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My Body, Our Illness: Negotiating Relational and Identity Tensions of Living with  
Mental Illness

Erin E. Casey

A thesis submitted to the Graduate Faculty of

JAMES MADISON UNIVERSITY

In

Partial Fulfillment of the Requirements

for the degree of

Master of the Arts

Communication & Advocacy

May 2016

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FACULTY COMMITTEE:

Committee Chair: Dr. Carlos Alemán

Committee Members/ Readers:

Dr. Melissa Alemán

Dr. Sharlene Richards

## DEDICATION

For those diagnosed

For those feeling lost

For those unable to find solid ground

For the manic

For the depressed

For the obsessed

For the chaotic

For the distorted

For the recovered

For the recovering

For those who don't even know what that means

For each of us,

And for those who stand with us.

We are not alone.

## ACKNOWLEDGMENTS

Entering my Masters program I had one goal: to get through it. I was nervous. I really didn't believe I had that much to offer as a student or as a scholar. I defined myself as a mental health advocate, and saw this program as a means to an end, an opportunity to advance my future career. However, at some point during the second semester of my first year that began to change. I asked Dr. Carlos Alemán to be my thesis advisor because of a sense of security I felt when talking with him and a connection that I felt because of his own advocacy work in the community. I sensed relatively early on that working with Carlos would be somewhat of an adventure, but I never could have imagined how truly transformative our work together has turned out to be for me as an advocate, a scholar and most importantly a person.

Through hours of Monday afternoon meetings, the hundreds of emails we have exchanged, and talking through my fits of self-doubt and insecurity Carlos helped me to re-experience my self as a capable student, a scholar, and person with something to offer the world. This part of my identity I believed to be gone - lost years earlier as I plunged into the depths of my mental illness, and in the often-exhausting endeavor of redefining myself in the recovery process. He never ceased to amaze me with his patience, humility, willingness to listen and desire to understand my perspective. He always had more confidence in my ability as a student than I ever did, and never failed to remind me of his unwavering belief in my abilities.

It was working with him that gave me the courage to believe in myself once again and the confidence to take new risks and put myself out there like never before. It feels

impossible to express just how grateful I am for the time we've worked together on this project here in these few words. But, Carlos, know that my life and sense of self have forever changed in a truly incredible way. Otis.

Additionally, I would like to thank my two other committee members, Dr. Melissa Alemán and Dr. Sharlene Richards for their time, energy and willingness to read my work. I've considered it a great honor having been afforded the opportunity to learn from Melissa in a directed study. She began my journey of autoethnography with me, and I couldn't have done this project without her preparation and encouragement. Melissa, I will always look up to you and admire the work that you do as an academic, a professor and an advocate.

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## ABSTRACT

This thesis uses an autoethnographic methodology informed by narrative theory to interrogate my experiences of relational and identity tensions as both a consumer of mental health services and an advocate for the care, autonomy and acceptance of those who identify with concepts of mental illness recovery. In doing so I am using my personal diaries and medical records from the past seven years as archival data to assist me in recovering and reconstructing narratives that represent meaningful truths about these experiences. I also call on heavily what Carolyn Ellis (2004) calls "relational ethics" because I know that while I am sharing my stories I am also sharing the stories of those closest to me, specifically my friends, family and treatment providers. Wherever possible I use pseudonyms and changing identifying information, however when that is not possible I think thoughtfully and reflexively about what sharing the story could do to them and to our relationship. Finally, I propose that this autoethnographic inquiry is a work of advocacy itself. We live in a world today where there are false boundaries between the mad and the sane and the sick and the well. However, I know a world much more fluid and fragmented than that. I hope to bring the reader into that world through the storying of my experience.



## INTRODUCTION: A PRELUDE

My dance teacher, Janelle<sup>1</sup>, sat behind a large, bulky brown desk in the center of the room. Her office felt empty and full at the same time. It was undecorated except for the overfilled brown cardboard boxes stacked up against the walls. Strips of neon fabric and strings of glitter poured from their brims. Seeing Janelle behind the desk made my stomach lurch with sharp bolts and swirl with waves of fear and anxiety. I had never seen her behind a desk, not in ten years. I just knew something bad was about to happen. She looked the same I guess, but different. A thick layer of makeup covered her face. It looked perfect. Typical. She would teach classes all day and her makeup would sweat, smudge and melt down her face, and she would still look perfect. I can still hear the voice inside me: *I want to be just like her.*

“How are things today?” she asked me, expectantly. Her tone was more stiff than normal. We had become close over the years. The strained distance in her voice seemed new.

“Fine.” I stared at the floor. Something bad was about to happen. I felt it in my bones and chaotic gut. I saw it written across Janelle’s perfectly made up face. Her eyes were soft as she looked down at the empty desk then back up towards me. My heart thumped loudly in my ears, pulsing painfully. Something bad was about to happen.

“Are your parents on their way?” she asked, attempting normalcy in her tone. She knew they were coming. She called them. I couldn’t look at her. We sat silently, listening to the beat of the music from the studio down the hall, I stared at the floor, focusing my

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<sup>1</sup> All names of institutions, businesses, or persons other than myself are pseudonyms.

attention on counting each individual square etched in the gray patterned carpet.

Something bad was about to happen. My parents showed up.

Two red plastic chairs were positioned directly in front of Janelle's desk. My mother plopped her purse on the floor, crossed her legs and said hi to Janelle casually. My father sat awkwardly in the other red chair, without saying a word. His large body shifted uncomfortably in the small chair. I sat in a chair off to the side. My dad cleared his throat, rested his hands on his legs, and glanced down towards the floor, back up to me, and then towards Janelle.

My dad was not a fan of Janelle or the studio. Each month my parents wrote a large check to the studio for classes, costumes, competition fees and choreographers. In return, I would spend my afternoons dancing and my evenings crying and obsessing over my mistakes, corrections, and fears about my placement within the studio. Each time my father suggested I quit, I adamantly explained my love for dance and my allegiance to my studio, my second home.

There we sat. My stomach dropped. I believed that if I were to open my mouth, I would vomit all over everyone. I concentrated on sealing my lips shut as tightly as I could. Janelle began the meeting. Something bad was about to happen.

“Thank you, both, Sam and Brenda for coming in today. We really need to discuss Erin. I'm very concerned about her.” She looked first towards my mom, then to my father.

I am invisible. I looked up at Janelle. Her lips shook slightly and her eyes filled with teardrops. *Please don't cry. Please don't cry. Please don't cry.* Seeing her nervous and sad shocked me. She was the most confident woman that I knew. She looked scared,

no sad. Scared and sad. She glanced over at me fleetingly, almost apologetically. She knew that what was about to come out of her mouth was going to hurt. *Please, don't.* I thought for a second that I had said “no, don't” aloud, but I couldn't have; my lips were still sealed shut. I stared back at the carpet; unable to remember which square I last counted. My father stared straight ahead at the white wall behind Janelle and my mother glanced down towards her lap. I suspect that they also knew what was coming.

“There isn't an easy way to say this, but Erin is very sick. She has been forcing herself to throw up and consuming a lot of diet pills, laxatives, and diuretics.”

She told my parents my secret in front of me, and I couldn't prevent an onslaught of tears from welling up in my eyes and pouring down my face. I was humiliated. Even worse, I knew my father was humiliated. My mom looked over at me then back to Janelle.

“You know girls these days,” my mom replied.

*No mom, tell us.*

“I know Erin has been dieting and trying to be healthy, I guess it went a little too far,” She rationalized to herself aloud.

*Very sick. A little too far.* Their words circled my brain.

Now sobbing, with streams of snot running down my face I turned to my mother. “A little too far?!” I screamed, my mouth now full, loud and open. “You think this is a diet?!” I stared at the ceiling for a moment, tears and snot flowing from my face down into my lap and seeping into the carpet. I am invisible.

“I—I hate myself!” I wailed.

It's true. I did hate myself, so much so that my body wasn't my body anymore but rather an object for me to manipulate, test, push, hurt, deprive and control. Which is what I needed because everything about me was wrong and bad. I was bad.

"Erin lower your voice, there are people in the other room." My dad spoke for the first time softly and sternly. I couldn't look at him.

"I don't care! It's not a secret!" I screamed more.

My father shut up and slouched back into his chair and crossed his arms. He became an angry child, pouting in the corner. As far as he was concerned this meeting was over. I had seen this behavior before. Typical. All three of them stared at me now. My entire body shook, and no amount of control or manipulation could stop it.

*I just want to go home.*

*I just want to be alone.*

*I just need space.*

My mother got up from her chair and kneeled on the floor beside me, wrapping her arms around my waist.

"Shhhhh. It's okay sweetie. It's all right." I regained control of myself and stopped crying, my mother still held on to me tightly.

*I just want to be alone.*

*I just need space.*

"I'm okay." I breathed, reaching for a tissue from the desk Janelle sat behind.

*I wish I could throw up.*

I needed to purge myself of my father's embarrassment, my dance teacher's betrayal, and my mother's stupidity. I needed to be clean from it all.

“We’ll get you help sweetie,” my mother whispered into my lap.

*I know what I need, thank you.*

*I just need to be alone.*

*I just need space.*

For a few moments, we all sat in silence. My body ached and twitched in weird ways, I couldn’t control it, it was happening around me. I was forcibly emotionally and mentally stripped naked. Nothing could have prepared me for this assault. I curled my knees to my chest and buried my head in them, forcing my mother to release her grip on me.

*I just need to be alone.*

*I just need space.*

*I need this to be over.*

Janelle broke the silence. “We really feel it is best for both Erin and the community here at the studio if Erin does not return to dance classes here in the fall.” Immediately I lifted my eyes to meet hers. She stared directly and intentionally at my father. She wouldn’t look at me.

*I am invisible.*

*I want to die.*

“You’re kicking me out?!” I said with all the accusation in my voice I could manage. My mom wrapped her hand around my leg and squeezed tightly.

*I wish she would stop touching me.*

“Well, yes, we are asking you to leave. You are not healthy enough for this environment and your behavior is affecting the other dancers.”

More silence.

“Are you kidding me?” my voice growing louder again as I stood up from my seat and paced around the room.

“This isn’t happening,” I mumbled over and over again.

*I am invisible.*

*I want to die.*

*I just need to be alone.*

My head spun remembering Janelle saying “I believe in you,” and “I see you,” and “You can trust me,” and of course “I care about you.”

Lies.

Tears began to come again. I tried desperately to push them back down. Proudful, I didn’t want her to see me sad. I wanted to show her that I didn’t need her or this studio, even if I couldn’t comprehend not coming every day. I continued to pace.

“If she gets help can she come back?” my mom asked, trying to salvage the place that I had called my second home for ten years. I was barely listening.

*I just need to be alone.*

*I just need space.*

*I need this to be over.*

“We feel that it is best to end our relationship altogether,” Janelle said, again looking at my father.

*Why does she keep looking at him? He isn’t going to respond.*

Then Janelle looked directly into my eyes for the first time during this entire situation and said, “Erin, we care a lot about you. We care more about you than you will ever know. We have to do what is best for you.”

My heart broke while more tears filled my eyes and a lump formed in the back of my throat. I officially failed as a student, dancer, and human being. People who supposedly cared for me didn’t want to be around me and felt the need to protect others from me. I was a problem. I was the problem. The solution was to remove me.

My father stood up. “Come on Erin, let’s go.”

I wanted to leave so badly, but now I couldn’t leave. I didn’t want to leave. This was my home. This was my sanctuary. My mother put her hand on my back and guided me towards the door. Janelle stretched her arm out and pulled me by the shoulder into a tight embrace.

She whispered sadly in my ear, “Promise me you’ll fight Erin. Promise me you’ll get better.” Without a word, I tore away and walked out into the parking lot with my parents lost and confused. As we pulled out of the parking lot, I gazed back at the two-story brick building that was once my second home. As I lay in bed awake, I listened to my parents argue:

“What are we going to do?”

“I don’t know maybe it’s not that bad.”

“I think it’s the studio’s fault.”

“She needs a doctor or therapist or something.”

“I’ll look at our health insurance benefits hopefully they cover therapy.”

“Janelle is an idiot.”

“We’ll look for a new studio tomorrow.”



## CHAPTER I

I will never forget that day at the Karis Dance Company. I was 15 years old. Even today my palms sweat a little and my heart races thinking about sitting in that room, and how I lost a role model, a mentor, and friend. More importantly, I lost the belief that anyone could protect me from the dark and scary hell that is my mind. I lost the ability to pretend that I was okay with my family and friends. I lost the kind lie that I told myself each night as I went to sleep: tomorrow will be better.

My family too was confronted with truths that they were not prepared for, truths that for which none of us could ever be prepared. Nonetheless, we owned them, they were and are our truths and came at us violently demanding our attention with the onset of my mental and physical deterioration.

The reality is that my medical records clearly document that over the past ten years I have been diagnosed with anorexia nervosa, bulimia nervosa, major depressive disorder, bipolar disorder, body dysmorphic disorder, post-traumatic stress disorder, generalized anxiety disorder and borderline personality disorder at varying times by varying clinicians. I have seen eight psychiatrists and 15 therapists. I have been through four acute partial hospitalization programs, two acute inpatient psychiatric programs, one long-term residential program and hundreds of individual outpatient therapy, group therapy and psychiatry appointments. Throughout these programs doctors and clinicians, I have been prescribed 18 different psychotropic medications. Within the pages documenting these illnesses from a professional lens, I have been described as “non-compliant,” “resistant to treatment,” and “combative,” among other things.

I know that the medical record of my life is just one narrow lens through which my experience has been defined and storied by others. It is a story written about me, but not by me; a professional account of my life as framed by diagnoses and treatments. But even as I acknowledge my awareness of the incompleteness of my medical script, I feel myself becoming nervous. I hear myself wondering how any reader could want anything to do with me or take what I have to say as legitimate. I am conscious that my narrative of negotiating mental illness, treatment and recovery is culturally stigmatized and to be shamed. However, this narrative is not just mine; mental illness is not just mine. It is not just my story, my stigma, or my shame to bear. How we story mental illness belongs to all of us.

According to a 2013 Fact Sheet by the National Alliance on Mental Illness, one in four adults experiences a mental illness each year, and one in 17 adults experiences what is considered a severe mental illness (NAMI, 2013). With 25% of adults experiencing some mental illness during their lifetime, it is likely that everyone is somehow affected. Experience with mental illness is virtually unavoidable. If you do not have a mental illness yourself, then the probability is that someone you know and love does, possibly without you knowing it. You may be unaware because we hide. We meet anonymously in support groups, confidential treatment settings, and online message boards and communities. I have taken refuge in these hiding places numerous times when feeling misunderstood, alone and lost in the world.

The stigma and shame associated with mental illness have undoubtedly helped to support many of the barriers for accessing the experience of living with a mental illness in academic fields outside of the psychiatric and medical sciences. Traditional methods

and inquiry of both quantitative and qualitative research in the social sciences are limited by ideals of objectivity and verifiability. Instead, Pilgrim (2009) argues for ethnographic “context-dependent” and “practice near” accounts of mental illness, treatment, and recovery, Pilgrim (2009) asks:

In practice, how might we judge that these people have recovered from their mental health problem? Whom should we ask to give us this verdict? What is wrong with these people and so what are they recovering “from”? ... What if patients have a different view of their significant others and their treating professionals about what they are looking for to recover from their difficulties (p. 447)?

These questions that Pilgrim raises are deeply embedded not only within the context of their environmental, cultural, social and political systems, but also an individual’s own sense of self and others, identity, biology, and physiology.

Pilgrim's questions about the nature and experience of living with the ambiguous nature recovery and mental illness are issues that remain within society. By similarly employing autoethnographic methods of inquiry, I seek to engage with some of these questions. I interrogate my medical records, my private diaries, and my lived experiences so as to produce narratives that share my experience of negotiating mental illness, my relationships, and my sense of identity.

### **Purpose and Objectives**

The purpose of this thesis is to explore relational and identity tensions I experienced while negotiating mental illness, with the intention of drawing insights for mental health advocacy. I utilized an autoethnographic method informed by narrative

theory to reflect upon episodes of significant interpersonal negotiations with my mental illness. I used my personal diaries and formal medical records as archives as I called on my own experiences navigating the relational and identity tensions in accepting myself and being accepted by others as an individual with mental illness and as an advocate for mental health. In the writing and sharing of myself through my stories, I emphasized that while I embody the illness, I am merely one of many owners.

Fisher (1985) describes human beings as natural storytellers; the stories we tell are persuasive, aesthetic and relational acts. Hutto (2007) adds that sharing stories is a self-reflexive practice that gives us the ability to empathize with experiences that are not our own. Our individual stories reflect upon and connect to larger narratives of the social world. Because of this, narratives and stories offer an important means of studying both our personal identities and the social world. Scholars such as Kirkman (2002) and Charon (2006) call for valuing and incorporating narratives within traditional fields of medicine and community psychology because of the in-depth insight and understandings of meanings that stories provide. Schiffrin (1996) further states, “The way we tell our stories also reveals a self that exists within a cultural matrix of meanings, beliefs, and normative practices” (p. 170). Beyond the richness of experiential knowledge that cultural and personal narratives provide, it is through narrating, writing and rewriting stories and narratives that individuals can re-write experiences, identities and relationships (Anonymous, 2015).

### **Narrative Theory and the Reflective Self**

For Fisher, it is paramount that we study narratives as constructs and fundamental aspects of human communication, but also as a social critique (1984, 1985). Fisher (1984) describes this narrative paradigm as,

...a dialectical synthesis of two traditional strands in the history of rhetoric: the argumentative, persuasive theme and the literary, aesthetic themes... [T]he narrative paradigm insists that human communication should be viewed as historical as well as situational, as stories competing with other stories constituted by good reasons, as being rational when they satisfy the demands of narrative probability and narrative fidelity, and as inevitably moral inducements. (p. 266)

Here, Fisher describes narrative as a rational act of accounting, describing and providing understanding and context to our lives, behaviors, and stories, embedded within the cultural, political and social contexts of our lives. Fisher this describes narrative rationality as means for evaluating and distinguishing narrative practices. Narrative probability refers to story features such as sequence and coherence; narrative fidelity refers to the truth qualities and logicity and reasoning within the narrative structure. Additionally, he argues that “narrativity as a legitimate and useful way to interpret and understand human relations” (p. 350). It is within this paradigm of narrative theory that people experience not one true objective reality, but rather multiple realities founded on meaning-making and narrative truths. It centers on being and becoming rather than knowing, henceforth there is no one true objective reality, but rather multiple realities founded on meaning-making and narrative truths (Spence, 1984).

Congruently, Baumeister and Newman (1994) say that our stories “serve both as ways of interpreting experience and as a means of communicating with others” (p. 680) which enables relational agency, and provides a mode for social interaction. This contextual relationship occurs through temporality and emplotment, allowing us to cognitively organize our stories and experiences in a temporal framework and construct a sense of significance from them (Polkinghorne, 1991). However, in scholarship and in dominant frameworks of narrative theory there is an assumption that the temporal framework needs to be linear, and based on my own advocacy work and my experience as an individual with mental illness I challenge that.

Looking back on my private diary entries and my medical records, it became clear to me that for a long time I did not believe that I had any narrative or story to speak of. My moments were lived in the present minute-to-minute, with the only reality being the one I existed within any given second. There was neither past nor future, or at least none that seemingly had any bearing on my present moment, feeling or thought. Through extensive therapy, I have been afforded the skills and awareness to make connections and understand my experience through cognitive ordering and narrative practices, such as emplotment and meaning-making. Crossley (2000) writes specifically of the use of narrative in the chaos and disordered experiences for the purpose of rebuilding a person’s shattered sense of identity and meaning, emphasizing the link between the self, temporality, relationships and morality. Other critical disability and narrative scholars similarly report that when a narrative is disrupted temporally by illness or traumatic experience, the purpose of narrative shifts from temporality and ordering to meaning-

making (Crossley, 2000; Cardillo, 2010; Burn & Birrell, 2014; Delbene, 2011; Torn, 2009).

Vollmer (2005) writes, “the view that a person creates his identity by forming an autobiography that conforms with the view of him held by others is called the ‘narrative self-constitution’” (p. 196). Vollmer’s words direct attention to the social and cultural meta-narratives that inform and constrain the communication of self. One meta-narrative that permeates modern society is the biomedical narrative of illness and disease as treatable and controllable. According to Decon (2013), “the biomedical model posits that mental disorders are brain diseases and emphasize pharmacological treatment to target presumed biological abnormalities” (p. 846). This focus on the physical body presents a stark contrast to pre-modern narrative of the spiritual revelation and philosophical expression found in stories of madness. According to Foucault (1988), this shift from spiritual to biomedical was an exercise of power and control over madness, and the uncertainty and fear that accompanied it.

Nguyen-Finn (2012) writes that such meta-narratives of control lead to warehousing and categorizing of the mentally ill so that individuals in mainstream society are able to distance themselves both mentally and physically from madness. Sedwick (2013) similarly asserts the traditional scientific paradigm “craves the comfort and security that the vision of a life devoid of suffering promises” (p. 317). This highlights and emphasizes the medicalization of mental suffering that still exist today. While the long-term mass warehousing of individuals with mental illness has ceased, a system of classification remains in the form of diagnostic psychiatry (Wilson, 1993). Through this

method, experiences of suffering are squashed into diagnostic criteria as a means to explain symptoms and behaviors that are socially deemed abnormal.

Fortunately, contemporary scholars have argued for the inclusion and value of illness narratives in spaces of the academy because of their cultural situation, standpoint and revealing nature (Skultans, 2000). Cardillo (2010) describes illness narratives as ‘giving voice’ back to the ill and disabled. She reminds us, “Our society privileges those with undamaged bodies and minds to speak with a stronger voice than the voice of ‘others’” (p. 42). Creating spaces that elevate the stories of mental illness advocate for a shift and a change in what is considered expertise and challenge the privileged ideologies of undamaged and able bodies and minds. In his seminal work, *The Wounded Storyteller*, Frank (1995) lays out a framework for understanding illness based on three general narratives: restitution, quest, and chaos.

Restitution narratives speak from the biomedical paradigm, reflecting both consumption and commodification as means to overcome suffering. Within this narrative, illness is described as a temporary period marked by a before and an after, and resembling the following: an individual falls ill, seeks help, receives help and finds himself or herself well again (Frank, 1995). According to Frank, the cultural power of restitution illness narratives is that its telling reproduces one of the best impulses of modernity: applied science as self-overcoming. Restitution stories inscribe a modernist narrative both in illness experience and in medical treatment, and according to Frank, is the most culturally dominant form of illness narrative. Restitution can frequently be seen in television commercials, newspaper ads and told and retold as part of our cultural



“norm” or sickness and health. This story offers and immediate hope that there is a light at the end of the tunnel.

Quest narratives differ in that they describe the illness as a journey or experience that has transformed the person who has fallen ill into something new, rather than a return to a previous state of health. Quest stories are narratives that turn illness into something meaningful by accepting the illness and using it for the moral good. It is reflected by the ill person taking control of their perspective and narrative as a means of sense-making, meaning-making and purpose (Frank, 1995).

Finally, chaos narratives are described as the most marginalized illness narrative (Frank, 1995). Chaos is depicted in expressions of despair, grief, fear, and weakness. It is a familiar narrative of chronic and mental illnesses. Frank highlights the importance of these chaos narratives on a personal level for the individual suffering, to be heard and to deal with their feelings of fear and distress. He argues that chaos stories need to be told to provide a rounded picture of a person’s experience of illness.

I find that even within this movement toward elevating illness narratives in scholarship and medical spaces there is still pressure to conform and perform them in particular ways. Their performance functions to voice and reinforce dominating ideals about what it means to be sick and to suffer. Cardillo (2010) echoes this stating, Autobiographies of disability and illness may be constrained by strong cultural expectations that the narrative is one of inspiration and the triumph of an exceptional person over his or her (unacceptable) disability (p. 529). These strong cultural expectations can mean negative implications for individuals whose narrated experience does not fit a socially desired model.

Hopefully, this causes you to pause. In our efforts to elevate illness narratives we simultaneously culturally stigmatize illness experiences that don't fit within our cultural expectation. In doing so, marginalizing narratives of suffering and healing that don't fit within the traditional dominant frameworks of narrative theory and linearity. The dominance of these meta-narratives of illness means that alternative accounts and experiences may be thoughtlessly rejected or actively altered to fit the expected narrative structure. This becomes highly problematic for individuals who experience illness in ways that don't fit into that paradigm, such as chronic illnesses, terminal illnesses, and mental illnesses (Cardillo, 2010).

Bulow and Hyden (2003) offer the constructs of turning points and shadowing as useful frames for more thoughtfully reflecting on the temporality of alternative illness narratives. Turning points resemble what Delbene (2011) calls a biographical disruption in illness narratives. Rather than pointing to the moment of diagnosis, turning points add emphasis to many different moments when an individual comes to realizations and revelations that change their perspective of their situation. Shadowing is a narrative practices used to gain greater understanding and insight into life events in light of the turning points. Bulow and Hyden (2003) describe "back shadowing" as looking back on illness experiences with more clarity or understanding after a turning point. "Sideshadowing" is when a narrator examines what their life may have looked like had their illness not occurred. Bulow and Hyden state: "It is a shadow that opens the door for other alternative courses of events both n the past and in the future" (p. 90). Finally, vortex time is used to describe stagnation and fixation on a specific moment of struggle without a feeling of movement forward toward or beyond anything.

## Methodology

I walk in my therapist's back office and plop down on her green sofa. I always feel comfortable here; her office is one of my safe spaces.

"How are you today? She asks as she picks up her tumbler to take a sip of water, and raises her legs up on the autumn.

"I am good," I say, trying to think about how this past week has been.

"I had a message from you - I think it was Sunday night. What happened that night," she asked concerned. I could not remember. I think I remember it being a hard night, but I do not remember now, it has passed.

"I am not sure, I am fine now, though." I smile. "Oh, but we do need to request all of my medical records." Jessica shifted in her seat.

"I've been thinking about that," she says. I knew this was going to happen.

"Erin, do you remember what happened last time you requested records and looked at them? She asked. I knew she was going to bring this up.

"Yeah, I remember. I fired you." I stated flatly. However, this was different this time, though, and she knows it is different.

"I am just worried that we are going to have a similar situation; you went into some pretty severe symptoms after that as well." I tried hard to think back to that time, but it was a blur.

"I came back didn't I?" I said with a wide grin on my face. T did not smile back. "You don't understand; I have to do this. It's for my thesis." I continue. "Remember I am doing an autoethnography?"

“I hear you,” She says, “I just want to be careful. Your health is more important to me than your school.” I rolled my eyes, even though I appreciated her saying that. We sat in silence for a few minutes, before she asked. “Have you talked to your family about it yet?”

### **The Self-Reflexivity of Auto-Ethnographic Writing**

Bochner (2000) writes, “Alternative ethnography only extends our understanding of and commitment to the multiplicity and plurality of legitimate goals for social science inquiry” (p. 268). Alternative ethnography, also known as autoethnography, helps to shift the focus of the qualitative inquiry, from constantly defining itself in comparison to the quantitative, scientific, and empirical modes of research to engaging in and exploring different possibilities, truths, realities and voices altogether (Bochner, 2000; Ellingson, 2009). Through the privileging of the complex-internal-contradiction-filled parts of life and through processes of introspection, self-reflexivity, and writing, researchers cultivate an “epistemology of insiderness” which gives the reader accesses to parts of the lived experience that an outsider's perspective could never achieve (Adams, Jones & Ellis, 2015). However, the work is not solely about an internal experience. The nature of autoethnographic inquiry is designed to combine both the deeply personal with the cultural and political context within which the lived experience occurred (Ellis, 2004). This enables us as researchers to not only address how we see the world but also why we see the world the way that we do (Goodall, 2004). It is this connection between the two, the self-reflexive personal and the cultural, social and political, that separates autoethnography as a method of scholarly inquiry rather than journaling or the simple act of writing stories. The method requires making the personal political (Jones, 2005).

I was drawn to autoethnography for many reasons, one being that I've been struggling with the notion of a mental illness advocate as "recovered." Which to me has seemed to falsify and simplify a very complex health, social, political and cultural situation. I appreciate that this mode of inquiry creates spaces for, and values the complexities and contradictory nature of human experience. Additionally, as a method, it is often used to investigate experiences and highlight voices that are underrepresented by traditional forms of quantitative and qualitative research. In traditional paradigms of research a determination for the researcher to remain objective and removed from the data and participants has created a gap in the types of knowledge that have been available and produced, including a lack of introspective and insider accounts of lived experiences (Ellis, 1991) This is often referred to as the "crisis of representation" and seemed to be a good fit and place for situating my lived experience of mental illness, advocacy, and relationships (Goodall, 2000, p. 57). As both the researcher and the subject of research in this project I have essentially eliminated a power dynamic and removed any false veil of objectivity and instead fully embrace my subjectivity as part of my methodology.

However, delving into autoethnographic inquiry is not as easy as it may sound or seem. It is not just about writing stories. The stories that we write should be evocative and self-reflexive, vulnerable and emotional, believable, demonstrate ethics and meaningful coherence, they should show and not tell, and offer a cultural critique, a new perspective, an insider view or something different altogether (Tracy, 2010; Bochner, 2000; Ellingson, 2009). This is how autoethnographic work is evaluated. Throughout this autographic writing processes these criteria remained in the forefront of my mind, as I grappled with the concepts or meaningful coherence, self-reflexivity and ethics, and will

be reviewed in chapter four at the conclusion of the narrative chapters to assist the readers in evaluating what they have read.

As I wrote, I became acutely aware that the tone of my reflection in my stories was heavily influenced by my mood and state of mind at the time. As a person with bipolar disorder, I can find myself immersed in an intense emotion that impacts how I process information, my memories, and my surrounding environment. I can't help but wonder how these states of emotion impact the evaluated quality of my work. If my narrated reflections appear incoherent or fail to ring true to the rational experiences of the reader. Should I expect them to be rendered less valid or of lesser value?

Life is messy, research is messy, and sometimes my mind is messy. In fact, sometimes my mind can be rather chaotic. As messy and chaotic as my stories of relationships and identity may seem, they present a truth of my personal experiences in negotiating mental illness. They demonstrate a truth, my truth. At times, I resisted the urge to rewrite parts of my reflections as my mood changed for I felt they were telling a story in and of themselves. However, at other times I felt a strong pull to write and rewrite stories and reflections because of what was happening within my current relationships and within myself I envisioned myself standing on a divide trying communicating life on one side of the line to the other. It didn't feel good. I felt afraid, and vulnerable, I felt needy and exposed, I felt isolated.

On my best days I felt competent, hopeful, and determined and would read reflections I had written on a hard day and think, *What the heck was I thinking? Why did I write that? It's so depressing.* On days when my mood felt much lower I would read narratives and reflections that I had written on my better days and think, *I'm so full of*

*shit. I don't actually believe any of this.* Coming to the realization that my writing was heavily effected my moods reminded me of a process that I went through of utilizing my journals in therapy to help me understand my mood shifts, and have attempted since that realization to appreciate it as a truth in my life, in my experience, in my reality that has emerged within this project and to honor that.

\* \* \*

I sat at the kitchen table with my mom and brother while dad finished making dinner. It was summertime, so I had a break from school and a little time off of work. The house smelled like sausage and garlic as my dad was making his famous one-pot spaghetti. Being at home was always hit or miss for me, sometimes home was triggering and other times it felt safe. My mom poured herself another glass of Merlot as I popped a question I had been nervously holding inside of me.

“So, is there anything that you guys do not want me to write about in my thesis? You know, family wise?” I looked at my brother first. I was terrified they were going to list several things. I had recently disclosed to them that I would be writing an autoethnography about living with and negotiating mental illness and advocacy within relationships.

My brother was the first to respond to my question, which was typical. “No. I am not ashamed of anything. Write me as you wish.” He answered my question, regarding the writing of my relationship and him effortlessly. My mom and I burst into fits of laughter because he said it with such an air of authority and resolution. It made me feel proud of him, of the seventeen-year-old he had become. I could not help but feel warm and thankful. We’ve come so far as a family.

“What?” he followed up. “Really,” He emphasized. “I am not embarrassed about my anything.” I smile at him. I love him so much sometimes actually it hurts a little bit.

“What about you, Dad?” He was standing at the counter chopping some garlic.

“Nothing illegal,” He said simply. We all laughed again. From probably an oddly early age my father has always taught us never to put anything illegal in writing, so this was perfectly characteristic of him. He moved on with busying himself around the kitchen, pouring himself and my mom another glass of wine. I looked at my mom, and she gave me a funny look.

Before saying, “Like what? Your dad and I have been perfect parents.” She said, with a high voice and big false grin.

I hesitated here. I knew this could either go very well or very poorly. “Well, like, what about your drinking, Mom?” I asked, nervously.

“You mean my social drinking?” She put her hand on her chest and looked at me as though she had been falsely accused. My brother quickly stood up in my defense.

“Okay, Mom, so social drinking is when you come home blackout drunk, break a window and fall asleep. Then in the morning, you wake all of us kids up, angry, trying to figure out who broke the window. Yeah, okay, that does sounds like social drinking.” Tyler was calm but determined to prove his point. My mom knew we were right. There have been far too many failed ‘I am going to stop drinking’ resolutions to count and even some wishful discussions of participating in alcoholics anonymous. My parents started drinking way before I got critically ill, but I always wonder if my years of intense struggle made their crave for alcohol more intense.



“Okay, okay,” Mom says. “I mean it is fine. You can write whatever you want but make sure you include all the hard stuff we’ve gone through. You have to paint the whole picture.” She follows up.

“What do you mean by the whole picture?” I asked, interested, but again nervous.

“Well, Granddad was an abusive alcoholic.....” Moreover, without a pause or hesitation, my mom listed family member after family member with some addiction or mental illness. “What I mean to say,” she finishes, “is we did not create this, we do the best we can.”

“I know, Mom. I know that. I would never intentionally paint anyone in our family as a villain. We’ve all been through so much.”

\* \* \*

At this moment in the story, I fill with anxiety. I did so as it was happening and again as I wrote it. We as a family have been through so much, and we as a family has come so far, and I know in my heart that my parents want me to do what makes me happiest, most fulfilled, and healthiest. After years of so much pain, I know they would do anything (nearly) to support me in my goals. So I have to wonder even though they say they are okay with my storying our relationship and by default them, are they? What if by some strange happenstance this thing goes public? Will they be hurt? What if reading it is traumatic for them?

I turn to four questions posed by Harter, Japp, and Beck (2005) when thinking about these matters: “What are the consequences my story produces? What kind of person does it shape me into? What new possibilities does it introduce for being in this world? How does ‘my’ story position readers” (p. 11)? These questions remind me of

Ellis' (2004) thinking on relational ethics, and how "writing about yourself always involves writing about others" (Ellis, 2009, p. 13). Relational ethics requires a level of consciousness and awareness to the fact that in autoethnographic writing, unlike other types of research, other people are not there because of voluntary participation; they are there because they are in your life. While we can story these shared experiences using pseudonyms and falsified identifying information, sometimes, as in instances with my family, such anonymity is not possible. It is in those instances that narrators have to be even more conscientious, reflexive and thoughtful. We are tasked with the burden of continually asking ourselves questions regarding information, representation, relationships, and the impact on self and others, including the reader.

The second area of anxiety that erupted at this point in the story was feeling the weight of representing the "Whole Truth" regarding my family, our experience, our relationships and the complexities that exist within it. I understand autoethnography as a method as concerned less with recreating the experience as it happened and more about making meaning of the experience using writing as a mode of inquiry. Because there is no absolute Truth, I cannot represent one in autoethnographic work, or any research.

Goodall (2000) states,

All representations are partial, partisan and problematic. From a strictly literal perspective, there is no available language for a representation that is capable of achieving some Achemedian, all-knowing, all-seeing, godlike point of reference. Words are representations of reality, but reality is far more complex - more full, more radically diverse, and more whole - than any representation of it (p. 55).

Each autoethnographic account is but a partial representation of a far more complex reality. Capturing my family's reality is not a matter of if I am a good enough writer - no matter how good I am all I could ever write is one partial truth, my truth at this point in my life.

\* \* \*

I walk around the table and wrap my arms around her. However she pops up and says, "When I go to MeMaws for my girls weekend I'll get a list of all the mental illness in our family, I know there is more." She walks out of the kitchen and looks for her phone. When she returns, however, she has a new question. "Who is going to read this Erin?" I hesitate for a moment. "If it is just your professor then I do not care what you write," she adds.

"Well, it is a little more complicated than that. I have three committee members so they all will read it definitely, and then I told you about the fellowship I am applying for if I get that then probably a lot more people will read it. It is also going to be available in the library at school" I finish staring at my mom, waiting for a response.

"Okay," she says, looking back up at me. "You were bound to write a book one day anyway." She walked over to my dad who was stirring his pot of sausage, sage, noodles and cheese. "That smells delicious love" and he turns and gives her a kiss.

"Erin and Tyler you guys got the dishes, all right?" He states in the disguise of a question.

"Okay," I say

“We got it,” Tyler adds as he began to set the table. My mom poured herself another glass of wine, and topped my dad’s glass off, and my dad dished the spaghetti out onto everyone’s plates.

For weeks after this interaction with my family, I thought about our interaction. How do I share the complexities of our family experience of mental illness without placing blame? wondered why we as a culture feel the need to find fault and blame. I felt a little sick to my stomach at the thought of exposing them, the people who have sacrificed everything to save my life multiple times. Why am I doing this? In thinking about that question, I refer to my inclination towards autoethnographic research and the value of the internal, the complex, and the underrepresented. I also think about the possibilities that autoethnographic has afforded me as a reader and other researchers as I have read. These include but are not limited to, the (re)writing of past experiences and past relationships (Anonymous, 2015; Poulos, 2014), the healing from traumatic experiences (Giorgio, 2009), and the exploration of grief and loss (Ellis, 1993). It helps me to remind myself that while this is about me, it is not for me. Giorgio (2009) wrote, “When writing to heal ourselves, we help others heal. In doing so, we can make our personal political” (p. 151). This is hope.

I recognize that some autoethnographic work seek to navigate the relational ethics of revealing personal information or misrepresenting the reality of a relational situation through different forms of “member checking,” such as inviting individuals in those stories read for accuracy and characterization. I decided not to engage in this practice for two reasons. The first was that I sought to respect what I heard as my family’s interests of not being too involved in the work and of painting a picture of our efforts as “doing the

best we can.” The second was that I sought to honor my own sensemaking of identity and relationships in this process (Giorgio, 2009). I recognize that this sensemaking process is impacted by my emotional state, which at times fluctuated between highs and lows, optimistic and dreadful, positive and sad.

\* \* \*

Jessica pulled a large packet out of her filing cabinet. “Some new records came in the mail,” She explained as she sat down. “How are you feeling about looking at these?” I sat back and thought for a moment. I did feel okay.

“I feel okay. I know these records of my therapeutic relationships are not records of how my therapists felt about me or if they cared about me or not, they are clinical records of my symptoms and how they were interpreting and making sense of my behavior.” As I finished carefully explaining this to Jessica, I felt proud. I felt like I had learned something and come to understand not only the purpose of these documents but also the role of the clinician in my life. I felt strong. Jessica smiled and handed me the envelope.

Fox (2010) describes his use of archival documents within his autoethnographic research in writing his experience of navigating the power relationships as an LGBTQ student navigating the dominant heterosexual structures of public education as an “auto-archeology.” For my autoethnographic writing and reflective process, I have utilized my medical records and documents as well as old journals and writings, drawings and advocacy related documents to situate my stories, my relationships, my illness and myself as they were happening. These documents also assisted me in accessing and temporally situating my illness experience in ways that have helped me to describe and narrative the

experience in ways that will hopefully make the most sense to an audience that may not have the same or even similar experiences negotiating mental illness as me.

Initially, when requesting my medical records with my current treatment provider, there was hesitation on her part, largely because of prior experience I've had in reading therapeutic records that ended poorly. It took many discussions with my therapist about how these records would be used, why I felt they were relevant to my project and careful planning in regards the inherent triggering nature of the records. We finally agreed that I would only work with my records while in her office so that if there were ever need for me to discuss something within them she would be there to process.

However, because of the great amount of time that I have been in treatment and the vastness of my record we ran into a problem that I really didn't have enough time to carefully go through them while in her office. Additionally, all of my therapy sessions were being consumed by my records when in reality, this project while an enormous portion of my life – was not the entirety of it. I found that to be able to spend time looking at and talking about my medical records I was neglecting other parts of my recovery and wellness that I had been working on during therapy. Eventually, we agreed that I could take my records home. At this point, I had gone through quite a bit of her office, and both Jessica and myself felt confident in my ability to process the records as well as my ability to ask for help in processing them if I need it.

Reading my records has felt different for me, depending on the day or the time that I decided to do it. At times I was very detached and robotic and moved through the records, notes, diagnoses and descriptions of my behaviors, interventions and appearance with little or no emotion – almost as though I were reading about someone else. During

these sessions of detachment, I seemed to be able to plow through quite a bit of material in just a few hours. Alternatively, some days as I would go through my records I relived experiences and emotions very deeply, sometimes so much so that I did not get any writing done at all. During these times, I found it almost impossible to put my experiences into words because I was almost reliving some of the emotions that had engulfed me. When this happened, I often returned to my self-soothing toolbox, reached out to both my professional and personal supports and sometimes when necessary went to sleep to give my brain a chance to calm down.

Though, I've moved through my records emotionally somewhere in the middle, making it a practice to regularly check in with myself and ask: How am I feeling right now? What am I feeling? How do I feel about continuing? Do I need a break? Is there anything that I need to process with my therapist?

I began by tabbing records that stuck out to me, and then returning to them and jotting down why they stuck out to me and following up with them by locating that time within my personal journals. Between the records and my journals I began crafting narratives based on those two archives, my memories, feelings and emotions that were brought up. Within the flagged records and the journal entries three primary types of relationships stuck out to me: my friendships, my clinical relationships, and my family. Initially, this project was set out to include all three of those relationship types. However, within my writing, processing and constructing narratives of my clinical relationships, I realized that not only were the complexities within them too emotionally demanding and complex for the scope of this project as well as for my comfort level in publicly sharing those stories at this time.

In my process of working with these clinical relationships in particular, I discovered histories that were altered and disrupted that created significant new lenses upon which I now had to re-view those experiences. This was beyond the scope of this project, thus I choose to remove the chapter focusing on clinical relationships and plan to continue working with those stories and relationships as an independent autoethnographic project surrounding the nature of these clinical relationships. Because of these things, the focus has now been narrowed to negotiating mental illness with friends and family. While compiling the stories into chapters, I was reminded of another body of work that I had written from October 2011 to January 2012. This is a collection of nearly 200 poems I wrote during the first few months of my considering myself to be “in recovery.” As I was piecing together the narratives into larger stories, I remembered writing particular poems and have since incorporated them into the chapters as well. Additionally, there have been documents and writings by other people that have impacted me and how I’ve interpreted my relationships with my family and friends that I have also included within this work. For both pieces, I obtained permission from the authors to share the pieces because of their significance for me in understanding my relationships with mental illness.

The next three chapters are one product of this autoethnographic research and writing process. Chapter two focuses on friendships and chapter three focuses on family. The conclusion of each chapter contains a short reflective epilogue. Finally, chapter four will reflect on the project as a whole as a form a mental health advocacy.



**Figure 1: Poem**

Where I stand  
Is not a good place to be  
That's what I said in 2003.

When I was on the outside  
Looking in,  
To the pain, the struggle, the lies.

Encouragement would stream from me,  
As confusion haunted endlessly.

You are really pretty,  
I would say so willingly.  
But the words were pushed away.  
Without care, without say.

Years would pass by.  
Building upon this invisible guard.  
The turmoil to a precious heart,  
Burning away with each drop of a cry.

On the outside looking in,  
is exactly where I stood.  
Trying to get her thoughts to bend,  
with each and every smile that I could.

Hanging out became a struggle,  
Too many calories, stats and negativity to juggle.  
But standing strong is where I stood.  
Bearing it like a best friend should.

As time passed,  
Growth and strength have taken her place,  
God, at last there are the smiles upon her face.

Where I Stand today is blessed and amazed,  
At a friend who has conquered so much  
Trials, tribulations, and such.

To all those on the outside,  
How beautiful it is  
To see the perseverance within,

A life-long friend who means the world,  
Even when at times,  
She thinks with a mind so negatively swirled.

Where I Stand is for you,  
And that's a good place to be,  
With an admirable friend,  
Who has accomplished so much since 2003<sup>2</sup>.

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<sup>2</sup> 2003: A poem written by a long time friend, printed with permission

## CHAPTER II

*Survival isn't selfish even though it often looks that way. – Grace*

\* \* \*

I sat on my front porch and drank Diet Coke directly from the two-liter bottle. There was a clear sky, but it was humid, and the air was thick. My skin was sticky, and I felt swollen as my shorts clung to the back of my legs. If I do anything this summer, I'm going to lose weight.

“Are you going to drink that entire thing?” Kathy scoffed as she walked from her parked car to my front porch.

“Yeah probably,” I smirked back, “is Margaret coming?”

“Yeah, she should be here any minute.” Kathy sat down next to me and stared up at the sky.

“Erin has anyone ever told you that diet soda is not good for you?” Kathy jokingly pointed her finger at me and used her mom voice.

“Yeah, mom. Everyone. And I tell everyone that I don't care.” I rolled my eyes and smiled back at her. We sat down on the edge of my parents blue painted porch to wait for Margaret.

“Ahhh, we did it. We made it through freshman year. I've missed you,” Kathy said, sounding both tired and happy at the same time. I nodded.

“It feels like we just graduated high school, doesn't it?”

“Not really,” I replied, struggling to remember that day. Everything was a blur.

“How was your year?” She asked, unable to stop talking.

“Great. You know, lots of new friends and good grades... all that stuff.” I couldn’t look her in the face. She would know I was lying. Margaret pulls up, and as she walks closer, Kathy and I jumped up to give her a hug.

“So, what are we doing tonight?” Margaret asked. Kathy shrugged her shoulders, and I finished the last gulp of diet coke.

“Ladies, it is time to celebrate. Let’s go skinny dipping.” I blurted out, without thinking. Margaret and Kathy glanced nervously at one another then back at me.

“Where?” Kathy half laughed, thinking I was joking.

“The lake where I work. Come on, we need to do something a little crazy.” I was restless, and they didn’t take much convincing. We piled into my car rolled all the windows down and took off. Music blared loudly from my speakers the entire way, and collectively we belted out verses off-key with often made up words. Once we arrived at the lake, I pull both of them down to the dock.

“Are we really doing this?” Margaret laughed nervously. I immediately pulled my shirt and bra over my head and peeled off the underwear and shorts that stuck to my skin and jumped in screaming, “CANNONBALL!”

“Erin, you are crazy!” Kathy laughed. Moments later they had joined me in the fresh, cold water. We laughed and splashed, but soon we were each floating a good distance away from each other. I floated on my back staring up at the almost full moon feeling energized. *This is how life is supposed to be.*

I used my hands to trace the different lines of my body. *My body isn’t so bad.* I could still feel definition in both my calves and thighs. *I am strong.* Dancing made me strong. My hips and stomach were round and soft. However, as I floated near the surface

of the open lake under the stars and the moon, they didn't seem so terribly large. My problems, my brain, my body, my life all actually felt rather small. I was a speck, like one atom existing on the earth alone yet a part of something bigger or a cell within this network of lives connected through breath, thoughts, memories, and God. *I am okay.* After a while, we began to get cold and climbed back up on the dock and squished our wet bodies back into our clothes. Having not thought to bring towels on our spur of the moment adventure we were forced to let ourselves air dry. We then sat back up on the creaky wooden swing at the top of the grassy hill overlooking the lake. *I feel alive.*

"I'm so glad we did this," Kathy said lifting her hands up to the sky and shaking out her hair so that water droplets flung everywhere.

"Yeah, we should do this all the time. We have to make this summer count." Margaret responded. I sat quietly on the wooden swing. The crickets chirped loudly, almost musically in the remote area, and the stars glistened. Thirty minutes or so had passed before Kathy began talking again.

"I've really missed you guys," She said.

"Me too" Margaret echoed.

More silence.

"Guys, I think I'm insane... actually insane... you know DSM insane. People are trying to help me, but I'm not sure that they can. How can anyone help if I can't even verbalize what is going on?" Out of my mouth poured what had been living and feeding on the insides of my brain for seemingly forever. I continued to stare at the stars, not wanting to look into my friends' eyes or see the worry on their faces. Kathy put her arm around me.

“I really struggled with making friends this year. I almost came home once. I almost came home for good. I felt like a failure because I wasn’t having fun at all.”

Margaret shared.

“At least, both of you have brains. I’m on academic probation after my first year and it wasn’t even because I didn’t try or partied too much. I’m scared I’m not smart enough for college.” Kathy added her confession. A soothing and calming silence took the place of our conversation.

### **Figure 2: Personal Journal Excerpt**

Dear God,  
Skinny-dipping is the most freeing thing I’ve ever done. Why can’t I feel that free all the time? That’s how it is supposed to be isn’t it? We’re supposed to be naked under the stars, connected and apart. We are both small and enormous. We’re supposed to be naked with each other. We’re supposed to be naked.

I think back to that night of skinny-dipping and confession often. Sometimes when I feel really alone I try to mentally recreate the embodied feeling of freedom and life that I experienced that evening. One of the hardest things for me to explain to people is how lonely living with mental illness can be, and how isolating it often feels. I at times find myself trapped in a world that only I perceive. It can be exhausting and takes an incredible amount of cognitive effort. Not only always reminding myself of the fact that my perception is or could be distorted, clouded or only true to me, but to use therapeutic tools such as cognitive reframing and behavioral dialectics<sup>3</sup> to correct my stream of reality, my sense of self, my sense of others and my sense of being is a continuous

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<sup>3</sup> Cognitive reframing is a therapeutic technique for changing thoughts; behavioral dialectics is a type of therapy that focuses on skill building in the areas of mindfulness, interpersonal effectiveness, emotional regulation, and distress tolerance.

process that often removes me from the present and requires that I live in my thoughts, analyzing them, questioning them, and challenging them. The result of this for me has been a hyper-awareness of myself, my thoughts, the processes within my brain and how I come to think the things that I do. This hyperawareness has developed as a survival skill. To combat the life-threatening and debilitating behaviors that have engulfed my life for over ten years I had to learn how to dissect myself, what I'm thinking, how I got there and how I can change or shift it. I've also learned that my brain works vastly different from most everyone I encounter in life, a fact that often leaves me feeling terribly lonely.

In treatment, my providers have emphasized developing and maintaining a support network as an essential component of my recovery and treatment plan. In these routine discussions, we often talk about the different types of support (i.e. professional vs. personal) and the ways in which different relationships in my life can play a role in either assisting recovery or becoming detrimental to it. Then again, I'm not all that convinced that "mentally fit" individuals are capable of differentiating friendship so neatly.

### **Figure 3: Hospital Behavioral Health Record**

Erin reported doing better compared to last week. Erin discussed feeling slightly better about her appearance and discussed where she believes her views about her body partly stem from. Erin discussed the sense from others around her that she needs to be well all the time. Discussed what being well means and sharing that more with her support system. Discussed Erin's expectations of herself and the sense that she does not like herself and how that impacts her relationships. Discussed Erin's treatment plan goals and progress made. Erin identified progress made while still wanting to work on current goals. Erin identified a new goal on wanting to understand her relationships better and how she interacts with others more.<sup>4</sup>

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<sup>4</sup> Medical record dated 3/20/12

*To understand is...*

“Erin, I’m going, to be honest with you. I’m concerned about your friendship with Grace,” my therapist said to me from across the room. I wasn’t surprised, I could see this coming from a mile away, however, I didn’t care. I couldn’t decide if I was going to ignore her altogether by switching to another topic or if I should acknowledge her concern. We sat in silence for a few moments, before I decided to engage in the conversation.

“Well, it’s a challenge, but we understand each other,” I explained, attempting to make a rational argument. “We’re the only people who can actually support each other because we’re the only two people who fully understand each other.” The look that stretched across Susan’s face radiated frustration. I’ve never been an easy client. I don’t try to be difficult; it just usually happens that way. I hate the feeling of being controlled and sometimes find myself rebelling against the constant dissection therapy often entails.

“I worry that the two of you increase each other’s level of self-destruction,” she responded. “You’ve seemed to decline in progress since the two of you have become close.” *How dare her. She has no clue what she is talking about.* I stared out the window and watched people shuffle by busily on that beautiful afternoon. *I’ve got to get out of here.* My hands had begun to sweat and I could feel my skin becoming restrictive as my heart raced a little faster.

“My symptoms are not Grace’s fault,” I said indignantly. “I’ve always been fucked up, or have you not been paying attention?” I was annoyed with this conversation, with therapy, with everything. “Can I leave?” I asked abruptly 20 minutes before our appointment was supposed to be over.



“If you’re done for today,” she responded without attempting to hide the frustration in her voice.

“Okay, bye.” I stood up and walked out of her office. *I can’t believe Susan was such an idiot today, ugh. I can’t wait to talk to Grace.*

*To understand is...*

*More than you will ever read in a book*

“Two large diet cokes. Light ice. Make sure they are diet,” Grace directed the cashier standing behind the register of the McDonald’s inside of Wal-Mart. I needed to debrief my therapy appointment today. We walked and talked around the Wal-Mart, a space filled with stimulation, distraction, and just enough of a crowd that two women can make several laps around store without a cart or basket and not appear strange.

“Susan doesn’t know what she’s talking about.” Grace comforted. “She’s a terrible therapist. I know. I’ve met her.” I wasn’t sure if I was in complete agreement with Grace. I didn’t think Susan was all terrible; I just didn’t think she was right about my friendship with Grace as being toxic.

“I know, how can we be bad for each other? We support each other all the time,” I responded exasperatedly. At the time, Grace was the only person who I could really be myself around. She was the only person I could be honest with about my feelings, my thoughts and my behaviors. *How could that be unhealthy? How could that be dangerous?*

Grace continued. “It’s like they want you to feel supported, but only by people who don’t actually understand, because when we understand each other, our relationships become dangerous.” She paused to sort through the water bottles on a stocked shelf, and

then turned back towards me. “They want us to be supported by them I think, and only them.”

As we continued to circle the store, I couldn’t help but think that Grace was on to something. It did feel like my therapists wanted to control the type of support I was receiving. In therapy I was being told of the importance of talking about the stigmatized and shameful things that I had been forced into silence about. But instructing me not to be friends with Grace, someone who was so very similar to me, made me feel like no one should be friends with me. “*Would Susan instruct people to not be my friend?*” I wondered to myself.

By being with Grace, I learned how to embrace myself, mental problems and all. I saw beauty and inspiration where I once saw and felt deep shame. *So how is that bad?* I loved that I wasn’t part of her job, a professional accomplishment to be checked off her to-do list. I didn’t have to pay her to listen to me. She was my friend, my equal. She chose me, she chose to be in my life, and she listened because she wanted to not because she had to. *So, how could that be unhealthy? How could that be bad?*

I met Grace during my sophomore year of college. We were introduced by mutual friends who knew we were having some mental health issues and thought we could relate. I doubt that our friends had any professional sense for what they were doing, or just how magnetic Grace and I would become to one another. I also doubt that it crossed their minds that we had the potential to spin each other into even more dangerous cycles of self-destruction.

“I think it would be helpful to have someone you can relate to,” Lisa said as I sat across of her sipping my black, bitter coffee and picked at a blueberry scone. Lisa was

my bible study leader. She had been trying to help me for weeks, and I sensed she was beginning to feel helpless in the process. I could see it in her eyes every time she asked me how I was doing. She was afraid of what I might say, of what I might disclose. I didn't blame her. "Another bible study leader also has a girl in her group with similar issues," she explained.

"Who is she?" I asked, quickly. I wasn't sure how productive meeting another girl with "problems" would be. After all, I had enough of them my own. I also seriously doubted that this girl could have possibly been as screwed up as me. Still, I was definitely intrigued.

"Her name is Grace. She is in Sarah's small group. Apparently, she has an eating disorder and bipolar disorder, too." As Lisa continued to describe Grace as a list of diagnoses and disorders, I wondered if Grace felt as hopeless and lost as I did. I wondered if she took handfuls of pills every day and cried for hours without a reason. I wondered if she was anorexic or bulimic. I wondered if she was skinnier than me.

"Well, when am I going to meet her?" I asked. Lisa reached down and grabbed her phone from her bag. I could see a smile spread on her face, and I wondered if it was because I had agreed to meet this girl. I wondered if she felt relieved and less burdened by me. I wondered if she was trying to get rid of me. I wondered if Grace was skinnier than me.

"Let me give you her number." I put Grace's number in my phone, unsure if I would ever use it. *I mean really, what would I say to this girl? Hi my name is Erin and I am screwed up and broken just like you. Do you want to be friends?* I laughed silently to myself. It was a nice thought, I guess.

The next day I received a message from Grace. “Hi, Erin! This is Grace Newman. I think Lisa told you about me. Do you want to get coffee tomorrow?” I stared down at the message for a minute before replying, unsure if I had enough energy for this. As I read and reread her message, my body began to tingle with nervousness and excitement. *She must really want to meet me. Maybe we really will be friends. She does sound nice.*

“Sure. Does 2 pm work? Starbucks on campus?” I replied and stared straight at my phone waiting for a response.

She responded within a moment, “Yay! Sounds great. I can’t wait to meet you!” I shoved my phone into my bag. *Maybe this will be good. Maybe she will be nice. Maybe she really will understand me.* Before meeting Grace, I had pretty limited contact with other people struggling with mental health illness. I had only been in two therapy groups and seen individual therapists. Truthfully, I never felt particularly connected to any of them. However, from the first second of meeting Grace, I knew she was different. Different like me.

“Hi, I’m Erin,” I held out my hand and she shook it aggressively.

“Erin! It’s so good to meet you!” She said with the biggest smile on her face, a smile that did nothing to hide the glassy and red purge eyes I was staring into. *She’s bulimic, just like me.*

“You too!” I responded back. We moved toward a black metal bench outside of the Starbucks and sat down. There were a couple of quiet moments and awkward silences, in the beginning neither of us really knew how to begin talking about why we were introduced. Our conversation initially resembled some sort of dance where we

alluded to “hard times” and “bad days” and “struggles” without really going into detail. We were both waiting for the other to initiate the specifics. Finally, Grace did.

“Erin, how did you get through your freshman year?” She hesitated for a moment, then blurted out. “You know, mentally?” She then quickly looked towards the ground. I was surprised but relieved she went *there* first. I stared at the ground for a moment; I honestly had no answer that question. *How did I get through freshman year?*

“Geez, I don’t know? Luck? God? A miracle?” We both laughed. We laughed because we knew how screwed we were. The first year of college is known to be a life challenge but with added mental illness and an inclination to self-destruct it seemed damn near impossible.

“I throw up every day,” Grace revealed. “My roommates have called the police on me twice, the counseling center won’t see me because I’m too high risk. I don’t know what to do.” As she listed her current fears, frustrations and worries related to her behaviors and instabilities, I was filled with thankfulness for her honesty, rawness and truth. I knew she wasn’t looking for anything from me, except maybe a reciprocation of that authenticity, which felt both inspiring and liberating.

“I throw up almost every day, too. But it was worse for me last year, much worse. Have you looked for counseling outside of the counseling center?” And just as I finished asking the question, Grace embraced me in a tight hug. *We are going to be best friends.*

Grace was the first person I had ever met who understood me. Up until that point I didn’t know what it felt like to have someone think the same way I did. I didn’t know what it felt like to have a friend who wasn’t the least bit afraid of me. Our friendship was exhilarating, terrifying, comforting and the most validating thing I’ve ever experienced.

In my mind, meeting Grace was universe telling me that I wasn't the only crazy person alive. Meeting Grace was the universe telling me that this wasn't just me. Maybe I didn't cause this to myself. Maybe I wasn't bad.

\*                    \*                    \*

*To understand is...*

*More than you can ever understand from a look*

*More than you can even grasp through spoken word*

*No matter how often or how loud it is heard*

#### **Figure 4: Hospital Behavioral Health Record**

Erin reported that she has been receiving a great deal of feedback from everyone that she should not be friends with this person and the matter is feeling all consuming and is unsure what to do. This therapist reminded Erin that she does not need to make any decision at this moment and for Erin to process what the boundaries of the friendship would be, what she needs to do to maintain her own health and recovery, and to give herself time. This therapist also encouraged Erin to engage in behaviors to aid in her taking her mind off the situation. Erin stated that she would do those things and felt calmer after the conversation<sup>5</sup>.

“Happy birthday, dear Erin! Happy birthday to you!” Grace’s family sang at their dining room table. Her mom, dad, and sisters had made a special dinner, wrapped presents and decorated a bunch of cards for me while Grace and I were out shopping. My eyes filled with tears as they sang.

“Wow, guys, thank you so much! Seriously, thank you!” Each gave me a hug and said happy birthday, then thanked me for being such a good friend to Grace. I wanted to

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<sup>5</sup> Medical record dated 5/1/12

say, “Don’t thank me. It’s Grace who has changed my life.” Instead, I just said, “Of course.”

“Gifts! It’s time for gifts!” Grace came in carrying a bunch of little things. “Open my card first.” It read, “Birds of a feather” on the front, “flock together” on the inside. She explained that the card meant that we’re both crazy and that’s why we were best friends.

“It’s perfect,” I said smiling, feeling more thankful than ever. *We’re both crazy.*

After presents and cleaning up dinner and cake, Grace and I rushed down into their basement. “Do you have it?” I asked. She smiled as she pulled out a bottle each of vodka and rum.

“Awesome,” I replied. Then Grace got quiet for a moment. I could tell she was hesitating to say something, and I knew what she was thinking.

“Look, this stuff has a bunch of calories and we just ate a big meal and cake.” She stopped, waiting for me to finish the thought.

“We should purge.” I knew exactly what she was thinking.

“Bingo – plus – the alcohol will work better if our stomachs are empty. It’s already been a little while since we’ve eaten, so I’ll go use the bathroom in the workout room and you can use mine.” I was thankful she already had a plan. I headed to her bathroom, lifted the toilet seat, bent over, and shoved three fingers down my throat. I stood up and stared at myself in the mirror. I wiped my puffy face and my watery eyes before washing out my mouth. A twinge of guilt panged my stomach. *I’m not supposed to do this anymore. This is the last time. It’s my birthday after all.* I turned sideways and stared at my stomach. I could see a bulge of fat under my belly button, and it was literally

growing bigger and bigger right before my eyes. I sucked my stomach all the way in and punched the fat pouch as hard as I could. *You are disgusting.*

Once we were back in her room, we began our usual routine. We rotated the bottles between the two of us, each taking big swigs as we listed reasons we thought we were unfixable. *My dad once threatened to put me in the military but then realized they wouldn't even take me; swig. My sisters hate me, or they think I hate them but whatever it is I'm on the outside, always; swig. I don't even remember how many therapists I've seen who say they can't help me; swig. I'm exhausting. I exhaust others, and I exhaust myself; swig. I hate myself, I fundamentally hate everything that I am at the very essence of my being; swig.* My throat burned having just thrown up my dinner, but I enjoyed the pain. It comforted me.

I stood up abruptly, "Let's dance. We need to burn calories." Grace put the music on, and we danced, and laughed until I began to get dizzy and sat down, but Grace kept going. At some point she got hot, and then everything changed. In an instant, we went from dancing, drinking, laughing and sharing too, well, I don't know. Suddenly, she was naked, and she reached under her bed and pulled out a sledgehammer.

"Grace, what are you doing?" I asked. At first, she didn't respond.

"My dad doesn't know I have this," she then said. She proceeded to hammer the wooden windowpanes that encased the glass. Years earlier her parents had permanently sealed the windows in her room. I stood, nervous.

"Grace, please stop," I begged. I did not want to get into trouble. I thought about how her family had worked so hard to make my birthday special.



“I want out,” she said as she continued to work on the window. I got my phone and texted Grace’s sisters. “Help.”

I tried to reason with her. “Grace, if you put your clothes on, then we can go out the front door.”

“They are coming to get me. I have to go,” she said.

“No one is coming to get you Grace – it’s late,” I tried to explain.

“My friends are,” she said. I didn’t know what she was talking about.

As Grace’s younger sister reached downstairs, Grace finally broke the windowpane and climbed out the window. I told her sister what happened, and her sister yelled aloud to their mom. I started to cry. *This is all my fault.*

“This sometimes happens, Erin. It’s okay. My mom will call the police.” Grace’s sister comforted. “I need to go look for her,” she said, as she climbed out the bedroom window. I followed.

I think about this evening often, because this is the first time in my life I watched someone that I loved and cared for enter into a world that I could not sense. At this point in my life, I had always been the one with the sledgehammer making everyone else nervous. I was the person in crisis. I was the person experiencing something that no one could see, touch or understand. Witnessing Grace, the person that I felt most intimately connected with, disappear into a place that I could not access filled every inch of my body with helplessness. I knew there was nothing that I could do or say to help bring her back to reality. I was filled with a painful guilt, as if I caused her to detach from the here and now even though I knew that I didn’t. This experience of watching someone so important to me dangerously disappear inside of her mind made me painfully aware of

what people in my life might be experiencing with me. I wondered if this is how my friends, family and treatment providers felt while watching me spin into cycles of self-destruction and enter a reality that only I perceived. For days after that night I reflected on how afraid I was, and I wondered how the people who care about me do it.

*To understand this illness, disease, addiction and obsession*

*You must first know, relate to, feel and touch the underlying pain and depression*

It was Thursday and I couldn't get out of bed. My brain said, "get up" but my body laid lifeless. My brain said "take the covers off," however, my arms held onto them. I listened to my roommates moving in the hallway outside my door. I heard them walk by, go to the bathroom, go down the stairs, go up the stairs, talk on the phone, and living their lives. I felt like my life had momentarily stopped, I was frozen, no paralyzed. I couldn't wrap my head around the idea of them going about their day seemingly simplistically. *How are they doing this?* I buried myself deeper in my bed. Occasionally one of my roommates would pop their head in hesitantly and ask me if I was okay.

Then Grace walked in, and climbed into my bed. She didn't knock. She didn't ask if she could come in bed. She just did.

"How long are you going to stay in here?" she asked, attempting to pull the covers off of me.

"I can't do this," I said as tears fill in my eyes.

"You can't do what?" She asked.

"Life. I cannot function. I cannot get up. I cannot put clothes on. I cannot do this." I was crying harder now. There was no stopping it. I wanted to scream. "There is some disconnect between my body and my brain Grace. I don't understand it, so I don't

expect anyone else to understand either but it's almost as if living isn't instinctual for me, but dying is." I hid my face. I was totally embarrassed. "What is wrong with me?" I asked from out of my covers.

"Erin Casey look at me," she said as she pulled the sheets down from covering my face.

"We are different and most of the time normal people and most of the world don't know what to do with us, but we're special. I know we're special. Life is harder for us in a lot of ways; we feel things differently because we're special. The world needs special." As Grace finished talking she rolled over onto her back and we both stared at my ceiling.

"I think being special sucks," I said.

"Yeah, but who wants me be normal?" she asked. The truth was, I didn't even know what normal was that day, and I'm still not entire sure I know what it is now. I mean, yeah I understand that according to my therapist "normal" was equated to a much higher level of functioning than I was at the time, however, I didn't understand how anyone was normal. For a long time after this interaction, I furiously declared that I wanted to be normal. I complained about it in therapy. I begged God to make me normal. I cried to my mom about not being normal. I wasn't sure what it felt like, but I knew it had to be better than being special.

\* \* \*

I was sprawled out on my bed desperately trying to write out a recovery plan for myself. I had all of my worksheets from the partial hospitalization program I was then enrolled in spread out before me. This shouldn't be so hard. I heard a knock on my door and for a split second wondered if I should hide the pages.

“Come in,” I called out.

“Hey,” Margaret said as she peeked her head in. “What are you up to?”

“Just writing,” I hesitated. Margaret smiled.

“Am I interrupting? Can you chat?” she asked timidly.

“Sure. I could use a break.” Margaret walked over to my bed and plopped down, as I made room for her by pushing my therapy worksheets to the side.

“What are you working on?” she asked.

“Well, for treatment I have to write a recovery plan,” I explained. “I have to finish it by tomorrow but I just don’t know what to write.”

“Can I see it?” Margaret asked.

“Sure, if you want to. It’s kind of stupid,” I explained as Margaret picked up the packet I was working on. For a second, she just read through the questions and the answers I had filled in quietly.

“Wow,” she said, putting the recovery plan down. “That’s actually pretty cool.”

“Cool isn’t exactly how I would describe it,” I laughed.

“No, actually, I think it’s awesome. I feel like sometimes that would be helpful to me.”

“Really?” I asked. From what I knew about Margaret, she didn’t have any sort of mental illness. “How so?”

“Well, sometimes I get really down. Not often. But when it happens, it would probably be really helpful if I had a written plan for handling it.”

“What do you mean when you say ‘really down’? Like depressed?”

“I don’t know if I would call it depression, but sometimes I just get into a head space where I feel like I can’t do anything right and that my life is pointless, and that I can’t breathe – almost like my own life is suffocating me.”

“I get that.” I paused. “But Margaret, have you ever told anyone that you feel that way?” I was concerned.

“Nah, I mean I can still function and that feeling always passes. I guess I also feel embarrassed about it because everyone else seems to have to have their stuff together,” she explained.

“Well, I definitely don’t have anything put together,” I half laughed. She laughed too. I wondered at that moment if she disclosed to me because she knew that I was less functioning than she was. I wondered if that made her feel safe to tell me what she was experiencing. I wondered how many other people seemed fine but weren’t really fine. These types of disclosures from my “normal” friends began happening much more frequently as I got further and further into treatment and also became more vocal about my experience with mental illness. Each time they would catch me by surprise, because I had usually assumed they were in the “normal” category of people. I started to believe that maybe being normal is just a face people wear. *Maybe we’re all a little crazy. Maybe everyone is just pretending.*

\* \* \*

*To understand the control, perfection, and deep self-dissatisfaction*

*Your brain must distort the general principles of attraction*

My phone rang. “Hey, Grace! What’s up?” I answered, as I saw her number on the caller ID.

“Erin.” I could hear the distress in her voice.

“What’s wrong? Where are you?” I asked. I was in the hallway of one of the academic buildings on campus.

“I’m not doing well,” She said. “I don’t know what to do.”

“Where are you?” I asked again.

“I’m in my room,” she answered.

“I’ll be right there.” I left school. I had two classes that day, but they were less important to me than Grace. I walked across the street to her house, went upstairs and into her room. She was laying in the middle of her floor. I sat down beside her.

“Are you safe?” I asked.

“I don’t know,” she answered.

“Did something happen?” I asked.

“I’m so fat I want to die. I’ve been thinking about taking all of my meds,” she replied. I physically hurt for her in the pit of my stomach, my chest and lower back. Her pain made me ache. I think because it was my pain too.

“Isn’t it stupid in treatment when they tell us that ‘fat is not a feeling’” I began, “and that ‘weight isn’t the most important thing.’ Jeeze, fat is an ever present feeling and the whole world emphasizes how important weight is.” Grace half-laughed with tears rolling down her face. I knew I couldn’t make her feel better; all I could do was be there.

“Yeah, these doctors and therapists think they understand what it's like to watch yourself expand in the mirror in front of you...” Grace said.

“... Or how it feels to physically feel the contents in your stomach turn into the fat on your thighs...” I finished.

“Do you want to go for a run?” she asked.

“Let’s purge first,” I replied.

“Okay.”

*Beauty is everywhere*

*Except in the mirror as I stare*

A few weeks later, Grace and I were sitting on the floor of my bedroom making collages. “How do you think you’ll die?” Grace asked, suddenly.

“Ummmm...” I hesitated. I wasn’t sure if I should tell her, or anyone for that matter, what I really thought. I didn’t want to lie to her, but I was scared she was going to freak out.

“Well, honestly, Grace, I’ve always kind of assumed that I will kill myself eventually. You know, at some point there will be a depression that I can’t come back from or something that my brain can’t handle.” As I finished, I grabbed the glue stick from the bucket of art supplies, glancing up at her for a response.

“Me too,” she said simply. “Suicide is the ultimate form of control. It’s comforting to know that we get to decide when it ends.”

“Yeah, I think it’s comforting too, knowing that I have the option to end it because sometimes it’s so, it’s so—“

“--it’s so terrifying, exhausting and overwhelming?” she finished.

“--and lonely.” I finished.

I feel sad when I think that at that time I really did believe that death was better than life. It's scary for me to now think about how much I flirted with death and my intrigue with its finality. I couldn't tell you exactly when the divide between life and death changed for me, but it did. Years later, the conversation continued with another friend.

Kathy and I sat in the empty parking lot facing the grocery store, tears were streaming down both our faces and neither of us had a clue why.

"We're so ridiculous," I said with half a laugh.

"I don't think I've ever seen you cry before," Kathy noted, laughing more.

"I don't do it unless I have a reason -- well usually," I responded

"What is wrong with us?"

"I don't think that can be answered very simply."

"Ha, no, definitely not."

"Kathy, can I ask you a question?" I turned toward her and got serious for a moment. I thought back to a conversation about death with Grace years earlier.

"Yeah, of course, what is it?"

"How do you think you'll die?" I asked, hesitantly.

She paused. "I don't know. I definitely don't want to drown or burn to death. Dying in my sleep would be nice." She looked back at me. "Why do you ask, hon?"

I felt stupid now. I shouldn't have brought this up, and I didn't know what to say.

"I don't know." I looked down, but she wasn't buying it.

"Erin, come on, it's me." She paused. "What's up?"

"Well, I don't know. This is going to sound worse than it is, but I have this feeling that one day I will probably die by suicide. I mean, not today or anything, but it



just makes sense to me. I know it sounds crazy and probably scary and it's hard for me to explain. Please don't tell anyone I don't want to be sent to the hospital." I was talking fast. I couldn't believe I actually told her. I desperately wanted to take back what I had said as soon as the words came out of my mouth.

"Shhhh. Erin, it's okay. I think it makes a lot of sense that you would believe that."

"You do?"

"Yeah. Given where your brain has been. But you know what?"

"What?"

"I think you're wrong." I stared at her, unsure of what to say. She doesn't get it. She doesn't get what it's like to be inside my head. She doesn't understand.

"I think you're wrong because I know how hard you work to make sure that you have way too much to lose." I sat back and thought for a second, thinking. Maybe she was right, I work incredibly hard to create accountability in my life, to have things to live for, but I've also been acutely aware that the boundary between life and death has been altered for me. I've been alive while I've felt like was dead. I've been alive and willed myself to die. I've excitedly flirted with death, standing at its doorstep; tempting it. However, there is no place for this conversation. There is no place for these thoughts. There is no place for this part of me, not with people who don't understand.

"Yeah. Maybe you're right."

*I will disappear, control what I can, chase perfection with all that is in me*

*In the hope that when looking in the mirror it is no longer I that I see*

“Grace, I have to go to the hospital.” It was 9 am and I was sitting in my psychiatrist’s office. I was talking to her answering machine. Grace was in day treatment and wouldn’t be done until 3 pm, but I knew she would sneak to the bathroom to check my message. I stared back at Dr. Grayson.

“I’m only going if Grace takes me,” I said wrapping my arms around my chest. “I can’t do this without her.”

“Okay.” Dr. Grayson replied softly. “We can wait, but I want you to stay here, or be with a roommate until then.”

Grace pulls up beside the counseling center in her black SUV. “Are you ready?” she asks.

“No.” I climb in the passenger seat.

“Do you want to get a Diet Coke before we go?” I shook my head yes.

“It’s going to be okay, Erin.” It was her turn to be the sane one. I couldn’t say much. I lay my head against her headrest. We pull into the drive through

“Two large Diet cokes with light ice. Make sure they are diet.” She says to the person working the McDonald’s drive through.

“I’m buying, today,” she says as she hands her money out the window. We sip our diet cokes in silence pulling into the Emergency Department parking lot.

“Before we go in I’m going to call my dad so he can pray for you.”

“Okay.”

“Hey, Dad, I’m taking Erin to the hospital. She’s not doing well.” I listen to her talk about me to her father. Her word run in my head: *She’s not doing well.* I’m not doing well.

“I’ll call and update you, OK?” She pauses, “Dad – that’s not funny.” A smile breaks out on her face. I look at her with a question mark written across my face.

“Bye, Dad,” she says. Grace hangs up the phone.

“What did he say?” I asked.

“He asked if there was a two-for-one deal at the hospital.” She rolled her eyes and smiled. I appreciated the joke. It made me feel less alone.

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“Erin, I think we need a plan,” my mom inserted abruptly into our conversation.

“What kind of plan?” I asked. Having not a clue what she was talking about.

“Well, we need a plan in case Grace--” she hesitates, “--in case Grace dies.” My heart dropped a little. “And, her family needs a plan, too.” These words were even more painful to hear. I was silent for a moment. This was the first rational conversation that Mom and I had ever attempted to have about suicide, and I didn’t like it. I was okay today. This was unnecessary.

“Mom,” I began, not knowing how to process her topic.

“Erin,” she interjected, “if something happens to her, then you should come home because I don’t think you will be able to take care of yourself. I don’t think you will be able to handle it.” I didn’t respond initially. I didn’t know what to say. She was right, though. If Grace died, I would, well I was planning to die too.

“Okay, mom, I’ll come home,” I responded. “I’ll tell her to talk to her parents. I love you, Mom.”

“I love you too, Erin.”

That conversation with my mom was the last one I remember before Grace and I mentally, emotionally and physically spun each other into the deepest darkness I have ever known.

**Figure 5: Hospital Behavioral Health Record**

9:00am Voice Message from patient requesting a call back after 3:15 pm.

3:15 pm telephone call to the patient as requested.

The patient reported she is not doing well and feels she has “messed everything up” in her life. She reported her friend Grace has been treating her badly, and it is triggering her own eating disorder and other symptoms. The patient is upset about treatment and is confused now since she read the notes from University Counseling Center She does not feel treatment is genuine. She feels she needs treatment but at the same time does not want to have to need it. Talked to the patient about where to go from here. Encouraged her to reschedule with her therapist for a counseling session and start to discuss this openly. Talked to her about how she needs to process her feelings about the past at University Counseling Center while balancing her current recovery. Also talked to the patient about having some “faith” in the treatment process and related this to her religious faith. Patient scheduled with her primary therapist<sup>6</sup>.

*No book will tell you of the true pain in my soul*

*Or how desperate my attempt was to be in control*

My psychiatrist sat across from me silently. I knew she was frustrated but I didn't care. “I can't go to residential because Grace is going and she doesn't want to be there at the same time as me.” I looked down at my lap feeling really lost, and sad. I didn't understand why she didn't want me to be there at the same time. She has never told me that she thought we weren't good for each other before.

“Erin, I don't care what Grace wants. I care about what you need – and it is hard for me to watch you continually put her needs before yours.” Dr. Grayson finished, as I sat back and crossed my arms. I was confused, and I felt very empty. In that moment, I

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<sup>6</sup> Medical record dated 11/13/12

couldn't fathom how I supposed to care about what I needed, largely because I couldn't figure out what exactly that was. It has always been easier for me to see other people's needs rather than my own. "Erin, look at me. You are very sick, and you need this treatment. I don't know what will happen without it. I need you to understand that, okay?" More silence. My stomach hurt.

"We're not going to allow you to come back to school unless you get some long term intensive care."

**I had no choice.**

There isn't a day that goes by that I don't think about this moment. My needs were invisible to me. I didn't have any needs.

**Figure 6: Personal Journal Excerpt**

Dear God,

Grace's mom just called me. She said I can't go to The Clover Clinic because Grace is going.... She said she doesn't think our friendship is a good thing for either of us and that I need to stop calling her and answering Grace's calls. She said Grace knows our friendship is not good but is not strong enough to do anything about it... she said that Grace is going to The Clover Clinic and if I go she won't get better. She said she needs to focus on her. I don't know what to do...

*No movie will teach you the damage I did*

*As I checked out of life and constantly hid*

The day I arrived in residential I was terrified (for many reasons) but mainly, I was scared to see Grace. The day before she screamed at me over the phone, "I can't believe you would do this to me! You don't want me to get better! I hate you!" I cried all night long and on the airplane.

Unfortunately, it was worse than I had expected. By the time I arrived, Grace had convinced all of the other girls that I was terrible and out to get her. My world shattered. I was in a strange place with no coping mechanisms. I had betrayed the one person who I believed understood me. I was in a group of women who wanted nothing to do with me. On that first day, they handed out evening snack. Mine was trail mix and yogurt. I threw it against the wall sobbing. I couldn't breathe. I couldn't think. I wanted to go home. I had lost the one person who understood me, the one person who felt what I felt, who didn't ask me to explain, who didn't need me to explain. It was worse than before because now I knew what I was missing. I knew I was alone.

In the months that followed residential treatment, I entered what my treatment team and I have called "recovery" for the first time. I totally surrendered to my treatment plan and painfully sat with feelings that I never even knew existed. I was a wreck pretty much all the time because I was choosing to not numb myself from morning until night. I started with a new psychiatrist, and we finally had reached a medication regime that was working. I wrote poetry and started to find solid ground. I even was allowed to return to school. Even with all of these considerable improvements in my ability to function that were happening at this time I felt painfully alone.

### **Figure 7: Hospital Behavioral Health Record**

Erin reported that she was doing well and starting school again. Erin discussed the difficulties she had during the summer regarding changes in relationships. Erin discussed finding it difficult to cope with the loss of a close relationship and being unsure of wanting relationships while also not wanting to be alone. Discussed ways of managing the loss and setting realistic expectations for herself. Erin discussed an increase in her need for perfection. Erin was able to identify where this stems from and began to brainstorm how to manage it. Erin was instructed to review her toolbox of skills to determine which ones she can use at this moment and to begin to

determine which ones she can use at this moment and to begin to brainstorm new ideas.<sup>7</sup>

“Erin, are you okay today?” Paige asked me from over the counter at the bookstore we were working.

“Yeah. I’m alright.” I lied. She didn’t look convinced but didn’t press the issue.

“Do you want to get dinner tonight?” she asked, looking hopeful.

“Nah, sorry.” I didn’t have an excuse; I just didn’t want to eat. She looked down and turned away. Paige knew about my problems, but I also knew she didn’t understand. A few minutes later she returned from the back room.

“My mom says that you have to come over for dinner and that you should spend the night with us too.” I wasn’t sure how to respond. I really didn’t feel up to pretending I was okay. I really didn’t feel like smiling and laughing. I really just wanted to crawl into my bed and cry.

“Okay,” I responded. “If she insists.” I felt torn between regret and warmth. I knew that Paige didn’t understand. Paige would never understand. I watched fear and concern regularly dance across Paige’s face. I often wondered when Paige would leave, when she would give up. I wondered when Paige would get tired. I was tired. I was ready. Waiting. Sometimes, I think I’m still waiting, not because I think Paige is a bad friend, but because given the choice, I struggle to understand why someone, anyone would choose to have this, and by relation me in their life. Given the choice, I wouldn’t choose this. I just don’t have one.

\* \* \*

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<sup>7</sup> Medical record dated 9/5/12

My phone rang, and I was surprised to see Grace's number appear on my Caller ID. "Erin, I need to go to the hospital." I heard as I answered the phone. I hadn't heard from Grace for months.

"What's wrong?" I asked as I looked at my shoes.

"I don't know, I need to get my foot x-rayed," she responded. "Can you help?"

"Yeah, give me a few minutes and I'll be over." I got my shoes on and grabbed my purse and my keys. I was nervous to see her, really nervous. I was surprised that she called me. I thought she hated me. I left to pick her up.

*No testimony can explain to you how hard it is to get your life back*

*Searching and seeking to get your life on the right track*

### **Figure 8: Hospital Behavioral Health Record**

Erin shared that she met with her ex-best-friend yesterday and that it was an odd experience for her due to her friend not doing well emotionally and well very much involved in her illness. Erin discussed re-entering that friendship and what that means for her. Discussed how to maintain healthy boundaries and what those might look like. Erin reported that it was difficult for her to establish those at the moment as she had not spoken to her friend for almost six months. Erin discussed feeling distant from her illness and it being a positive thing while being a different experience for her. Erin agreed to continue to allow herself to process and experience the emotions associated with reconnecting with her friend, and the discussion will continue at the next session<sup>8</sup>.

Grace and I were sprawled out in the middle of her floor working on homework and drinking large Diet Cokes from Sheetz. Grace said that Sheetz had the best Diet Coke in Harrisonburg because it has the most fizz. I liked it, too. While I was struggling to finish my paper, I sat up on her floor.

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<sup>8</sup> Medical record dated 5/1/2012



“Grace, do you think recovery is possible? Like really possible?” She looked up after a moment of writing.

“I don’t know, you’re farther than I am,” she replied. She was right, in the several months after returning from treatment when we were not speaking, I made my first real, measurable amount of progress, but everything was still such a freaking challenge. Breathing was hard. The thinking was hard. Living was hard, and everything felt excruciatingly painful. This couldn’t be recovery. It’s too hard. I wanted desperately to believe there was more to life than this.

“But like, you know, freedom. Do you think freedom from all this crap is real? Do you think it’s possible to be better - like really better?” I needed an answer, and at this point, Grace might be the only person I actually trust to give me one. She sat up and looked at me. My desperation was obvious, and I know she could tell that I needed an answer.

“No,” she said, before pausing, “I don’t believe in freedom, at least not like that.” My heart sank, not because I was expecting her to tell me that she did believe but because as I suspected she would. Instead, she confirmed my own thoughts, assumptions, and beliefs - ones I really didn’t want to believe at all.

“What’s the point?” I asked her, feeling hopeless and tired.

“I don’t know. I think it’s so that we don’t have to live in the hospital.” And as soon as she said it she returned back to work. But I sat there thinking, and eventually pulled out my journal. I had too many thoughts swirling around in my head.

**Figure 9: Personal Journal Excerpt**

Dear God,

Everyone uses the term “recovery” like it’s something that I should own, something that I should achieve, something that I should accomplish, something that I should do, something that I should want, something that I should work for but I’m not sure I understand what it is. What is the goal of recovery? Staying out of the hospital? Is it freedom, because that seems impossible? Can you fail at it? Can you succeed at it? Everyone keeps saying it, but it doesn't make sense.

After a few more hours we finished working and headed to Chipotle, after eating I sat at the table while Grace spent 20 minutes in the restroom. When she returned, I saw a burst blood vessel in her eye. She took a sip of her diet coke, and said “Ready?”

“Sure.” I needed to get out of there. I could feel the weight of my meal sitting, churning in the bottom of my stomach. I want to throw up. I want to throw up. I want to throw up. We walked to her car and climbed in, silently. I’m getting fatter. I just gained ten pounds. My arms are going to be twice as big tomorrow. Oh my god, why didn’t I throw up, too? I’m so disgustingly weak. Grace will always be smaller than me.

“Hey, can we stop here? I need to run in and get something for tomorrow.” I pointed to the Kroger as we passed.

“Sure.” I’ll wait in the car. I ran in -- straight to the bathroom. I didn’t notice if there were people in there. I stepped into the third stall, locked the door, lifted the toilet seat and shoved three fingers to the back of my throat and kept them there until the contents of my stomach flooded my throat and poured out of my mouth.

### **Freedom.**

I rinsed out my mouth and washed my hands then headed back out to the car with Grace.

“I thought you needed something,” she said, while giving me a knowing look.

“Oh right, I forgot,” I replied. “Do you want to get Diet Cokes?”

“Always.”

\* \* \*

Jessica sat across from me. We were silent. Until -- “Erin, I want you to talk about your relationship with Grace.”

“What about it. We’re best friends.” I defended. I was tired of defending my friendship with her to others. No one could possibly understand and everyone was quick to judge.

“Do you think it is a healthy friendship?” she asked, gently.

“Yes,” I responded immediately. “We keep each other alive.” She didn’t get it. She didn’t get that we were the only two people in the world who understood each other. More silence.

“Do you keep each other alive, Erin? Or do you keep each other near death?”

“Alive. Definitely alive.” I responded forcefully.

“Okay, how so?” she asked knowingly.

“She’s the only person I can really talk to when I’m not okay, because she gets it, and I’m there for her too.” There is no way she is going to separate us. Grace is the one person that makes me feel not alone.

“Do you ever feel like you might make each other worse?”

“Worse how?”

“Does she make you want to use behaviors?”

“NO! That’s ridiculous.” I yelled a little louder than I had intended.

“Erin, do you think Grace cares about you as much as you care about her?” As she asked me the question, my stomach began to hurt. I wanted to be able to say yes, but I couldn’t with certainty. The truth was I didn’t know if Grace needed me as much as I

needed her. I couldn't accurately assess if she cared for me when it was convenient and beneficial for her or if she really deeply cared for me. I knew I would do anything for her. I would sacrifice anything for her. I would give anything to her, but I didn't know that she would do so for me.

“Of course, she does.” I looked out the window.

*It is more complicated than anyone could possibly fully understand*

*Unless an eating disorder took over your life unplanned*

*Everyone has their story and struggles too*

*Though not the same, equally troublesome and true*

“Mom! Grace is going to be home for treatment in time to speak at *Where I Stand*” I excitedly explained.

“That’s great sweetie, but do you think she’ll be ready?” she asked. Her question was legitimate, and the truth was I wasn't completely sure. However, I did know that the hope of getting involved in *Where I Stand* was the only thing that kept her from signing herself out against medical advice too early.

“I think so. She seems excited about it, and if she changes her mind, that’s okay too.” *Where I Stand* was going to be my first advocacy event in my hometown. Grace, Paige and I were set to share our stories and experiences of dealing with mental illness alongside poetry readings and local performances. The purpose was the raise awareness, education, and funds for the treatment of eating disorders. As we approached the event, Grace and I talked endlessly about the people who may or may not be in the audience for the upcoming night and what messages we hope to send.

“It has to be real,” I told her as we chatted on the phone. She was still in the hospital.

“Yeah, it can’t be all cheery fake, but at the same time we don’t want to trigger anyone,” she added. “I mean, we knew how dark and twisted this stuff is, and we know that vulnerable people are sometimes drawn to that, we don’t want that.”

“Definitely. We are not trying to prove we’re the sickest, nor are we trying to prove we’re the most recovered. Those conversations are beside the point. We want people to know that it’s okay to struggle, and it’s okay to ask for help.” I responded, thinking about how long it’s taken me to learn those things. “Grace, can you imagine how many years of our lives we would have saved if we had learned those things when we were little?”

“I prefer not to think about that,” she said, “but yeah, we would be better off if our parents and grandparents and great-grandparents had not been taught to that mental illness was shameful.”

“Everybody would have been better off.”

*But please don't act like you understand this horrible disease*

*Because you've read books, seen movies, or taken classes with ease*

*...And whatever you do or say to someone who is in the midst of dealing*

*If you don't get it; don't you dare say, "I know how you're feeling."*

### **Figure 10: Hospital Behavioral Health Record**

Erin discussed having a difficult weekend due to trying to deal with a variety of emotions. Erin reported that she purged on Sunday, but was able to resist the urge the other days and was able to resist the urge to cut herself. Erin shared some artwork that she did to help her cope with emotions. Erin was able to identify the emotions that she

was experiencing and reported that she was able to allow herself to sit with them. Discussed how this different experience for her and uncomfortable. Erin was given praise and positive feedback. Discussed how Erin allowing herself to experience emotions was a step in having healthy and reciprocal relationships<sup>9</sup>.

Paige, Grace and I stood backstage of the Andrew Lewis Middle School Auditorium in a circle.

“I can’t believe there are people here,” I whispered to them, as I peered around the curtain. “I can’t believe people showed up to this.” My hands had begun to shake, and I was beginning to freak out. Over the past year, I had developed organized, planned, and promoted the *Where I Stand* event. The purpose of it was to raise awareness, education and hope for the treatment of eating disorders in my hometown as well as create a scholarship that would hopefully help someone with treatment. All year long I had channeled every bit of energy I had for this event. I knew both in my heart and from my personal experience that it was needed, and I felt called to do it. I just couldn’t believe it was happening.

“Of course, people showed up.” Paige grabbed my arm. “This is going to be so good Erin; you have worked so hard.” I had worked hard, and I knew Paige wasn't talking about the event planning she was talking about my recovery work. I promised myself that to go through with the event, I had to maintain stable recovery for one year. In my mind, this meant I had to put my recovery first always, I had to commit one hundred percent to the process of giving up what felt safe but what was killing me and unlearning and then relearning how to live my life.

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<sup>9</sup> Medical record dated 6/5/12

“I know, I just can’t believe people are here.” I looked down at the paper in my hands; it was the story, my story as I understood it at the time that I was about to share with the two hundred people sitting in that audience. I wondered how they would feel about it and how they would think about me. I wondered if they had expectations for how this was supposed to go. Grace pulled me over to the side and gave me a hug.

“I’m so proud of you, Erin, and I can’t believe we’re about to do this.”

“I’m so proud of us, Grace. I couldn’t have done any of this without you. I wouldn’t even understand any of this without you.” Leslie stepped backstage and walked over to us.

“Are you ready girls? I’m going to dim the lights so tell everyone to settle in. Then I’ll wheel the podium out and then when you’re ready Erin you walk out and give me the thumbs up, and I’ll lift the lights, and you can start whenever you’re ready.”

“Okay,” I nodded. My hands were sweating and shaking. I honestly couldn’t believe this was happening. Paige and Grace each stood by a side of me as Leslie dimmed the lights and moved the podium out on the stage.

“Here we go,” I said as I move forward to take my place at the podium and let go of their hands. As I stood there for a moment in the dark, I said a short prayer of thanks to God because I had never felt more empowered in my entire life, and then turned toward Leslie and gave her the thumbs up. The lights lifted and the sweat on my palms became more intense, and my stomach jumped around.

“Good evening, my name is Erin Casey, and *This is Where I Stand.*” As I opened the benefit and welcomed the audience before even starting to share my story, I was filled with energy and peace that I didn’t often experience in life. I was intentionally becoming

vulnerable, naked, with hundreds of people that I never met, and I had never felt freer in my entire life.

\* \* \*

October 27, 2015, was my fourth recovery anniversary. I hear Paige knocking on my apartment door, and when I open it, squeals of joy erupt and she tackles me.

“Happy Recovery Anniversary Day!” Her eyes are filled with tears. “Erin, I know I always tell you this, but I’m so proud of you. I just can’t believe it sometimes. I just can’t.”

“Me either Paige. Me either.” I’m smiling ear-to-ear, so thankful that she drove in from out of town to celebrate with me, and wondering what I did to deserve such a wonderful friend. She hands me a gift. “Paige, you really shouldn't have.”

“Are you kidding?” I open the bag and find three candles and a journal. She knows me well. I give her another hug. We walk to my room where she examines all the things I have hanging on my inspiration board. I also get the feeling that she is looking for signs of anything unhealthy in my room that she can confiscate while she’s there.

“So, what’s the plan?” she asks excitedly.

“Well, I thought we could hang out just the two of us for a while and then later I wanted to get ice cream with some people,” I explain.

“Okay! My mom offered to take us out to dinner too,” she offered.

“Yay! I love your mom.” We climbed on my bed and began to chat about how much things had changed over the past four years, then suddenly Paige got a little more serious.



“Erin, have you talked with Grace recently?” She asked looking concerned. Paige knew a lot about Grace and had crossed paths with her several times because they were both so close to me.

“Um,” I hesitated. I knew Paige wasn't a fan of my friendship with Grace. “Yeah, a little, but it's been okay. I think she's struggling, but we haven't gone into detail.”

“Be careful Erin,” Paige said. “I've never told you this before, but I've always felt uneasy around Grace. It's had nothing to do with her mental illness; it's something else. I mean Lord knows mental illness doesn't bother me, but she-- she has always felt dangerous to me, in my gut. I don't know it's hard to explain.”

“Why haven't you ever told me that before?” I asked. I was surprised because Paige was never one to hide her thoughts and feelings about things from me, nor was she one to shy away from having hard conversations.

“I guess I was afraid that you would pick her over me if it came down to it, and I knew she gave you something that I couldn't, even if I didn't think it was healthy. So I just waited.”

This conversation with Paige about Grace filled me with sadness, first because Paige was so afraid to tell me how she felt about Grace. Paige was one of my best friends, one of my soulmates. I couldn't imagine how difficult it must have been for her to not say anything, to smile and hang out with both Grace and me together when she felt so awful about it. It also made me respect her that much more. Paige knew that parts of me and parts of Grace were so magnetically connected that to try to persuade me from our friendship would be to risk our own, and so she sacrificed a lot. She sacrificed a level of stability; she sacrificed control, and she often took a back seat even though she felt like

she knew what was best or better or healthier for me. In doing so, she taught me something valuable. She taught me that advocacy, true advocacy that is about the good of the person that you are serving had to be built on sacrifice. As advocates, we have to be willing to sacrifice what we want, what we think is best, what we believe to be best and be willing to learn, wait and listen patiently for how best we can serve those we are advocating for, and that might be the hardest part. It's easy to try to fix people, it's easy to try to show someone the way, it's easy to attempt to control or whatever, but service is hard because it requires that we abandon what we think we know to be best and love and value people where they are.

### **Narrating Friendship and Illness: An Epilogue**

In writing chapter two, I transitioned frequently between two emotions: shame and thankfulness. As I entered into my medical records over and over again it was easy for me to feel ashamed of their contents. I couldn't help but look at the record of my earlier self and think, "What the heck was wrong with me?" I struggled not to judge myself, as I felt insecure about writing those stories. I spoke with my advisor about this, nervously, and journaled endlessly about the things people might think about me if they knew some of *this* stuff. One afternoon, during our weekly thesis meetings I explained some of my embarrassment and shame to my advisor.

His response struck me. "This is how you survived," he said. *This is how I survived*. I've returned to this interaction between the two of us many times. *This is how I survived*. Each time I reflected on this I filled with gratefulness, there is nothing embarrassing about survival. *I am not bad*. As I pieced this chapter together I filled often

with thankfulness, and love for each of the people whom I wrote about, acutely aware that without them, I might not be where I am today, in recovery. I am in recovery.

There were several times, during the researching and writing process of this chapter, and others throughout the thesis, where I had to emotionally, mentally and physically stop working because of the intense emotion and vulnerability that it required. My therapist gave me a few instructions prior to beginning this writing process. First, she told me that I was only to go into my medical records, journals or other archives when I felt stable. This sort of stability for me comes with following my daily M.E.D.D.S.S., (mastery, exercise, diet, drugs, sleep and spirituality). It's a skill that I've learned to use as a way to provide accountability for taking care of myself. Typically if one of the six things is off or neglected my sense of stability is challenged. So, I agreed that if I wasn't able to take care of myself then I would not engage with the project.

The second thing Jessica asked of me was that I check in with myself while working on the project. She insisted that if I ever felt my anxiety increase beyond a certain level that I put the work away, process what was happening in my journal and then engage in a self-care activity. I admit this was difficult for me to do, the hardest part being convincing myself to stop working.

Finally, the last instruction that Jessica gave me was to attempt to be aware of how doing this work could be triggering certain distressing emotions or behaviors. This, I found to be relatively easy. Chapter two triggered my desire to purge most acutely. What many people don't know about me is that I loved purging, totally and completely loved it. It's disgusting and painful but it calmed me down in ways that I've only ever experienced through that behavior. So, naturally as soon as I started thinking, and writing about the

moments in which I engaged in that behavior a little voice popped up in the back of my head: *You should do it, you'll be able to write about it better if it's fresh in your memory. Remember how good it felt.* I had to work really hard sometimes, especially when I was tired or stressed, to remind myself that I didn't really want to do it, and even if I did, I didn't want the hell that came with it.

The second thing that chapter two triggered for me was loneliness. Just as this work has reinforced and highlighted my sense of difference it has increase my feelings of isolation and loneliness. I really don't believe that I always feel as lonely as I have at times while writing this chapter. I think it's because I really did reenter a time in which I was so incredibly lonely and isolated in my own head and in my own self-destruction. While writing it was hard for me to remind myself that I am not the same person I was in those stories. It was hard for me to separate that past from my present, and often took processing with someone else – my therapist, a friend, my advisor to realize that. Additionally, I still am unsure about how the chapter ends. I keep wondering: *How do you end a never-ending story?* I still don't know the answer to this, and maybe there isn't one.

I decided to end it with the beginning of my first advocacy event. This project's intention was to highlight mental health advocacy, and the deeper that I seemingly fell into my medical charts the farther away from the advocate side of me I felt. However, what strikes me with this is that my identity as an advocate emerged within, out of, and because of my illness not in spite of it. My work as advocate and my illness are intricately connected and I don't believe they ever can or should be separated because as

an advocate I am battling against the false illusion between the sick and the well and sane the insane and I don't want my life or my work to recreate that dichotomy.

**Figure 11: Process Poem**

It is more than you will ever read in a book  
 It is more than you can ever understand from a look  
 It is more than you can even grasp through spoken word  
 No matter how often or how loud it is heard

To understand this illness, disease, addiction and obsession  
 You must first know, relate to, feel and touch the underlying pain and depression  
 To understand the control, perfection, and deep self-dissatisfaction  
 Your brain must distort the general principles of attraction

Beauty is everywhere  
 Except in the mirror as I stare  
 I will disappear, control what I can, chase perfection with all that is in me  
 In the hope that when looking in the mirror it is no longer I that I see

To know an eating disorder, what it means, and how it feels  
 You have to be one of the sufferers; one of the people who deals  
 To understand its implications and major effects  
 You have to be the ones with whom the sufferer lives with and connects

No book will tell you of the true pain in my soul  
 Or how desperate my attempt was to be in control  
 No movie will teach you the damage I did  
 As I checked out of life and constantly hid  
 No testimony can explain to you how hard it is to get your life back  
 Searching and seeking to get your life on the right track

It is more complicated than anyone could possibly fully understand  
 Unless an eating disorder took over your life unplanned

Everyone has their story and struggles too  
 Though not the same, equally troublesome and true  
 But please don't act like you understand this horrible disease  
 Because you've read books, seen movies, or taken classes with ease

If you want to be a therapist, doctor or some other treatment provider  
 Do an internship working with the people who suffer to make your eyes wider  
 And whatever you do or say to someone who is in the midst of dealing  
 If you don't get it; don't you dare say "I know how you're feeling."<sup>10</sup>

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<sup>10</sup> To Understand, a poem by Erin

**Figure 12: Process Poem**

Mother and Father, I love you so  
 I was your princess, my King, and Queen  
 Brother and Sisters, I love you so  
 I was your comrade, my partners in crime  
 Hugs and Kisses – laughter too  
 Dancing and spinning, singing and talking

Darkness fell one horrid night  
 ED attacked, and terror jumped inside our home  
 Ugly words, fear, hate and blame  
 Tears were never-ending

Exhaustion, frustration, anger  
 Exhaustion, frustration, anger  
 Exhaustion, frustration, anger

I ran from you and the darkness of our home  
 ...darkness followed  
 At times, terror consumed my very being  
 I wanted you, your warm embrace  
 You rescued me a number of times.... But tensions always returned

It is not until now  
 After facing the darkness  
 Do I see your Love  
 Was there always  
 Each day  
 Holding your breath  
 Hoping for  
 Recovery<sup>11</sup>

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<sup>11</sup> Hoping for Recovery, a poem by Erin





## CHAPTER III

*Mental illness doesn't come with an instruction book.  
We're all learning this at the same time. – Mom*

In addition to my friends, my family makes up the other primary component of my personal support within my support network. My parents have bared the brunt most heavily regarding the financial and emotional burden during the darkest and most difficult days of entering and navigating the mental health care system. My family as a whole had to confront our embedded mental health and addiction issues on a much deeper level as they surfaced in the form of my acute suicidal ideation. Questions arose: How did this happen? Whose fault is this? Is this genetic? Where did it start? What do we do? What don't we do? What can we say? What should we say? What shouldn't we say? As my mental illness took over my life; my body and my brain it entered our family puncturing our sense of security and calling into question our beliefs about ourselves as individuals and as a collective unit.

*Why is it so hard to turn to those that love me?  
....and simply say: "Mom and Dad – I am not Okay."*

I was home alone, which was typical these days, after returning home from treatment my parents were often at work while my siblings were at school. It was time for lunch so I pulled out my meal plan sheet (even though I had already memorized it) and busied myself making a grilled cheese sandwich. The phone rang.

"Hello?" I picked up in my Dad's office. It was a reminder for a doctor's appointment. While scrounging around on the desk for a piece of paper and pen to write down the details I moved the mouse and a letter my dad had written popped up on the

screen. I don't know why I read the letter. My dad wrote a lot of things, like a local column for the paper in our hometown - he writes constantly, but quickly I realized that this was not just any letter. This was an invitation to my funeral. My heart dropped to the pit of my stomach and tears welled up into my eyes but I could not stop reading. "I am writing today to invite you to my 21-year-old daughter's funeral when that happens." *My dad thinks I'm going to die. My dad doesn't believe in me. My dad thinks I'm hopeless.*

**Figure 13: Letter from father to insurance company<sup>12</sup>**

Dear Ms. Woodward<sup>13</sup>,

Congratulations on your ascension to the top post in Central Insurance<sup>14</sup>, the parent company of my health insurer, Larkin Health<sup>15</sup>. I am writing today to invite you to my 21-year-old daughter's funeral when that happens.

I hate to sound like a whiner but the truth is we are not big consumers of health care here in the Casey family of Clyde, Pennsylvania . I am 53, my wife is 48 and we are working stiffs with four kids, three of whom are covered by Larkin. The good news is we're pretty healthy. We go to the doctor once a year or so to get some blood drawn, or for the flu and stuff. We pay into the system like other workers whose employers have decided that Larkin is the best carrier.

We hit a snag last year, though, and it involves my daughter. Her name is Erin Elizabeth Casey and her birth date is 1-18-82. She's a rising senior at Thomas-Green University in Southville, Ca. It's a good school, and she is a good student. She makes As and some Bs.

The problem is Erin has mental health issues. Those involve an eating disorder and bipolar syndrome. And we are more or less broke now, and facing God only knows what bills to come, because of Erin's illness and because we did not realize how much of her treatment Larkin, our health insurance carrier, would decline to cover.

They did not cover Erin's treatment the first time she expressed suicidal ideation, back in November 2010. Our bad on that. We failed to get pre-authorization for

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<sup>12</sup> Written and shared with permission by author

<sup>13</sup> Pseudonym

<sup>14</sup> Changed Name

<sup>15</sup> Changed Name

the partial hospitalization psychiatric treatment her psychiatrist recommended. Actually, we didn't realize soon enough that we needed it -- it seemed like an emergency. And Erin's docs had raised our expectations by telling us we had unusually good health insurance. So Larkin denied the claim. Those are the breaks, and I guess we deserve to take that hit. The bill is in the thousands.

The second time Erin was referred to this program things got a little trickier. That was this year. At that time, based on our earlier experience, I insisted she NOT enter this program until Larkin pre-authorized it. I thought I was being intelligent in this decision. But we were outfoxed again.

Larkin sent us the forms authorizing coverage. My wife and I thought, "Great! She can go in this time and she's covered." Little did we know that Larkin had authorized coverage for something other than the program the doctors had recommended. We didn't realize it and the hospital didn't realize it either. But apparently Larkin did. Larkin reps later explained to my wife they had authorized inpatient care rather than the recommended outpatient.

My wife Brenda keeps arguing with them, saying, "But we followed the rules. You sent us the pre-authorization forms." And the claims reps who she has dealt with on this matter keep responding, "I'm sorry, but we approved something else that Erin didn't get. You're on the hook for this one, too." I suppose we should have known the difference, eh?

That is more thousands down the drain. Maybe the hospital will sue us for the money because we don't have it. Maybe they will attach the equity in our house. At least, they won't want our cars because we drive old ones.

The third time Erin was talking suicide, in April, her roommates carted her to the ER. And they locked her up in a psychiatric wing of a hospital for three nights. I can't honestly say that did her any good. She did some "group therapy" that involved a coloring book. Most of the other patients were elderly and on major tranquilizers, and they drooled a lot. She got herself out of there after the mandatory waiting period because there was little if any treatment. The hospital wanted to hold her longer, but that seemed silly. Larkin covered it, and for that I thank you. But the truth is Erin kept your bill down by insisting on leaving on her own.

This summer her eating disorder, which the doctors say is a key element of her bipolar syndrome, got out of hand. Her psychiatrist recommended she go to The Clover Clinic, an eating disorders hospital in Arizona. The good news is, The Clover Clinic is in Larkin's network. The catch is, she had to be evaluated there before Larkin could make a decision as to whether they would cover her treatment. So we bought her a plane ticket, paid for the evaluation up front (in cash, because Larkin doesn't cover that) and crossed our fingers.

Larkin initially agreed to cover a stay there; and for that, I guess I should say thank you again. Erin was there for 22 days, which were approved by Larkin in several stretches of days at a time. The Clover Clinic doctors had recommended 90.

Yesterday afternoon, on Aug. 18, I received a call from Erin's very concerned counselor at The Clover Clinic. She informed me that Larkin's coverage had ended on Aug. 17. Through many, many subsequent phone calls on this workday afternoon, I was able to piece together what had happened. Basically, it was that a doctor at Larkin who has never examined Erin talked to a doctor at The Clover Clinic who is treating Erin and who was trying to get her coverage extended because the Clover Clinic doctor believed it was necessary.

The Clover Clinic doctor said, "She needs this." And the Larkin doctor said, "No she doesn't." And the Larkin doctor got the final say on that one. I guess he -- or she - knows best.

Just to figure this out took many phone calls to Larkin and The Clover Clinic on Thursday afternoon and night. At Larkin, I spoke with Parker K in customer care, and his team leader, Greg Samson. He tried a couple of times to reach The Clover Clinic without success. Then he went off duty at 5:30 p.m. (which is 2:30 p.m. Arizona time). He also gave me the phone number for Behavioral Health. I called it and spoke to Willow Myers and later Melvin Zab. They are in Missouri. They explained there was nothing they could do about this decision because they were simply taking calls for the East Coast Behavioral Health office, which already was closed by then.

At least, Willow Myers did give me the secret code term, "Appeals and Grievances," which Greg Samson had failed to give me earlier. That would have gotten me through to someone who might be able to do something, Willow said. But there was another catch: By then it was too late to reach Appeals and Grievances because they were closed, too. They would not reopen until 8 a.m. on Aug. 19. I didn't call them because I couldn't see the point. The Clover Clinic, which had recommended keeping Erin, was going to kick her out the morning of the 19th because her Larkin coverage had expired on the 17th. We had to make arrangements for her to fly herself. As you might imagine, I've given up hope that Larkin will provide coverage that could help avoid that, based on recent events. And so one of these days we will probably have her funeral.

I'm thinking about putting LARKIN in big letters on her tombstone. And Greg Samson' name, and Willow Myers 's name and Willow Myers', too, in smaller letters.

It will stand as a monument to the disembodied voices in Larkin-limbo that panicked family members must deal with in a crisis situation. It will also be a monument to all the tricks and Catch-22s that inexperienced health-care consumers, such as the naive Casey family, get caught in when they try to use the insurance they thought they had. Little do they know.

And then maybe we will declare bankruptcy. Because we can't afford the funeral, either.

Hope to see you there.

Sincerely,

*Erin's Dad*

I read and re-read this letter over and over again, before falling onto the floor and crumpling into the fetal position. My lunch no longer happening. I sobbed, convinced that I had completely ruined my family's life. *Maybe it would be easier if I died. Maybe it would be better if I was gone. Maybe it would be less stress. Why can't I stop hurting them? Why am I so screwed up? Why can't I just figure my shit out? I hate myself. I hate myself I hate myself.* My brain took over and I moved towards the bathroom, desperately searching for a release, and just before I shoved my hand down my throat, I paused. *We're all losing. There are no winners. Everybody suffers. We're all are dying.*

I grabbed my phone and called my friend and mentor, Pat. Thankfully she answered

"Pat- I- I - I," I couldn't speak, for one.

"Erin, take a deep breath. Shhhhhh it's okay." She attempted to soothe me.

"My dad wrote a letter to our insurance company inviting them to my funeral." I got out in one breath. My body was shaking. I felt sick, I couldn't believe I was admitting it to another person. I still couldn't believe it was real.

“Oh, Erin, I’m so sorry you saw that. But you know as much as I do that your dad writes to process just like you do. That letter was him getting his emotions out more than anything else,” she calmly explained.

I knew she was right, but I couldn't stop thinking about those words. “Pat, I’ve ruined my family.” I cried again.

The impact of my illness on my family is something that haunts me. I cognitively understand that my mental illness is not my fault. Still, knowing that *part* of me has caused them so much pain makes me feel sick to my stomach. My dad told me once that for years my parents were afraid to answer the phone, thinking that it was going to be someone telling them that I was dead. I often revert back to the helplessness I felt when Grace got sucked up into her brain’s disorder and taking a sledgehammer to her window. It makes me feel sick to think that my parents, and my siblings lived with that sort of helplessness for years.

*Maybe it’s because they care too much*

*I hate hearing their heartbreak over the phone*

“You’ve always had a different brain.” My mom once told me. She often says that all the “wires” in my brain did not really connect until around fourth grade. Sometimes, I could hardly read at all, and then other times I could read at grade level. I would fail my multiplication tests and other times I would pass them with flying colors. Because of the inconsistency in performance, teachers were quick to put me in the remedial classes. In return, my mother was quick to schedule parent-teacher conferences.

Mom says, “They thought you were dumb and I knew you weren’t.” And, in every grade-level that my mother believed I was put in the lower level class, she had me moved. She would explain to me that I was just as smart as any of the other kids but that I just had to work for it harder. We would sit together at the kitchen table after school doing math problems and taking practice-spelling tests. I would read aloud to her as she cooked dinner. She worked harder with me on my homework than my teachers ever did in school. Showing me that she knew I could do it. It was in fourth grade that I got straight A’s for the first time and after that, I was hooked. I loved the feeling of succeeding in the classroom and as time went on I needed less assistance from my mom with my homework and studying. However, my mom’s fight wasn’t over.

In our school system during the summer before sixth grade, the most advanced students received letters inviting them to start Spanish one that year. My older sister had gotten the letter and I was anxiously awaiting mine after getting almost straight As in fourth and fifth grade. However, when I didn’t get the letter and my friends had my mom called to the school to set up a meeting with the principal. We both went and I sat nervously twisting my hands in my lap.

“I want Erin put in Spanish. I don’t understand why she wasn’t.” My mom opened directly. I stared at Principal Henderson.

“Well, based on Erin’s test scores I don’t think she would be very successful. The transition to middle school can be challenging and put too much stress on students their first year can be a problem,” Henderson responded

“What test scores are you using?” Mom asked

“Her third and fifth-grade state standards of learning.”

“Third grade was a long time ago,” I chime in. I did better in fourth and fifth grades.

“Does her improvement mean nothing?” Mom asked directly

“No, I do see a lot of improvement between the two,” Henderson responded. “I tell you what. I’ll put Erin in Spanish, but she has to make an A in the first nine weeks to stay there. How does that sound?”

“I’ll talk to my husband.” My mom stood up and I stood with her. She shook Mrs. Henderson’s hand. Then, I did as well, and we went home. That night, my parents talked about the meeting during dinner. Neither agreed that I should have to get an A during the first grading period if none of the other kids did, so my dad wrote a letter for me to take to Mrs. Henderson on the first day stating that they wanted me to put in Spanish, but that no standards should be applied to me that were not applied to the rest of the class.

\* \* \*

“I’m going to stay on the phone with you while you get yourself ready.” My mom’s voice echoed through the phone to me. She feels so far away. I threw my heavy down comforter off my body and onto the floor.

“Okay, the covers are off.”

“Good. Now, sit up.” I didn’t want to, but I knew my mom would drive up here the second she thought I was too far in the “dark place” and I didn’t need that. I sit up and plant my two bare feet on the shaggy green carpet that covered my dorm room floor.

“I’m out of bed.”

“Good job sweetie,” she encouraged robotically.



“Now get some clothes on.” I begin looking around on my floor for something that smells remotely clean unable to remember the last time I did laundry. I grab some black sweatpants, my green sports bra and an old T-shirt from the lake where I used to lifeguard.

“Hang on Mom. I’m going to put the phone down while I get these clothes on.”

“Okay, sweetie. I’ll wait.” After slipping on the semi-clean clothes, I return to my mother.

“Okay, I did it.”

“Good job.” Her words stayed with me.

*Good job.*

This is not a good job. This is pathetic. I need my mother to talk me through getting dressed to make sure I get out of bed.

Good job.

“Do you have your socks and shoes?”

“Yeah. I’ve got them.” I set the phone down on the floor beside me as I slip on two mismatched socks and my gray sneakers. Picked the phone back up, grabbed my key and left the room.

“Okay. I’m walking down the hallway now, I’ll be outside soon.”

“Uh-huh” came from the other end of the phone. I could hear the banging of pots and pans. I guess it is almost dinnertime.

“I’m outside mom.”

“Good, now go for a walk and call me after okay? Being outside will be good for you.”

“Okay.”

“I love you, Erin.”

“I love you too, mom.” As I hang up the phone and begin to wander around campus.

I watch people and smile as they pass by. I wave to two girls from world religion class then look away quickly. I wonder if they have noticed my absence.

*What am I doing here? I ask myself as my chest tightens. Groups of people shuffle through the crosswalks, up and down stairs talking, laughing and living. Smells from the nearby dining hall are making my stomach growl. I stop and watch a puppy pee in the grass. Maybe I need a puppy.* I realized I stopped walking and was disrupting the flow of traffic. *I don't belong here.*

#### **Figure 14: Personal Journal Excerpt**

Dear God,

I wish I weren't alive. This is not how things were supposed to be. I'm exhausted. I try to be happy. I try to be pretty. I try to be smart. I try to be everything. I don't want to try anymore. Everything aches as I swim in self-hatred. My brain reminds me “always a failure, never enough.” Secretly I long to be held as I keep everyone at a distance. Who am I supposed to be God? As a little girl, I had everything figured out. I was going to be a dancer. Now I'm confused and hollow. Why is this happening?

*Maybe it's because they won't care enough  
I hate hearing the distance they sometimes portray*

“I talked to my parents about the medications you suggested,” I explained to Tina.

“They said that I can't take any meds.”

“Yeah, I've spoken with them as well. You're right they don't seem receptive,”

Tina responded looking frustrated. “How did the conversation go?”

“I don’t know, I just brought up that we’ve been talking about meds and my dad said that he doesn’t want me on drugs because my brain is still developing,” I explained. Tina rolled her eyes.

“It drives me crazy that people think this type of medication is optional.” She had set her notepad down. I was fifteen and Tina was my first therapist, my parents forced me to go after an incident at my dance studio.

“Did you tell them that you wanted to try medication?” she asked.

“Yes, but then my dad read me all the side effects online and weight gain is pretty much a side effect for all of them, so I’d rather not now. He also told me a story of someone he knows who gained fifty pounds because of one of the medications.” Tina picked her notepad up and began scribbling.

“Erin, I think you need this, but obviously, we can’t do anything about it without your parent’s permission because you’re only 15. We can revisit it again at a later time.” I didn’t see Tina for long, a few months maybe, until I was able to convince my parents that I didn’t need it. I think I believed I didn’t need therapy too. I didn’t want to need help as a sophomore in high school, and I certainly didn’t want to talk to someone I didn’t know about things I didn’t understand about myself. I just wanted to be normal, whatever that meant.

*Maybe it’s because they will blame themselves*

*I hate when they take my problems on as their own*

“Erin is doing much better... Yes, she only has to go to therapy once a month now.” I heard my mom on the phone with someone as I walked passed her bedroom. “We

are so proud of her. She is definitely ready for classes in the fall.” *Is she talking to Janelle? Am I going to back to the studio?* My heart feels like it going to burst from my chest. I walk into my mom’s room. She holds up her finger, telling me to wait. “Uh-huh.... Yes of course” she continues. Finally, she gets off the phone.

“Mom, am I going back to the studio?” I held my breath.

“No, honey, you’re starting the new studio,” she replied. “I was just confirming that you were allowed to take the extra classes you wanted.” My heart broke all over again, as the minute long thought that I would be returning to my place of worship disappeared as quickly as it had reemerged.

“Oh,” I replied, defeated. My mom stroked my face.

“Smile sweetie, you get to take as many classes as you want because you’re all better now! That’s something to be happy about.” I looked up at my mom and smiled weakly.

“Thanks, mom.” I walked out of my mom’s room. Is this what “better” is? Is this what healthy is? I don’t feel any different. It doesn’t matter, though, because as long as people think I’m “better” I get to dance, my parents are less stressed and I don’t have to go to therapy. So yeah, I’m “better.” Maybe I was never sick at all.

\* \* \*

“Erin, I can’t let you leave here today. You need to go to the hospital.” I stared blankly at Dr. Grayson.

“Will it help?” I asked.

“I think so.” She looks sad.

“I have to call my mom. I don’t know what to say.” I say to her, beginning to panic

“We can do it together,” she replies calmly. I walk over and sit in her desk chair and we put the phone on speakerphone. I dial my mom’s cell phone number. The phone rings twice. My hands are sweating and my chest beats loudly.

“Hello?” The hesitance in her voice tells me that my mom doesn’t recognize the phone number.

“Mom. Hi, mom, it’s me.”

“Erin? Where are you?”

“I’m in Dr. Grayson’s office, she’s here too.”

“Oh good,” my mom says, now relaxed. “Hi Dr. Grayson, I called this meeting because....”

I look up at Dr. Grayson. My mom didn’t call the meeting, what is she doing?

“Mom, mom, stop – you didn’t call the meeting. What are you talking about?”

There was silence.

“Oh, sorry I’ve just been thinking about wanting to talk to her I guess. Why are you calling?”

“Mom I’m going to the hospital.” More silence.

“Oh Erin,”

“I’m sorry Mom..”

“Honey, it’s okay, I just, I just don’t understand. This is so confusing.” I look to Dr. Grayson signaling to her with my eyes that I need her to take over.

“Hi Mrs. Casey. I don’t think Erin can keep herself safe right now, so this is our best option. This is our only option.”

“Why is this happening to her? Why is she like this? Why can’t she get better? Nothing is working. Is it our fault? Did we do something wrong?” I heard my mom’s voice break. I knew I was hurting her. I knew I had been hurting her for a while. I knew what to say, but I didn’t want to.

“Mom something bad happened to me when I was in 9th grade. I don’t want to talk about it, and I don’t want you to tell anyone.” There was a thick, painful silence. Dr. Grayson put her hand on my back.

“Was it someone in our family?” My mom asked.

“No.” I began to tear up.

“Can I tell your father?” she asked.

“Yes, but I don’t want to talk about it and I don’t want people to ask questions. I’m not ready.”

“Okay, honey. You know that we love you, right?” She asked.

“Yeah, mom, I do.” We hung up the phone and I burst into tears, my hands were shaking and I wanted to throw up. I wasn’t sure I wanted to disclose that information to my mom but I also couldn’t handle the hopelessness in her voice that I knew only grew with the lack of answers. I wasn’t sure what I shared was an answer or reason but it was something.

*Maybe it’s because they will give up on me*

*I don’t think I could handle another person doing that... again*

I wailed as my mother drove me to dance class. Tears were streaming down my face, and I struggled to get a full breath of air. I watched my mom's knuckles tighten on the steering wheel.

“Why did you marry him?” I sobbed. I didn’t understand. My mom was the most kind-hearted and loving person I had ever met, and my dad could be angry, rude and hurtful when he spoke to me or my siblings. It didn’t make sense to me.

“He wasn’t like this when I married him. He was different. He was kind and sensitive. I don’t know what happened. Everything is taking its toll. I don’t what to do.” I stared out the passenger side window. But how could someone change so much?

As my mom spoke, my heart broke into a million pieces. They are trapped in a world where they constantly feel stupid, inadequate and helpless. I could feel myself hating my dad for not being able to cope with me, with us.. As we pulled up to the dance studio, I checked my eyes in the rearview mirror to make sure I didn’t look too teary.

“Later mom. I love you,” I said. I gave my mom a big hug.,climbed out of the car and headed inside. As I sat in the waiting room for dance class to start, I promised myself that I would never get married. I don’t want to risk falling into the same trap.

\* \* \*

My brother came into my room and climbed up into my bed. “Why is dad so mean?” He looked little, and I felt a twinge of sadness for him because he was just now realizing that our Dad wasn’t the same guy he used to be.

“Mom says it’s because of his depression. Did you know that Granddad was an abusive alcoholic?” I asked Tyler this question, trying to make things make sense for him

and trying to believe them for myself. “Sometimes, when people are hurt, they hurt other people.” I continued.

“I don’t care. He doesn't have a right.” Tyler began to raise his voice.

“I know he doesn't, but sometimes it helps me to understand.”

*Maybe it's because they will be angry*

*I hate when they scream, cry and yell*

“You know, I’m not surprised you have bipolar disorder, Erin.” My mom said casually as we drove to the grocery store.

“Really? Why not?” I asked, confused because this was my newest diagnosis.

“Well, your grandmother has it. It’s in our family,” she continued. “I mean, we didn’t know what it was back then. But I remember sometimes I would come home from school and the house would be sparkling clean and there would be a snack on the table, mom would be working on some new project.” She told me.

“You think she was manic?” I asked, curious, I had never heard this before.

“Oh yeah, and then there were the other days when walking up to the house I would notice the blinds were pulled and inside mom would be in bed. I would come inside and dig around in the kitchen for something for me, Diana and Denise to eat.”

“Oh.” I didn’t know what to say.

“Yeah, I remember this one time I walked into MeMaw’s room and she had one of pop pop’s guns to her head. It really freaked me out.”

“What did you do?”

“Well, I walked in, and she put the gun down. It really scared me.”

“Is MeMaw on medicine?” I asked, hoping that she was.



“I don’t think so. She likes the highs; she says the medicine stifles her creativity. Erin, promise me you’ll always take your medicine.”

“I promise, I will Mom.” I turned away and stared out of the window of the van. I got this from MeMaw.

I will never forget being in the van with my mom processing the story she had just shared with me. Initially, I didn’t know what to say. Seemingly instantly I went from being the only known person in my family diagnosed with bipolar disorder, to one of two. I couldn’t believe that my mom went through something so traumatic as a child. I imagined how helpless she must have felt, how afraid. I couldn’t understand how I didn’t hear about this before that moment. I thought about all those times when I had called her, ready to take my own life. *Does she think about her mom’s disorder often?* I felt incredibly sad for her and sad for the little girl who shouldered so much. In part, I also wondered why she shared the story with me, and why she had not shared it with more before. Did she believe I couldn’t handle the truth? Did she hope that her experience of growing up with a mentally ill mother would fade into the distant past? Did she want me to learn from it? Did she want me to not feel so alone? Was she hopeful that in hearing her experience of her mother, my grandmother, I might be encouraged to stay on my medication? Was she trying to scare me?

*Maybe it’s because of the money I have already cost them*

*I hate when I hurt their lifestyle and the comfort of our home*

“Erin, we cannot afford for you to go to the hospital again. I don’t know what to tell you.” My mom explained to me on the phone. My therapist and psychiatrist were recommending it again, and the insurance didn’t cover it the last two times.

“I don’t know what to do, Mom.” I began to cry. “You don’t know what this feels like for me. I don’t want to live. I think about ending it all every day.” I’m bawling by the end of the sentence.

“Erin, I hear you, but I don’t know what you want us to do. We cannot keep doing this. We cannot afford the bills that we have. And you’ve already done this twice without it working - what makes you think it will work this time?” I didn’t know what to say or how to answer her questions. I was just trying to do what my doctors were telling me.

“I don’t know mom. I’ll talk to you later.” I hung up on the phone and climbed into bed. I couldn’t help but wonder if they cared, mostly because I felt like if they understood the depth of the hell, I felt myself in and they did care they surely would be doing everything in their power to help me out of it. But then I felt incredibly selfish, which only compounded my depression and worthlessness and climbed into bed. I needed to sleep.

\* \* \*

My parents stopped to visit me at school while driving through town. I gave them the tour of the house that my friends and I were renting out and then we settled in on our picnic table out back for a bit.

“Your house is nice, sweetie,” my mom said.

“Thanks, we really like it.” I began to explain to them about how the girls and would all watch TV together and makes meals once a week, but my dad interrupted me.

“Erin, do your hands always shake like that?” He asked staring at my hands. I quickly rested them on the table.

“Yeah, they do, it’s because of the medication. It’s not that bad, I’ve gotten used to it.” I felt embarrassed because my Dad looked worried or angry or frustrated. I was sure to keep them on the table the rest of the time they were there.

\* \* \*

“Hi, Erin.” I could hear the pain in my mother’s voice as I pressed the phone to my ear. The phone only rang once; my mom has been waiting for my call for days. I had finally been granted phone privileges.

“Hi, Mom.” I exhale, fighting back tears. I fight everything inside of me that is telling me to beg her to book me a flight home. I want to promise her I’ll be better and I’ll take care of myself and that I’ll never ever need help ever again. I want to apologize for being so difficult and causing so much pain. I want to tell her I can do this. But I don’t. Shaun, the behavioral tech, sits next to me writing notes listening to our conversation. I hear my dad yelling in the background.

“How are you? Are you okay? Do you need me to send you anything?” Mom asked, trying to comfort me from across the country.

“No. I’m okay. Who is Dad yelling at?”

“He’s on the phone with the insurance company. You know, the usual.” My chest tightens, and my skin burns hot. I am hurting them. Treatment is thousands of dollars a day, money that we don’t have. I think about my dad’s heart, and his blood pressure. This is going to kill him. I’m going to kill him. I hear more yelling.

“What’s going on? Did they stop coverage? I’ll come home.” I cannot cost my family everything. I’m not worth it. This might not even work. I cannot ruin their lives.

“It’s just something about a form sweetie; we’ll get it straightened out.” My heart sank. I could hear the lie in her voice. Tears began to burn. She can’t hear me cry.

“I love you, Mom, but I have to go, someone else needs to use the phone.” I force the end of the conversation about to burst into tears.

“I love you too, Erin. Get better.”

“I will, Mom.” I hang up the phone and rest my forehead on the wooden table where Shaun and I sat. Then standing up I pushed the phone onto the floor screaming “I CAN’T DO THIS.” Tears flow, unstoppable, my head spins and my skin tingles. Shaun moves towards me.

“DON’T FUCKING TOUCH ME,” I screamed storming past her and into the hallway. I wanted to rip all the skin off my body, so I pace the front hallway up and back up and back, crying loudly. Marie, another behavioral tech, ushered the other patients into the common room. Shaun sat in the hallway with me as I slid my back down the wall sobbing, grasping at my skin tightly pulling for relief.

“Susan is on her way in, Erin,” Shaun said softly.

“I don’t need a fucking therapy session. I need a plane ticket.”

*But...*

*Maybe just maybe it is because I’m scared and I don’t know what I need*

*Maybe it is because I’m hurting and I’m ashamed I can’t fix this myself*

*Maybe it is because I’m angry that these words must be said*

It was October 2011, and I was back in Harrisonburg, by this point I had been through several years of intensive individual and outpatient group therapy, a few rounds

of partial hospitalization, one acute inpatient stay, and one long-term residential treatment center. I felt like I had been through it all, and then some, regarding drug therapies and behavioral and rehabilitative interventions. I was tired, but I also understood how to be a patient. I had learned the language. I knew how the process worked, and I felt comfortable with people telling me what was wrong with me. However, I was a far cry from healthy. I was completely dependent upon my therapists and doctors as well as still completely terrified of myself, filled with self-doubt and distrust for other people.

One afternoon I had a meltdown, which was a typical occurrence for me, but this one felt more urgent. My skin was suffocating me, and I felt like everyone in Harrisonburg was watching me. So, I called my therapist and left her a panicked message, got in my car, and drove to my hometown. As I flung our front door open and fell to my knees sobbing I heard my Dad in the back office.

“Hang on a minute.” He had been working from home that day and was on the phone. I started to try to tell him that I wasn't okay but I was mostly just sobbing. He went back into the office to finish his call. “Hey, my daughter just got home, I'm going to need to call you later.” He came back toward me and said, “Let's go walk up Mill Mountain” a mountain that my family hiked regularly growing up. We walked and talked as we worked our way up the mountain, and for the life of me can't remember our conversation until we were almost to the top.

“Erin, you're going to be okay. I don't know when and I don't know how, but I just know. And this bad moment, this scary moment will just be a memory.”

And right then I realized how much I missed my dad, and the rest of my family, my friends, school, and doing things that didn't revolve around crisis management and operating in survival mode. I felt loss, a really deep loss and was terribly overwhelming.

*But, maybe, just maybe I can find them and find me again. Maybe that is recovery.*

### **Figure 15: Process Poem**

I have danced on a stage with thousands watching  
.....many many times

I have given speeches in my high school  
I have talked in front of a campus ministry  
I have told a very cute boy I liked him.... A lot

So... Why is it so hard to turn to those that love me?  
...and simply say: "Mom and Dad – I am not Okay."

Maybe it's because they care too much  
I hate hearing their heartbreak over the phone  
Maybe it's because they won't care enough  
I hate hearing the distance they sometimes portray  
Maybe it's because they will blame themselves  
I hate when they take my problems on as their own  
Maybe it's because they will give up on me  
I don't think I could handle another person doing that... again  
Maybe it's because they will be angry  
I hate when they scream, cry and yell  
Maybe it's because of the money I have already cost them  
I hate when I hurt their lifestyle and the comfort of our home

But  
Maybe just maybe it is because I'm scared and I don't know what I need  
Maybe it is because I'm hurting and I'm ashamed I can't fix it myself  
Maybe it is because I'm angry that these words must be said

It is hard not knowing how they will react...

It is hard not knowing what they will say...  
 It is hard not knowing what they will do...

But when we're not Okay  
 We don't mess with the maybes  
 There is not a lot of time to delay

So what might seem simple at first glance  
 Is really not so simple at all  
 But no matter how difficult or complicated it may be  
 You are worth all the 'maybes' because  
 You deserve a fighting chance<sup>16</sup>

### **On Family and Illness: An Epilogue**

In writing chapter three, I began by thinking I was going to be writing about my relationship with my father and our negotiation of my illness. However, what was written in the process was less about my father and much more about my mother. This makes sense to me now. It has been my mom who has done so much of the relational and emotional work with me since childhood, through the darkest days of my illness and into recovery. My father has inconsistently shown up in moments, and those moments are highly emotionally charged, either positively or negatively. On the other hand, my mother's presence in my life has been characterized by a certain consistency. Living in an unpredictable sometimes scary, sometimes volatile, and seemingly always changing brain, I've come to a realization that consistency mattered most. Consistency still matters.

I started this chapter with a quote from my mom, "Mental illness doesn't come with an instruction book. We're all learning this at the same time." She said this as we generally talked about this autoethnographic project. The moment she said those words,

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<sup>16</sup> Not so simple, a poem by Erin

and then again while reflective writing about relationships with family, I felt an enormous amount of appreciation for the vulnerability required to deeply engage and maintain relationships with people with whom mental illness is constant. In chapter three, I reference the financial and emotional burden that my parents have faced in light of my illness, and the ways in which my illness has ignited, punctured, created points of reflection or conversation. In contrast to my relations with friends, my family has literally had to take on a certain level of ownership of my illness in order for me to recover. The responsibility my mom took on paralleled her ownership of my education as a child.

I became both uncomfortable and vulnerable while writing chapter two because I feared that emerging through the stories was the fact that I am still a child. I felt painfully needy while constructing these narratives and stringing them together. I became angry at myself for needing help. I attempted to push people away, in some illogical effort to prove to people that I wasn't needy; that I wasn't a child. I fought myself (and my therapist) on the issue. *I shouldn't need treatment anymore. I can do this on my own. It's embarrassing to need so much help. I should be better than this by now.* I felt guilty and embarrassed when I needed to reach out for help. I couldn't stop thinking about being a little girl put in the low classes, needing my mother to fight for me.

An emergent truth is that I am needy. I do need help. I can't do this on my own. What's beautiful about this though is that I don't have to do this alone. For as long as I can remember, I have fought my own needs and I've never won. Through destructive behaviors and a desperate attempt to deny my own humanity, I almost died. It wasn't until I learned to surrender to the fact that I need other people, and sometimes need them a lot, did I ever make any progress in my recovery. Through this writing, I've relearned



that, but more so I've realized that that neediness isn't bad. It's okay to need other people. Everybody needs other people. I'm not supposed to be able to do this alone.

Additionally, while writing chapter three, feelings and tensions related to blame surfaced forcefully, as I was conscious that I did not want to this chapter to blame anyone for my illness. Reviewing my medical records and personal diaries entries revealed the blame I put on my family for how messed up I felt all the time. I used to think everything was their fault. I had a narrative written for it that listed all of the ways in which my mother forced me into dieting, how my father emotionally abused me and the rest of my family, and how my sisters excluded me. This narrative began to unravel a few years ago, but not all at once. Slowly, as I began to heal, I realized how much more there was to the story of our family, and of me. When I began looking at the archives of illness and recovery in my family, and began moving toward a realization that my mental illness wasn't their or my fault, I became worried that the reader would still find someone to blame. Schnittker, Freese, and Powell (2000) explain that there are many various beliefs regarding the causes of mental illness:

Much like mental health professionals, the public harbors a variety of conceptions of the causes of mental illness. Some emphasize biological causes, such as genetic inheritance or chemical imbalances in the brain. Some see mental illness as rooted primarily in environmental factors, such as family upbringing or social stressors. Still others reject the "nature-nurture" dichotomy entirely, either by endorsing biological and social explanations simultaneously or by viewing mental illness as a matter of individual culpability or divine judgment (p. 1102).

Navigating responsibility and blame while interacting with the healthcare, financial and social systems, while determining authority, identifying and accessing resources and attempting to gather knowledge and understand this illness and chaos is almost inevitable. Healthcare communication surrounding illness and disease is very reflective of cause and effect. What caused the illness or disease? What treatment will have the best effect (Klienman, 1988)? The inability to explain “what caused Erin’s mental illness” created large spaces of uncertainty for my family to speculate responsibility and cast blame, and with those attributions, guilt and shame. Shame not only silenced me, but silenced my understanding and experience of my family as compromised of whole, multidimensional persons.

## CHAPTER IV

In the previous two chapters, I utilized autoethnographic inquiry to construct narratives that reflect truths of my experience negotiating relational and identity tensions of living with mental illness. In doing so, I utilized my medical records, personal diaries, and various archival documents. I accept that at this point of the thesis project, some readers may be wondering what to do with this work called “my life.” In this concluding chapter, I review ways in which autoethnographic writing is often evaluated and how such writing positions itself within qualitative inquiry as a whole. Next, I share specific challenges faced while doing this work. I conclude by describe how I see the use of autoethnographic methodology with mental illness as an act of advocacy itself by connecting themes that I identified within the previous two chapters to broader bodies of advocacy literature.

### **Valuing and evaluating auto-ethnographic inquiry**

The use of my records and diaries was vital for the production of this project and an awareness of how I negotiate identities and relationship throughout my recovery. Because of my illness, my medications, and the disrupted nature of my life, there are big portions of my past and present that blur together. The production of my narratives began by sifting through my medical records. Initially, I reviewed my records in my therapist’s office because of the triggering nature of the documents. However, my therapist and I quickly realized that this wasn't an ideal situation because of the sheer quantity of my records and the time it was taking away from doing my everyday treatment and recovery work. My therapist and I agreed that I could review my records in a conference room in

her office and after checking in briefly to see if there were any questions, concerns or triggers I could then take them home with me. She continually reminded me to use self-care during this process and to employ the recovery tools that I have learned in treatment over the years if I became triggered. As I read my records, I flagged entries with different colored sticky notes that activated memories of negotiating my illness within the context of my important relationships. After flagging these specific medical records, I would then turn to my personal diaries to find the same relationship, situation, or experience written in my own thoughts and words.

Between these two archives, I then drafted many narratives that appear in the preceding chapters. The writing and rewriting of these narratives occurred over the course of a year. The first drafts were the raw experience as I remembered and interpreted from my medical records and personal journals. I then reflected, selected and rewrote the most illustrative of stories representing emergent and recurring themes, guided of course by my state of mind and relational ethics.

Thus, the production of this project was one of crystallization (Ellingson, 2009) more so than a writing process of triangulation of facts and artifacts. The medical records that I used provided a removed, third person account of my behavior, environment, and experience at the time. My personal journals contain raw stream of conscious and emotional record of what is happening inside of me at any given moment. According to Richardson (2000),

Crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know. Ingeniously, we know that is always more to know (p. 934).

Ellingson (2009) emphasizes that truths are multiple and it through reflexivity, thick description, and different genres of writing that researchers can access different perspectives or view points of different truths. She proposes that in qualitative, auto-ethnographic inquiries such as this, crystallization manifests itself as projects that: “offer deep thickly described, complexly rendered interpretations,”...“represent several contrasting ways of knowing,”...“utilize more than one genre of writing,”...“include a significant degree of reflexive consideration of the researcher’s self and roles in the process of research,” and eschew “claims to objectivity and a singular, discoverable Truth” (p. 10).

Tracy (2010) further provides eight ‘big tent’ criteria for evaluating qualitative research. In laying out these criteria for evaluating qualitative work, she argues that criteria are useful for pedagogical purposes and in assisting those who are not trained in qualitative methodologies with tools from which they can digest, utilize and value qualitative research. Tracy’s criteria include a worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence. However, as Tracy (2010) warns, there are some serious reservations about the use of criteria at all for evaluating qualitative work, especially, autoethnographic or alternative ethnographies.

Bochner (2000) similarly writes:

I have a strong desire to create new and more interesting ways to talk about the work that many of us are doing under the rubric of alternative ethnography.

Frankly, I find most of the incessant talk about criteria to be boring, tedious, and

unproductive. Why do we always seem to be drawn back to the same familiar questions: ‘How do you know?’ ‘Which methods are the right ones to use?’ ‘What criteria should be applied?’ For most of my academic life—almost 30 years—I have been baffled by this obsessive focus on criteria. (p. 267)

He explains that we turn to criteria to simplify the complicated, make the messy clean, and the uncertain certain essentially removing a part of the humanity from the data, from the work, from the messy subjective process that is intricately embedded within research. Ellis (2009) similarly echoes that research has seemingly become so determined to deny our sense of humanness through the emotional distance that it could be argued that we’ve neglected an entire realm of knowing and being.

Even within narrative theory there is a risk of closing our minds around what is supposed to be within a narrative, and therefore huge potential for marginalizing narratives that do not fit within that normative framework of “good narrative.” Bochner (2000) writes, “A poetic social science does not beg the question of how to separate good narrativization from bad, though it may be more open than other views to diverse answers to the question” (270). His choice of the term “alternative ethnography” to describe autoethnography highlights its intent and purpose to counter the more traditional and mainstream forms of research, and in doing so calls for the generations of opportunities and spaces for marginalized voices and experiences not heard even in many realms of qualitative research. Autoethnography seeks to position the researcher within the cultural and political landscape and utilize the researcher’s perspective, subjectivities, introspective accounts, and reflexive narratives to create a different type of knowledge an “insiders perspective.” Bochner explains that these narratives are “usually, but not

always, narratives of the self” and that “the purpose of the self-narratives is to extract meaning from experience rather than to depict experience exactly as it were lived”

(p.270).

Bochner (2000) also explains how he evaluates this type of work:

First, I look for abundant, concrete detail; concern not only for the commonplace, even trivial routines of everyday life but also for the flesh and blood emotions of people coping with life’s contingencies; not only facts but also feelings. Second, I am attracted to structurally complex narratives, stories told in a temporal framework that rotates between past and present reflecting the nonlinear process of memory work—the curve of time. Third, I almost always make a judgment about the author’s emotional credibility, vulnerability, and honesty. I expect the author to dig at his or her actions and underneath them, displaying the self on the page, taking a measure of life’s limitations, of the cultural scripts that resist transformation, of contradictory feelings, ambivalence, and layers of subjectivity, squeezing comedy out of life’s tragedies. Fourth, I prefer narratives that express a tale of two selves; a believable journey from who I was to who I am, a life course reimagined or transformed by crisis. Fifth, I hold the author to a demanding standard of ethical self-consciousness. I want the writer to show concern for how other people who are part of the teller’s story are portrayed, for the kind of person one becomes in telling one’s story, and to provide a space for the listener’s becoming, and for the moral commitments and convictions that underlie the story. Sixth, and finally, I want a story that moves me, my heart and belly as well as my

head; I want a story that doesn't just refer to subjective life, but instead acts it out in ways that show me what life feels like now and what it can mean (p. 270-271). I thought about how Bochner evaluates alternative ethnographies many times during my writing process. I faced dilemmas as I negotiated trying to make some experiences coherent enough to be understood as a narrative, while also capturing the feelings and meanings of the experience that lacked coherence, unity, and closure. I felt the weight of relational ethics as I composed and revised my storied self and the people in my life. At times, I felt a piercing vulnerability of my needs as a person -- a person with mental illness and a person in recovery --and attempted to share that with my readers.

### **The demands of the method and recovery**

I realize now that I had only a vague idea how challenging it would be when I first started. Almost naively I believed that because I had been through so much therapy and treatment in my life that processing and restoring these experiences would be relatively easy. However, the discoveries that I made about myself and my relationships in this process, as well as the things that have happened in my personal life while engaging in this method of inquiry, were incredibly challenging and sometimes seemingly too much to manage.

My advisor has reminded me several times during this process that the only reason he could sleep at night knowing that he was supporting my inquiry was the fact that I was under the care of a therapist and psychiatrist. I can't stress how important that care was for me. First hearing my advisor explain to me his professional limits in the directed project was helpful in establishing boundaries and expectations for me. Additionally, it reinforced to me that he valued my well being which helped me enact



agency in making decisions that were healthy for me. I don't think I completely understood just how much emotional labor would be involved in this work when I started. However, he has indicated that he knew what I was getting myself into which makes his insistence on keeping up with my treatment team all the more important.

On a very basic level, my recovery is a balance of sleep, food, medications, triggers, relationships, physical health and self-care. What I've learned is that if any one of those areas gets thrown off or irritated then, my recovery is at risk. Typically, when something goes wrong for one day (like I don't sleep well for a night) then I can bounce back pretty easily, I just have to make adjustments and be attentive to that recovery balance. However, if my system gets thrown off for too long I will begin to experience an increase in the severity of the symptoms associated with my mentally illness, such as my moods swings, intrusive thoughts, energy levels, paranoia, etc., problematically, once these symptoms begin increasing in frequency and intensity my sense of personal stability is shifted. When this happens, it often takes an outside source of support to assist me in returning to a sense of stability. This source of support in the past has usually been my therapist or my psychiatrist, at times additionally I have entered into higher levels of care to access more support.

Understanding this situation as I entered my project was essential for my success in completing it. During various times throughout the past year, I've needed to adjust my schedule, my timeline and my expectations as to what this was supposed to or needed to look like because of needing to accommodate to my needs and my recovery. I found this very frustrating at times. I struggle with feeling like I can't do something and usually find myself rebelling against that to varying degrees which have been extremely unhealthy for

me in the past, so having my therapist meet with me weekly to hold me accountable to honoring my limits, and my recovery has been primary. Overall, I would say that this system worked well and assisted me in processing some of the difficult emotional work that comes with autoethnography.

Before engaging in this work, I knew that I've largely perceived the world in ways that are different than the majority of people. However, the depths and extent of that difference were uncovered and reinforced in the process of writing and reflection. I would compose and share drafts of my narrative to outside readers, only to learn how they derived a remarkably different understanding of the experience than I sought to story. In the past, this loneliness was something that I relieved with my tumultuous relationship with Grace. This time around, that sense of loneliness was shared, if not challenged, as I invited my friends, family, and advisor into my experiences. Needless to say, the amount of trust, vulnerability and faith to do relational work was immense, but what I discovered was rather profound: To some extent, the loneliness that I wrote of was a choice. This project has taught me that with energy, time, and trust I can feel connected to others, even if they don't share my same experience.

Additionally, I found in going through my records and diaries, and then writing and (re)writing the relationships that existed within those pages, I started to have feelings associated with those former relationships within current unconnected relationships. This was deeply distressing to me, particularly since I had already written nearly 40 pages on that relationship. While I talked about this experience during sessions with my therapists, I initially struggled to be open about it with my advisor. I was experiencing embarrassment and shame, not only for my feelings, but with my inability to work

through these feelings. After an important conversation with my advisor, we made the decision to remove the drafted chapter. I did not feel like I had enough time or energy to both work through what was happening and complete this project. I hope to return to it in the future.

As with any autoethnographic inquiry, the happenings of my life impacted my ability to write, and the way in which I reflected upon my writings. This became incredibly challenging at times, particularly toward the completion of this project. I struggled to reconcile what I had written months earlier with the recent events that were unfolding before my eyes. For example, as I composed stories of negotiating mental illness with my family, I struggled in determining if it was a healthy decision to attend my oldest sister's wedding. I was filled with guilt, shame and embarrassment at the thought of missing it, but also knew that flying across the country to be surrounded by alcohol, a large crowd and in an environment that was going to be focused on body image and appearance would be highly triggering for me. I cried, sometimes sobbed over my narratives and questioned if recovery was actually worth all of the sacrifices and hard work that I had to put into it. After deciding to miss my sister's wedding I wrote in my journal,

...What's the point of recovery if I don't get to experience life? Is this life really better? Maybe I should just have a short life and live it recklessly. I'm a horrible sister. I know \*\*\*\* is so mad and doesn't get it. Recovery makes me miss so much in life. I hate this....

I think the tension between my sisters and I at the time and the amount of guilt I was experiencing because of my inability to attend her wedding was one of the reasons I focused chapter three on my relationships with my parents.

At other times, my anxiety seemed to part and parcel of this methodology. The constant act of delving into my past medical records and journals on some level made me question my own recovery. In some ways, I thought I could see myself in my writing, believing that my life wasn't worth living. I became so immersed in such a dark time of my life I almost felt like I was back in an unhealthy and sick place again, disappointing everyone in my life again, worrying everyone and causing a problem for everyone who cared about me. However, unlike that past, I felt a greater sense of awareness of my self, my needs for assistance, and my trust with professionals who I believed could help me find my way out of that dark hole.

The second semester that I spent working on the project turned out to be a very challenging. In addition to engaging an emotionally exhausting methodology, I suffered an acute illness that required out-patient surgery, and was dealing with upsetting relational situations with two of the close friends I included in Chapter Two. It all feels like a blur to me now, but I could have never anticipated how quickly my recovery balance got off kilter. I kept thinking that I would get myself back on track. In reality, I was using disordered behavior after disordered behavior to survive symptoms that had become so frequent and intense that I had forgotten what healthy felt like. I woke up in the hospital thinking, *How did this happen so fast?*

That's how it happens sometimes. Sometimes, as a person with mental illness, I have found myself and continue to find myself seemingly disrupted. However, I also found a parallel between writing and recovery while working on this project. Within writing, I found a choice to recreate, construct and enact agency regarding what happening next. That is exactly how my recovery experience has felt. Recovery afforded

me to the ability to recreate and restore relationship in ways that were safe and meaningful, construct narratives that allowed featured me as someone with strength and power and enacted my agency by giving me that ability to choose how my story will end.

Even with that agency, I nonetheless noticed some significant constraints on my writing by my mood and state of mind. In doing this research, one of the most challenging aspects for me was becoming aware of how my mood was affecting my interpretation and reflection of and on my medical records, journals, and stories. For example, in writing the opening narrative of chapter three when I storied the experience of finding the letter written my father, I returned to extreme feelings of helplessness and guilt. I became angry with myself for hurting my parents so much that I became temporarily consumed by and paralyzed by those emotions. My skin felt too tight and I could feel my body expanding. I couldn't think clearly and I needed an immediate release so I drove to CVS, bought a bottle of extra-strength stimulant laxatives. I carefully counted out 10 from the bottle and swallowed them in one gulp with a blue Powerade-Zero. Almost immediately I felt more in control, the pressure released and I could breathe again, my thoughts slowed down and I drove back to my apartment and waited for the cleansing to begin.

These feelings and behaviors triggered by my research and writing, as well as the medications prescribed and adjusted at different points over the past year, halted and influenced my reflective process, but also how I interacted with others. I wasn't sure if I could tell my peers and mentors what was happening, afraid that they would think I was not mentally fit to complete the project. I didn't want to worry anyone, so I felt pressure to produce regardless of what was happening within me, as to not appear off or incapable

or raise any red flags. I kept telling myself that I was fine, and would write what I could, sometimes avoiding, sometimes triggering, sometimes detaching. In the moments and days after events like the one with the laxatives, I was well aware of how unhealthy behaviors were, how not recovery-centered they were. There were times when I wondered if this project was healthy for me. There were times when I thought to myself *maybe there is something to be said for moving forward and not going back into the darkness.*

For good and bad, my stubbornness, my sheer willfulness to survive, kept me going. I do not yet know the full value and toll of this project. What I do know is that without my professional, personal and academic support system, I absolutely would not have completed this project, and might not be here today.

That is not to say that during this entire project I have operated solely from an emotional place all the time, but it's more reflective of the fact that my moods and emotions have impacted me more intensely than someone who does not have the same mental illnesses as me. I found myself feeling low and noticing that my writing reflected that. My mood is impacting me right now, even as I reflect on the previous chapters. Going back and reviewing my work later, when my mood had improved, was interesting, because it seemed as though someone else had written it sometimes. An example of this is below:

One of the hardest things for me to explain to people is how lonely living with mental illness can be, and how isolating it often feels. I at times find myself trapped in a world that only I perceive. It can be exhausting and takes an incredible amount of cognitive effort. Not only always reminding myself of the fact that my perception is or could be distorted, clouded or only true to me, but to

use therapeutic tools such as cognitive reframing and behavioral dialectics to correct my stream of reality, my sense of self, my sense of others and my sense of being is a continuous process that often removes me from the present and requires that I live in my thoughts, analyzing them, questioning them, and challenging them. The result of this for me has been a hyper-awareness of myself, my thoughts, the processes within my brain and how I come to think the things that I do. This hyperawareness has developed as a survival skill. (p.42)

When I wrote this and was reflecting on a couple of the narratives in Chapter Two, my mood was very low and I was feeling very alone and misunderstood. However, a few days later my mood had improved and while re-reading this section I felt almost worried. I explained to my advisor that day that I felt like my moods were really impacting how I was reflecting on my experiences and my narratives. My fear was what if I am unable to *accurately* reflect, because of how I experience the world. This became exhausting and distressing before I realized the value in it.

My writing process was an aspect of the lived experience of living with a mental illness, and it can be very exhausting. I do not doubt that a person reading the previous paragraph might be feeling alarmed or concerned for my wellbeing or safety. I do not know what to say to comfort that person other than on a good day, I have these same thoughts and feelings. On a good day, I am concerned for my wellbeing and safety. Over the course of my years in treatment and in learning and understanding myself as an individual with mental illness I've learned that I have two different types of moods. One type is the "normative" type that every health adult has that fluctuates throughout the day based on what is happening. The other type is part of my mental illness. These moods are

different in that they are all-consuming and there is usually not a cause for them other than something inside of me. I utilize treatment and medication to help me manage the mood shifts that are part of my illness but that is an ever present and ongoing process and emerged throughout this writing process.

### **Illness narrative as advocacy**

Narrative theorists assert that as human beings instinctively make meaning of their lives and experiences by storying them. These stories both inform and are informed by larger social, political and cultural narratives (Fisher, 1985; Harter, Japp & Beck, 2005). Sometimes, the cultural, social and political narratives have a silencing and shaming effect on personal experiences and impact the construction of identity and sense of self. Often, when stigmatized by the stories we are told, we hide in some form or another, through secrecy, pretending or lying, etc. which can result in a heavy emotional burden that can translate into increased physical, emotional and psychological distress (Charon, 2006; Frank, 1995).

The previous two chapters collectively story the beginning of my journey in becoming a mental health advocate. I started this project knowing that my transformation into a mental health advocate was intricately connected to my relationships. However, I didn't know exactly how. I utilized my journals, my medical records and my memories as archival data and dug into my past constructing narratives that embodied the experiences of understanding myself, my illness and its effects on my relationships. I didn't expect at the get-go that such early stories of my illness and recovery would emerge, however, they did forcefully. In this writing and research process, I found myself mentally and emotionally immersed in some of the most challenging, chaotic and scary moments of my



life. I worried initially because this project's intention was supposed to be on advocacy. I couldn't help but feel like I was failing as a researcher each time more stories of struggle emerged. I kept thinking about how this isn't who I am anymore, and wondering how I was going to turn the project around.

It wasn't until later that I realized how essential early illness and recovery stories were to my identity as an advocate. I often tell people that I became an advocate by accident. When I say this, I don't mean to imply that I lacked agency and was forced into doing advocacy work. What I mean is that my experiences within the mental health care system, the feelings of shame and embarrassment that silenced me - almost to my death - and coming to understand and know true beauty through my own and others suffering have fundamentally changed me.

So it is through this project that I have come to understand that my stories are my advocacy. It is through embracing them, sharing them, reflecting on and recreating them I've learned how truly vital and imperative illness narratives, and even more so, mental illness narratives are, to reducing stigma and shame, healing disrupted identities and facilitating social and political change. Hayden (1997) writes,

One of our most powerful forms of expressing suffering and experiences related to suffering is the narrative. Patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice. This is probably one of the main reasons for the emerging interest in narratives among social scientists engaged in research on biomedicine, illness, and suffering (p. 47).

It is through the narrative that individuals can enact their sense of agency, establish a sense of coherence and create meaning and significance within their lives (Adler 2012;

Bulow & Hayden, 2013; Charon 2006). In this work, I have found that to be especially necessary for writing, sharing and recreating my narratives of mental illness because of the innate shame, lack of coherence, ambiguous nature, and cultural and social stigmas that are characteristic of the experience of mental illness and recovery.

In doing this project, even now as a public advocate for mental illness and recovery, I've (re)experienced deep feelings of shame. I struggled to create a sense of coherence for the reader that ultimately was lacking in my lived experience, often questioning if I should sacrifice some of the truth that I have lived for a potential narrative construction that might be easier for others to read and understand. I grappled with how to express the confusing experience of being diagnosed with illnesses that come with conflicting accounts of the cause, responsibility, and existence. Additionally, I experienced periods of great fear and insecurity regarding the level of disclosure I was committing to paper, because of deeply ingrained cultural and social stigmas. However, all the while I reminded myself and was continually reminded by my friends, fellow advocates and advisor, that this is the messy nature of and importance of this work and of autoethnographic methodology. In the writing process I utilized my own experiences of suffering, relational tensions, and vulnerability to call attention to the dangers of the stigma that silence individual narratives and can disrupt a sense of one's self. I also demonstrated a way to combat those very things, which is through communication. This is, through the writing of, sharing and elevation of narratives of mental illness.

In elevating the narratives of mental illness, through communicative practices such as writing and speaking, we can begin to create safe spaces for the acceptance of the difference of self and others. By engaging in brave acts of telling and listening, learning

and understanding, being and becoming, we invite individuals in society to question their privileges, standpoints, stigmas, stereotypes and adopted meta-narratives about what I means to be ill and mentally ill, and to question the false boundary that has been socially and culturally created between health and wellness, and sanity and insanity.

In doing so, we come to understand that those with mental illness have specific and valuable understandings, experiences and perspectives that can fill certain questions regarding the nature of time, space and narrative linearity, the lived experience of recovery as it applies to the everyday living and the challenges associated with being a patient of psychiatric services, as well as personal and social assumptions about the causes of mental illness and suffering (Kirkwood, & Brown; 1995, Torn, 2011, Pilgrim, 2009; Nehls, 2000, Haidet, Kroll, & Sharf, 2006). But to do so, we must refrain from the categorizing, rationalizing, restructuring or dismissing these experiences, or their different way of existing in the world as merely incoherent irrational and chaotic. Because in doing so we fail to listen really or understand anything.

Through narrating the lived experience of mental illness intrapersonally, interpersonally and publically we have potential to: (1) relieve ourselves of a heavy burden; (2) create spaces for other people to feel safe enough to narrate their lived experiences, henceforth assisting in relieving their burdens; (3) create opportunities for people to gain an understanding of the lived experience of mental illness and suffering, and; (4) challenge cultural stereotypes, expectations and assumptions learned through the dominant discourses and rhetoric of mental illness, madness, psychiatry and recovery. We allow those with mental illness the freedom to live, define and narrate their experience as a person, a brother, a mother, a teacher, a veteran, a patient, a doctor as

they wish and even more use their differing perspectives, voices and experiences as contributions within and for the betterment of society rather than being silenced by it's misguided misunderstanding and fear. This I first learned of my relationship with Grace and had aspired to continually recreate through living my illness out loud.

One of the many mental health challenges that we face as a culture is that individuals who would benefit from mental health services are not seeking those services, and when they do they wait until their mental and emotional state is at or near a critical condition and end up needing a higher level of care (Kessler et al., 2007). This is largely a result of stigma and shame and the cost and lack of coverage associated with mental health services that link back to the biomedical model's need for results and psychotherapy and psychiatry's inability to produce quick and easy answers (Lidz, 1966; Wilson, 1993).

Through mental illness narratives, we have the ability to reduce the stigma and shame associated with utilizing mental health services and demonstrate through our lives and stories that it is socially acceptable and potentially a good thing to engage with the services that someone may need. This could assist someone in making the difficult decision to seek care that they need more quickly or more comfortably, knowing that they are not alone. Additionally, by openly acknowledging and narrating our mental illnesses, we open ourselves and others up to examining the role of emotions, feelings and traumatic experiences in our lives in a world where we are told to "rub some dirt on it" and move on.

### **Writing from a place of support**

At times, writing about my relationships and my mental illness intensified my feelings of shame as I entered into spaces of my life that consumed me with feelings of unworthiness. I also became painfully aware of my dependence on other people, my friends, my family, my medical professionals and all those in my life that I so carefully place my trust in. I struggled with this tension of feeling thankful for “my people” and feeling angry that I need them. At times, I found myself at times wanting to push all of my people away, disgusted with my own dependency only to frantically want to pull them back close to me in a panic and fear of abandonment and loss. I felt like I was losing my mind, which is funny coming from me, I know, but I was aware of the chaotic pattern that had developed and I felt exhausted as I negotiated it.

As I wrote about my friendship with Grace, I realized that it was my relationship with her that gave me the courage to speak the words of my illness aloud. I struggled writing about Grace because our friendship illustrates the some of the challenges of relationships between people who are experiencing similar mental illness and addictions. There were many times when we were probably more harmful than helpful to each other's' mental wellbeing, not to any fault of our own, but because of the illnesses that we were both extremely immersed in at the time. I would never recommend someone who is actively struggling with dangerous, life-threatening behaviors to seek actively out another person who is also actively struggling with those similar behaviors. But I also think about the reasons that I only found what I needed by being with someone who was struggling as much I was.

I've come to understand more fully that social support is a crucial component to working through the murky and painful experiences of shame. Eventually, the secrets of my mental illness, which had been silenced by shame, begged to be told so loudly, so adamantly, that I had no choice but to voice them. Of secrets, Poulos (2008) similarly writes that "no matter how much you try to ignore or bury them, they won't stay put" (p. 50). But, I now struggle to reflect on how I, and maybe a more collective we, are to advocate about the "new" nature of our recovered lives when we are so radically different from those around us? Is the heavy shame something that I as someone with mental illness have to lift each and every time I wish to disclose, wish to live, and wish to be? McNay (2009) writes, "[T]here are no easy answers to questions about if, when or how a secret should be disclosed" (p. 1184). Eventually, in some way, these silences are broken perhaps abruptly, loudly with streams of tears and snot, or perhaps quietly with whispers and dry eyes. It is through the radical act of narrative, telling or writing that we allow ourselves and others the space to say, to tell, to understand (Charon, 2006).

Grace taught me not to be afraid of my darkness, which afforded me the opportunity to examine that part of myself without shame. It also empowered me to seek help and first begin to advocate for myself, because for the first time in my life I realized that I deserved it. Maybe I wasn't bad. This exploration gave me the words and the courage to begin to narrate my experiences which ultimately became the pathway forward towards discovering my sense of recovery.

As Paige explained, as an advocate, one of my biggest platforms is that I help people understand mental illness by inviting them into my experience. I like to say, that I intentionally live my illness out loud. Problematically, however, it is through this

autoethnographic project that I've come to realize that as an advocate I am once again silenced through the shame of my own experience. I have learned to carefully and strategically invite people into illness experiences that are manageable, and packaged for consumption while performing an illness narrative that is actually much less vulnerable than my actual lived experience of negotiating mental illness. The public praises me for my vulnerability and I feel empty. As I wrote these narratives I shook with fear and shame and only then did I realize why I had been feeling so empty, why I had been feeling so shallow.

### **Finding a truth about mental illness in writing**

In the writing of this work I couldn't help but sometimes get stuck on what Fisher describes as narrative rationality using both narrative probability and narrative fidelity as means for evaluating and distinguishing narrative practices. According to Fisher, narrative probability refers to story features such as sequence and coherence and narrative fidelity and refers to the truth qualities and logicity and reasoning within the narrative structure (Fisher, 1985). In the process of doing this work, I began to ask: *What does this mean for someone with a mental illness? What does this mean for me?* At times during this work, I found myself acutely aware of the fact that my reflections on my experiences were heavily influenced by my current mood. I couldn't help but wonder if these reflections were still valid. This pressed on my anxiety, and even had me question my own legitimacy not only as a scholar within this work but also as a functioning adult within society. *Why should anyone ever believe anything I say?* This question churned in my stomach and entered some of my relationships. *Am I useless? Do I have anything to offer this world? Do I have anything to offer anyone?* I felt myself growing more timid

than I had felt in years, more hesitant and less confident. My friends kept asking me what was going on and as I dogged the question. How was I supposed to tell them that I had developed a newfound fear over my own sense of perception? One friend almost angrily told me she didn't know what to do with me because she has never seen this side of me. "I don't know this timid Erin, you're not like this." I didn't know this version of me either, but I didn't know how to make it stop. I worked on reaccepting, and adjusting my expectations. I reminded myself, that this is how I experience life. At times, my sense of reality, and my sense of truth are dictated by how I feel. That is a truth, which is one of my truths. It is through narrative, we are afforded the opportunity to explore, accept and experience not one true objective reality, but rather multiple realities founded on meaning-making and narrative truths (Spence, 1984). My truths of my emotions. My truths of my relationships. My truths of my mental illness.

What I think became even more distressing to me than the illegitimacy of my truths, or perhaps the perceived illegitimacy of my truths, were the barriers that I felt ground themselves in my life during this writing process. A year ago, two years ago for the most part I believed that I could do anything I wanted. I had dreams of taking my non-profit organization, Where I Stand, to the next level, I thought a lot of about pursuing a PhD, and I wanted to move to bigger city with more access mental health advocacy opportunities. I wasn't afraid to speak in public, I wasn't afraid to really do anything. Towards the end of this work, I felt afraid of all of these things.

Before starting this project, I knew I was different. I thought differently. I perceived things differently. I experienced things differently. I was different. However, in the constructing of these narratives, processing and attempting to explain the



significance of them, my feelings and sense of difference became much more intense. Cardillo (2010) found that chronic illnesses are often accompanied by feelings of difference; difference as devaluation, difference as a hard reality, difference as oppression and difference integrated. In this writing and researching process I allowed myself to very vulnerably explore my difference through the writing and sharing of narratives. Cardillo wrote that accessing this difference could be difficult because of the distance between the researcher and the participants in traditional forms of qualitative and quantitative research. These problems include the researcher imposing their sense of reality upon the participants' data and more so their sense of temporality to make meaning out of the participants' experience (Bulow & Hayden, 2003).

While for this work, there is virtually no distance between the researcher and the participant, as I am one in the same, I have experienced difficulty in narrating my chaotic, disordered and experience of difference in ways that both may make sense to the reader and ring true to my experience. Milbourn, McNamara, and Buchanan (2014) write about the importance of understanding the often-externalized narrated experience has an inherent mismatch between the narration and the actual reality of the experience. As illness bearers we are encouraged to impose dominant biomedical language and narrative structures such as linear temporality to help others understand and make sense of an experience that no cultural or social scripts exist for. Understanding and accepting the concept of difference creates a space for the voices of people with chronic illness and disability in places that they would not traditionally have one (Cardillo, 2010). While the emphasis on structuring and telling a narrative in a certain way may add a layer of disenfranchisement and feelings of otherness to the already marginalized group.

This reminds me of Frank's (1995) third illness narrative type, the chaos narrative. Chaos which is often depicted in expressions of despair, grief, fear, and weakness is a familiar narrative of chronic and mental illness. Frank (1995) highlights the importance of these narratives on a personal level for the individual suffering, to be heard and to deal with their feelings of fear and distress. While Frank argues that chaos stories need to be told to provide a rounded picture of a person's experience of illness, it seems as though we may have entered into another realm of classification and marginalization. I am chaos. Furthermore, the types of narratives that are highlighted shared and elevated (and those that are not) within society continue to speak and reinforce our desire and current ideas about what it means to be sick and to suffer.

### **Writing from a place of coherence**

One of the biggest challenges in writing and most likely reading this work is its lack of coherence. When I started this process, I didn't know how challenging it would be for me to write coherent accounts of these relationships. I found in entering my medical records and my journals that my life and my illness experience are not necessarily coherent in the narrative sense. I lived chaos, and sometimes still do. Using a chronological temporal framework for illness narratives is usual for many people and congruent for how medicine and illness are culturally defined. These chronological temporal frameworks resonate with Frank's (1995) restitution and quest narratives frameworks. However, as others and I have found, linear and chronological temporal frameworks are not always appropriate for capturing the lived experience of mental illness (Torn, 2009; Bulow & Hyden, 2003; Hydén, 1997; Delbene, 2011). Even so, mental health and recovery are often discussed in a linear fashion noting progression,

movement either forward or backward and using a frame of a road, path or journey, because of the cultural, social and biomedical discourse that has been provided for us (Burn & Birrell, 2014). However, as Charon (2006) states, time is often experienced differently for the sick and the well.

The experience of time might be one of the most telling aspects of the divide between the sick, and the well, health professionals have an urgent need to examine and make at least imaginative sense of how patients might experience time (p.121).

I've held on to Charon's (2006) words as I've battled my sense of time, structure, experience and meaning. I've also turned to Torn (2009), Bulow and Hyden (2003), Hydén (1997) and Delbene (2011), as they have provided alternative ways to understanding the narrative of experiencing and living with chronic illnesses.

Alison Torn (2009) explains chronotypes to understand other ways in which people experiencing mental illness might understand, experience and share their narratives. Torn writes: "the chronotype addresses the temporal and spatial complexities of the narrative structure to reveal the meaning and experience for the protagonist" (p. 136). The concept of chronotypes, and change from the linear concept of time and space, for Torn, is critical for individuals attempting to make sense of their experience of recovery and "construct meaning out of chaos and distress."

Additionally, the idea of 'biographical disruption' has been described as a disruption because of the onset of an individual's chronic illness (Delbene, 2011). While the onset of the illness acts as a disruption or turning point in the individual's life, the model of biological disruption approaches the narrative in a way that emphasizes a before

disruption. The 'before' disruption relates to the restitution way to thinking about illness narratives (Delbene, 2011; Williams, 1984).

Crossley (2000) writes specifically of the use of narrative in the chaos and disordered experiences for the purpose of rebuilding a person's shattered sense of identity and meaning, emphasizing the link between the self, temporality, relationships and morality. Several other critical disability and narrative scholars also report that when a narrative is disrupted temporally by illness or traumatic experience, the purpose of the narrative shifts from temporality and ordering to creating meaning (Crossley, 2000; Cardillo, 2010; Burn & Birrell, 2014; Delbene, 2011; Torn, 2009).

### **Writing from a place of shame**

Brene Brown, a distinguished scholar in social work, describes shame as a sense that a person is bad. Brown (2012) states that the feeling of shame is attached to our existence as human beings rather than to our behavior, which is rather conceptualized by feelings of guilt. As I reflect on the process of writing Chapter 2, I have to come to terms with the feelings of shame that reverberated within my core that I am bad. Reflecting on these feelings, it's hard for me to distinguish if shame was causing my mental distress or if it was a byproduct of my mental distress. Probably both. Regardless, that feeling of shame amplified kept me trapped in a silent hell, killing me slowly.

With roughly a quarter of the population suffering from some mental illness at some point in their lifetime and one in 17 suffering from what is designated as a severe mental illness you would think that socially and culturally we would have moved beyond that stigma and shame, however, we have not (NAMI, 2013). Hinshaw (2006) writes that despite a rise in efforts to increase awareness and additional legislation to protect the

rights of those with mental illness, the mentally ill continue to suffer discrimination in housing and employment as well as live in fear of their documented diagnosis being used against them within the judicial system. Additionally, the media continually personifies, fictionalizes, stereotypes and often vilifies individuals with mental illness.

It is because of shame that I learned to be silent about my abnormal behaviors, my dark thoughts of depression and self-destruction. For the most part, until I met Grace, silence felt the safest place for shame. In silencing my illness, one huge part of myself I was never able to hear what it had to say. That silence then disrupted not only my story but also my sense of self and my sense of identity.

One primary tenant of narrative theory is that self and identity are constructed through the integration of the stories that we tell ourselves, and the stories that we are told socially, culturally and politically (Harter, Japp & Beck, 2005). Adler (2012) states, “Narrative identity is the internalized, evolving story of the self that each person crafts to provide his or her life with a sense of purpose and unity” (p. 367). It is through plotment, configuration, meaning-making, and cognitive organization that we assemble our narratives of self to create lives of meaningful coherence, distinguished by personal identities, empathic relationships, and agency. It is the act of living that we create stories, modify stories, retell and revise stories and create new ones altogether (Adler, 2012; Giogio, 2009; Crossley, 2000; McNay, 2009; Charon, 2006; Harter, Japp & Beck, 2005). Through silence and shame, my stories and identity became disrupted, and an understanding of myself, others and the world around me as I knew it shifted.

Through the process of going through my medical records and journals and reflecting on significant relationships in negotiating and understanding both myself and

my illness, stories of friendship emerged. Grace taught me not to be afraid of my pain, my darkness or myself. Through the literal act of climbing into bed with my darkness and me she gave me a counter script for shame, as my brain screamed *no one wants me, no one wants this*, Grace inched closer. Brene Brown says that there is no way around shame, which she explains is one reason that it's such a challenging thing to study with people because it's so painful (Brown, 2012). To understand shame, to address shame we have to enter it, and Grace joined me there, giving me the confidence and agency to break my silence. Inadvertently, she taught me that it's the fear of my darkness that made it so dangerous - not that it exists. I had become afraid of myself, afraid even to attempt to figure out what was going on inside of myself and in the process disrupted my sense of self, my story, my identity-constituting narrative. So through knowing Grace and being with her, I first learned what it felt like to have someone not be afraid of my mental illness; not to be afraid of me. And in a world where it felt like everyone was afraid, I was given permission to live, to discover and be my actual self without fear of judgment. While writing these stories I couldn't help but wonder: Should it have taken 10 years of silence for me to meet someone unafraid of my illness, an illness that 1 in 17 people share? Am I really unafraid now? How much has changed since the day I met Grace?

There were several times, during the researching and writing process of this project where I emotionally, mentally and physically slammed into a metaphorical wall composed of my past illness experiences and traumas. I, and this project, jerked abruptly to a painful halt because of the intense emotion and vulnerability that was rushing through my body and mind.

*You are crazy. You can't share this stuff. You are a burden. You are too much. You are weak. No one wants you. No one likes you. People pity you. No one could ever take you seriously. I can't believe you thought this was a good idea. Who do you think you are Erin? What makes you think your story matters?* I berated myself, sometimes for hours feebly trying to fight back with my voice. *My story does matter. My story does matter. People do like me. People do like me. I am worthy of love and respect. I am worthy of love and respect.* Once the onslaught of negative emotions and triggers had passed and the loud angry accusatory voice inside of my head had subsided I was repeatedly struck with a truth that seemed to take my breath away. It was that this internal fight I was having in the moment, this intense shame and embarrassment, this fear and self-loathing that I felt in waves of fire and ice had not disappeared, had not changed. Perhaps though, my response to it has. This realization saddened me while also reminding me why this project was so important. At a fundamental level, even as a public advocate for mental health and mental illness I realized that I privately still live in shame.

**Figure 16: Process Poem**

## Where I Stand

So far in the course of my life  
I have stood for many things  
These things have often caused me harm and strife  
Hurt too, terrible pain, and those harmful things that always sting

My mind would always say:  
I should  
I would  
I could

The truth is....  
This is where I stood:

On a mountain of shame and guilt  
That I myself built

In an ocean of depression and doubt  
Where I stayed silent then acted out

Below a cloud of anger and fear  
Words of comfort and hope I could never hear

But today that has begun to slowly change  
One foot in front of the other  
I move from that dark place to brighter other

That is where I stood  
This is where I stand  
Here with you  
Struggling my way through

Making the decision to do what is hard but right  
So that my life may reflect light  
Holding on when I want to let go  
Knowing it's okay if I go slow  
Walking with others who choose to fight for light too  
For what seem impossible for one is possible for a few

So this is where I stand  
Fighting my own darkness  
Fighting for light



And from where I stand you must know  
We'll be alright

This is where I stand  
You choose where you want to be  
My hope is that you will see  
When it comes to mental illness, strain and strife  
The only choice is to stand for life<sup>17</sup>

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<sup>17</sup> Where I Stand, a poem by Erin

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