and grief.

As I continued to write, it slowly unfolded into a journal. So, in essence, this is about a collusion path with a disease. A path that I am still navigating. This is one part of my 'illness narrative'. I had to learn how to be, how to create a 'conscious life' and 'mind the gap' that the disease was creating. Developing this journal allowed me to express, at a deeper level of consciousness, what I was thinking and feeling without interference or judgment; but mostly it permitted me to be vulnerable with myself, preparing me for interaction with others about the disease. Every section of this journal reflects my losses and struggles; but it also reflects growth, and the work that I did to learn how to 'be' and co-exist with a body gone 'rogue'.

As you read and reflect on the material in this journal, I want to emphasize the fact that, there is no protocol for grieving; everyone grieves differently, at the same time, there are some shared experiences. As I have learned in my journey, coping with a disease is usually not an easy process and cannot be dealt with in a cookbook fashion. I wish I could give you a recipe on how to grieve your losses. Even my experience as a clinician who engages with individuals with chronic illness, and other autoimmune disease did not prepare me for this. I want you to know this is not prescriptive. This is my first-hand experience, it may or may not be similar to yours; take out of it what works for you. Grief goes beyond any emotion ever encountered; it takes you to unexplored internal terrains. In the beginning loss & grief can leave you on the 'outside looking in, into the spaces where you use to be'. Your journey with whatever disease you have been diagnosed with will be different from mine—you have an 'illness narrative', which only you can tell in ways that matter to you.

This is meant to be a guide in your journey to getting 'unstuck in grief'. It is devoted to the 'human' side of vasculitis and auto-immune disease in general. It is at its heart about loss and grief. But is also about overcoming. "How do I go on after being diagnosed with an auto-immune that is so encompassing and brings so much loss? I hear this asked, sadly, too many times in my private therapeutic practice. So many individuals are touched by auto-immune diseases such as vasculitis, and other chronic illnesses. This journal describes the pain of grief, for those of you who are struggling to move forward. You may recognize the emotions, thinking and behaviours brought on by grief. My hope is that as you read and engage the materials in this journal, the discussion and suggestions for coping will help you make sense of what you are going through and you will arrive at a place where you will honour your grief, learn acceptance, become more compassionate with yourself and redefine you.

I underestimated the effects of vasculitis in my everyday life; and I believe the same is true for many of you. We underestimate how we experience our body and space, grapple with suffering and loss, and sustain or transform. My wish is that this helps you give voice to the story your body tells. I am inviting you to explore the challenging terrain in ways that provide opportunities for self-discovery and reflection.

Additionally, my hope is that talking about loss and grief at this deep level will move auto-immune diseases like vasculitis out of the strictly medical context into other arenas—psychological, spiritual and social that offers the possibility for greater meaning and hope. Lastly, I hope you will understand and acknowledge your loss and grief experience without fear. I have come to the realization that grief continues throughout the disease trajectory, and therefore, the goal is not for grief to be over, but rather for me to find meaningful ways to allow grief to transform from all encompassing, and disabling to a more transient and gentle presence I will experience throughout the disease life span.

I name this **PROJECT R** because for me it was about **RESET**, but it can mean renewal, re-birth, revival, reengaged, or renew—you decide what **PROJECT R** this is for you and begin journaling.

VM

CHAPTER 3

THE EXPERIENCE OF LOSS

“Anyone who has lost something they thought was theirs forever finally comes to realize that nothing really belongs to them.”

Paulo Coelho

I now realize that the experience of an illness like vasculitis is consistently one of multi-losses, the complexity and scope of which can sometimes be hard to comprehend, and consequently hard to speak about. However, at this point I have made a commitment to bring into my awareness narratives of this illness. I am discovering it is not easy to open myself to the slices of life and the trustworthiness that this willingness entails but, living as I do in an unreliable body, it seems the right thing to do. I do not think it is just sufficient for me to list my losses so I will try my best to show you how the losses impacted me.

After the diagnosis things began to evolve. For a while, I had in my mind that I would eventually evict the disease from my life. At the time, I did not realize that a disease like this could swing my sense of being, belong and becoming in ways I never imagined. A sense of being, belonging and becoming is fundamental to, and intersects with many important aspects of a person’s identity, as well as, facets of needs, rights, development, wants, desires and well-being. Essentially, vasculitis disrobed many of the characteristics that form me while concurrently causing incapacity. The totality of the losses was and have been immense. I have to say, the cumulative losses became taxing, hence, making sense of it and adapting to it totally altered my life.

Because I had not anticipated the losses or the impact of them, I think it is safe to say that my sense of self was slowly budging. In hindsight, I realize that the shift in my sense of self started early—pre-diagnosis with symptoms, that it continued to grow insidiously from there should not have taken me by surprise.

There was both a yearning for the person I use to be, as well as a desire for the end of pain, and fatigue and for getting on with life. I felt like I was on the margins, on the outside looking in, on my life and I did not recognize it. This was especially hard to talk to anyone about.

Now, looking at it globally, I have experienced repeated physical, personal, social and spiritual losses (*see my original diagram below.*) Most striking was and have been, the loss of some sense of self (*the person I use to be before*), sleep, energy, comfort, relationships, as well as a loss of autonomy at times. The loss of my health also lead both to a diminished ability to perform tasks at home, hobbies, and activities (e.g., yoga, swimming, boxing) of daily living that I once enjoyed. It disrupted an established career, seemingly preventing me (at least that how I perceived it at the time) from achieving my goals while putting on my dreams and vision for my career on hold. Gradually, a small degree of hopelessness sneaked in. I also started losing my independence, nothing in my experience to that point prepared me for becoming reliant on other for a ride to the doctor or even for helping with things that I once did without giving it a second thought. My day consists of planning around what I could carry out: cleaning my room, taking a walk, or doing some work. I felt like I need to rest during and in-between tasks otherwise I would just be completely drained of every bit of energy. This is a something that is still difficult to wrap my mind around. I am learning that I can be more mindful of listening to my body and trying not to consciously beat myself up for what I can and cannot do. I fail at this periodically.

The loss of friends, family and colleagues followed. There are many ways to understand and describe a sense of belonging and there are many dimensions to belonging. Knowing where and with whom you belong is integral to human existence and fundamental to well-being. Belonging acknowledges our interdependence with others and the basis of relationships in defining identities.

Because illness have a way of isolating people, initially, I found it difficult to navigate a sort of forced isolation that wasn't intentionally chosen. By virtue of having vasculitis, which none of my friends had heard of, I became more isolated in my experience, than say someone who has a disease like diabetes or even cancer. When I told a few of my friends, about being diagnosed with vasculitis none of them had any idea what that meant for me, some didn't even bother to ask what it was. As time elapse I started losing friends, I think in part because people just don't know what to say to you. To be frank, although illness, loss and grief are seen as fundamental human experiences; being equipped to tackle these complexities is a challenging enterprise. In general, our illness and grief makes us uncomfortable, therefore, it's not surprising that the illness and grief of others makes us uncomfortable. So, our friends, families and workplaces often reflect this tendency as well.

Further, friends, family and in general people who haven't gone through a life-changing experience such as what a disease like vasculitis can impose on you, sometimes can't understand the immense feeling of loss that you experience. Consequently, it is not uncommon for them to impose on you unrealistic and unsustainable expectations of 'positivity' that can minimize your losses or sidestep it all together. Well-meaning friends, and families often compounded the difficulty. Some, for example, tried to add a helpful perspective by saying, "it could be worse" or "you look fine considering..."—at the core those statements really invalidated my physical and emotional suffering, but more specifically it meant that my losses remained invisible to them. This was a gigantic roadblock for me in having dialogue with these individuals. I suppose I construed it as trivializing and indifferent and further deduced from it that they were unconcerned about the losses I was experiencing and adjustments I was having to make—truth be told that wasn't their intention at all.

An auto-immune disease or chronic illness changes the power and role dynamic in relationships. It also, shifts the independence, interdependence and co-dependence continuum. For me, it felt like in my small circle of trusted individuals some became caregivers in a sense. This not only challenged some of those relationships, but

created tremendous tension, which in turn lead to irritability and frustration on my part and poor communication in general.

Not being able predict when I might have a ‘good day’ or a ‘bad day’ – or even intermittent ‘bad spells’ during any given day meant that the stability of a work day that I would typically enjoy was dwindling. For a while I could work and excelled at it. However, as time went on, it felt like I had to restrict all other activities to combat the fatigue, as well as manage the demands of my job. Disruptions in my days soon became the norm. At some point, I essentially lost the ability to minimize my physical condition, and the symptoms began to occupy my concentration, living me in constant discomfort, and with many medical appointments. The nuances of the disease occupied not just my thoughts and energy, but also my days. At times, I had to take breaks to simple just breathe through the depths of what I was experiencing. I was hanging in there when I was sick and trying to figure out ways to carry on my work demands despite my symptoms. In my mind, I could not just stay home each time a I had a flared up. At some point, short term disability became the most viable option—but coping with the decision affect me, in more ways than I wanted to disclose to anyone. Two weeks of disability quickly turned into a month, which turned into another month and before you knew it, five months had gone by; I had used up my short-term disability and I wasn’t in a place to transition back to work yet. I felt like I had loss my career—that was a massive blow.

The loss of some degree of autonomy that rendered me voiceless on some occasion proved a hard pill to swallow. This loss of some sense of autonomy and agency often occurred and still do sometimes in interaction with medical professionals in decision-making process regarding medical processes, or how I should thinking and feelings. The resultant effect was often reflected in my diminished internal fight and motivation to sustain engagement with medical professionals at times. Pre-diagnosis many Physicians discounted what I was feeling when I was seeking help for early troubling symptoms, some were dismissive and even talked downed at me and rendered me both a passive recipient of care and a voiceless partner in processes about me. The consequences of the disease—with friends, family and doctors – have been far-reaching and it has led at times to despair.

For me, autonomy and being an active participant in processes that have implication for my well-being has intrinsic value. I had a difficult time engaging with any medical professional that discounted my thoughts and feelings or told me how I should think and feel about something I was experiencing. I think I would have been more receptive to letting someone played a greater role in decision making processes if those interactions were collaborative, and empowering.

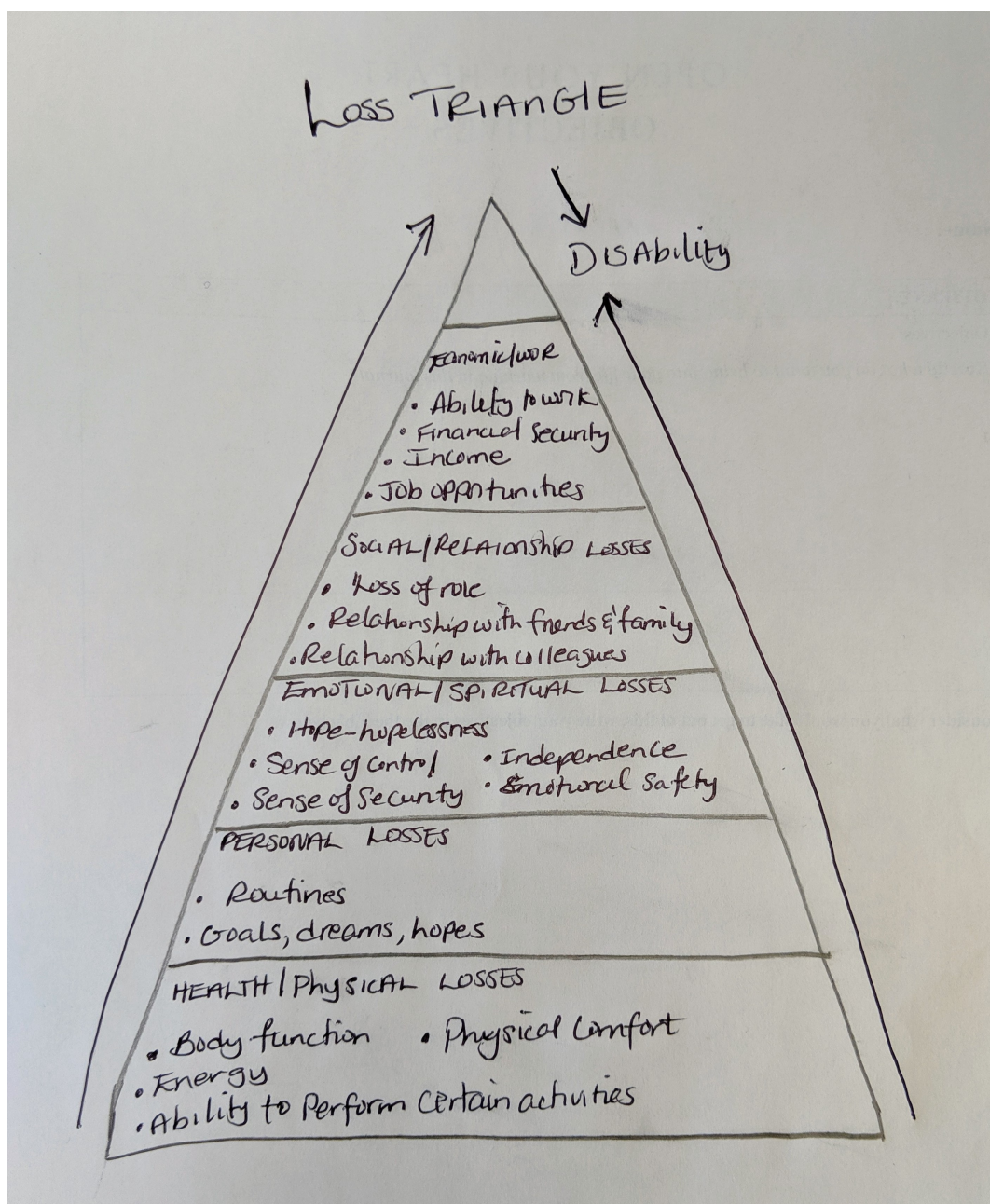
In all of this, I discovered that It was difficult for people to see my losses, so, how could they understand my losses when it was obscure to them. It created many an awkward moment and I must confess that my silence at times was probably too much for most to bare. Consequently, some of my friends and family were not able to validate the experience of the losses and help me move through and beyond grief. I do not even think loss, grief and illness in the same sentence ever crossed some of their minds. To be fair, I don’t believe that most of them would be adept in distinguishing the signs of grief or loss. Most people may recognize sadness after someone dies, but grief and illness is a lot harder for people to conceptualize.

Importantly, the lesson I learned from all this is that loss, like illness and grief, shifts the landscape and consequently changes the plot in your story. Along the way I have lost many friendships and familial relationship, the dynamics of inclusion and exclusion, support and no support had implications on my perception of where or whether I felt I belong. I now realize that it is not about how many friends or family is here for me, it is about me having a sense of positive belonging, and that when that happens I am more likely to invest in letting people in, engage with others and focus on who I want to be outside of the disease.

Since the diagnosis I have had to carve a different sense of being, belonging and becoming. When we go through challenges, especially illness it takes a concerted effort to not identify as the 'disease' or the predominant emotion we experience. Because vasculitis marked a shift in my plot, without that conscious awareness I found my identity shifted to reflect the illness. I had to work at getting to a place where I understood and accepted that illness, and grief are not personal characteristics or personal flaws.

Therefore, it became important for me to appreciate that the concept of being is about valuing, perceiving and having an understanding and acceptance of myself for who I am, rather than seeing myself as a diagnosis. When I saw myself as 'the diagnosis' I did not recognize 'me', but when I saw the disease as separate from me, I had a better perspective on how I could evolve in all this. It truly was about recognizing when I was doing the best I could to navigate and engage with the complex layers the disease was throwing at me. It was also about being aware of my emotions, thoughts and behaviour with regard to the losses I was experiencing without judgment. I think, in general, the dynamics of loss from auto-immune disease or chronic illnesses involves dissolution, alienation, loss of personal identity and/or a sense of meaninglessness. You have to adjust your aspirations, lifestyle, and employment.

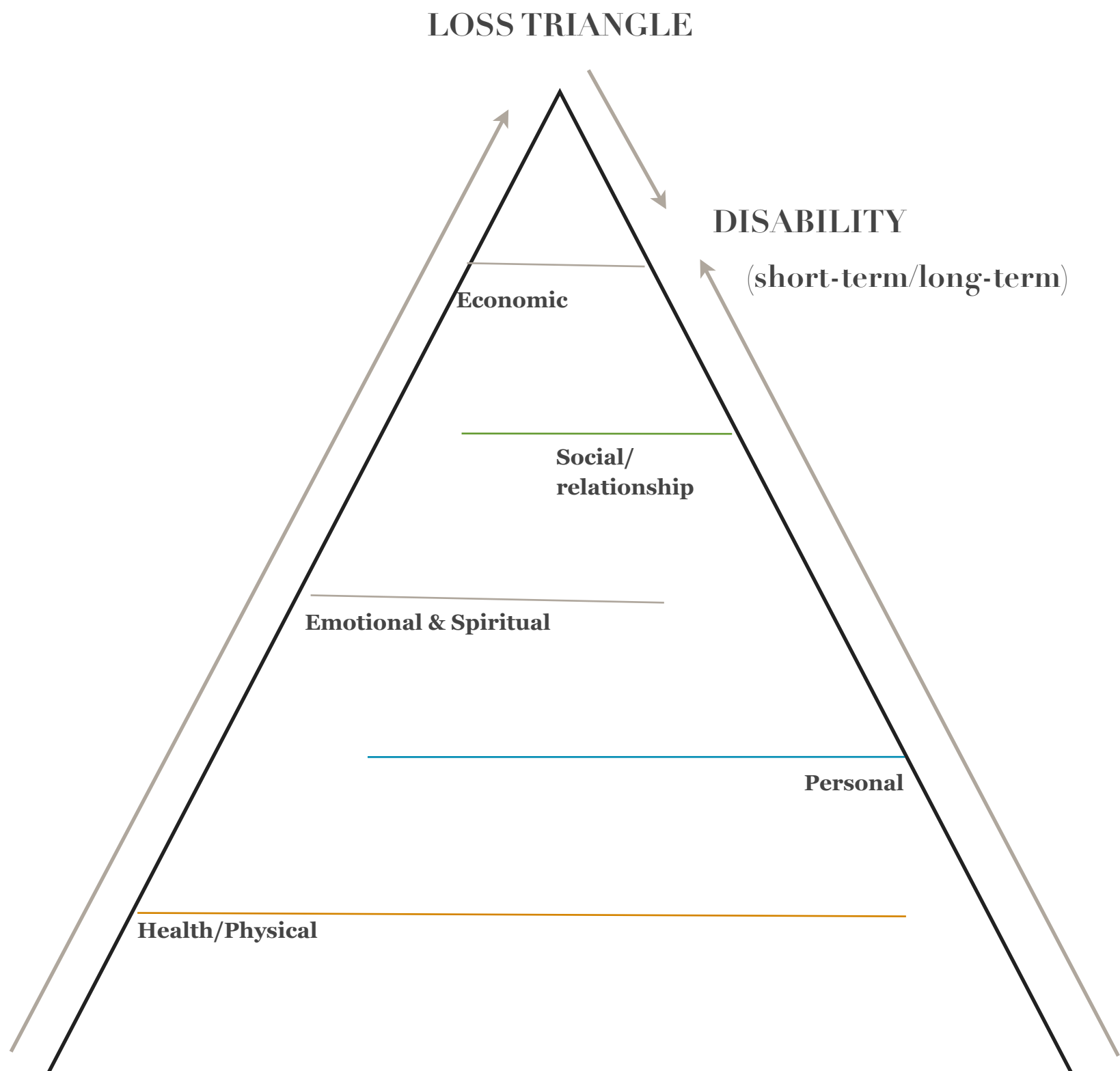
Below I have included my drawing, which I called my loss triangle. I used it to help me take a deeper look at my losses, it was also my way to really see the losses and acknowledge them.



YOUR PERSONAL REFLECTION

OPEN TO THE PRESENCE OF YOUR LOSS

It is necessary to open to the presence of your loss. Naming the losses and acknowledging them are the first steps to dealing with them. It's actually the process of becoming attuned to your losses that will help you heal. Take some time to list your losses in the triangle below.



Auto-Immune diseases/chronic illnesses are often unpredictable and the way you respond to it requires constant readjusting. In the table below explore your losses.

Name a loss you have experience	How have this loss affect you?	How has this loss impacted your relationships?	What were some of the reactions you had after this loss?	When you think about the lost, what was the hardest or worst part?

"Loss is part of life. If you don't have loss, you don't grow".

Dominick Cruz

FREE WRITING

Think about your experience of loss and write about it.

"Every sickness has an alien quality, a feeling of invasion and loss of control that is evident in the language we use about it."

Siri Hustvedt,

