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## Everything is Fine: Self-Portrait of a Caregiver with Chronic Depression and Other Preexisting Conditions

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Everything is Fine:

Self-Portrait of a Caregiver with Chronic Depression and Other Preexisting Conditions

by

Erin L. Scheffels

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
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College of Arts & Sciences  
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*For my dad, Klen  
and for Sky Bear*

## TABLE OF CONTENTS

Abstract .....	iv
Acknowledgements .....	v
Chapter I.....	1
Prologue: The Call .....	1
Background and Purpose .....	1
Caregiving in Autoethnography.....	3
Chapter II .....	9
Prologue: Storytelling as Method .....	9
Autoethnography and Reflexive Writing.....	9
The Narrative Arc .....	15
Ethical Considerations .....	21
Chapter III.....	23
Everything is Not Fine .....	23
Terriers, Ravioli, Divorce .....	24
Bars .....	26
Imperfect Symmetry .....	27
Switchblades and Bowler Hats .....	27
The Call.....	29
Mom.....	32
Survivors.....	33
The Purge.....	34
Lesser Evils.....	35
Public Assistance .....	36
Aliens .....	37
Jon’s America .....	39
Master of Nothing .....	42
Professors.....	49
Orientation Day.....	52
Lost .....	54
Poor Choices .....	55
Jon Anderson, December 19, 1985 to September 19, 2016.....	56
Chapter IV.....	60
Don’t Kill Yourself.....	60
Stay in School, Forever.....	63
Moving.....	64

The Storage Closet.....	67
Broken Brain.....	69
If You Ever Need to Get Tested.....	74
The Free Clinic.....	82
Thanksgivings.....	88
Drinking as Method.....	89
Chapter V.....	99
Molecules.....	99
Perishables.....	100
Bad Traffic.....	102
Crow Pose.....	103
Attitude Problem.....	104
Rituals.....	105
The Dog Pound.....	106
Silence and Sound.....	109
Blood Types.....	113
Fallen and Can't Get Up.....	113
Evicted.....	116
Wheelchairs are Fucking Heavy.....	116
The Living Hell Curve.....	119
No Dogs Allowed.....	121
Fleas.....	121
El Diablo.....	122
NYC, Sad Chili and Louis.....	123
Practice for Death.....	125
Not Father's Day.....	127
Not a Guilt Trip.....	130
Christmas Beer.....	131
Chapter VI.....	133
A Meditation on Caring.....	133
A Narrative Education.....	137
Take What You Want and Leave the Rest.....	141
Like a pro.....	141
Revisiting el diablo.....	142
My dad is my dad no matter what.....	143
Waking up a different person.....	144
My pretend family.....	146
Messages of love.....	146
Relational Ethics in Narrative Writing.....	147
The Writing Process.....	149
Chapter VII.....	151
Family, Interrupted.....	151
Community, Interrupted.....	154

Epilogue: Sky Bear and the Heart that was too Big.....	159
References.....	161

## **ABSTRACT**

This dissertation documents the joys and terrors of caring for my father throughout my twenties and early thirties. The story is autoethnographic and demonstrates the value of narrative research in fostering understandings of self, other, and the world around us. I call this reflexive practice of writing *narrative education* because as I engaged in it, I learned what it means to care, and how mental health and illness factor into the ways in which care is expressed and provided in my own relationships and beyond. In addition, throughout the story I was a member of the academic community, which makes caring more than an act or behavior, but a concept to unpack, an ideograph. This dissertation begins with the goal to write my story and learn from it so others might learn from it as well. While the narrative portion of my dissertation focuses on story and the craft of creative nonfiction, the final chapters present a discussion of narrative ethics and the writing process. I also delve into concepts of care, family, and community to shed light on the narrative and create a space for reflection.

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nonfiction writers that Lorraine and I were lucky enough to join. Because of Heather, we learned to kill our darlings and face our demons, to take no care for our dignity, and write fearlessly.

## CHAPTER I

### **Prologue: The Call**

My hand grips the steering wheel as I press play on a voicemail from a hospital in Livonia, Michigan. I'm driving to my apartment from aerobics class in cigarette-burned Central Michigan University sweatpants. The woman on the message recording says, "This is about a patient we have in the Intensive Care Unit at St. Mary's Hospital, Mr. Klen Scheffels."

My hands shake as I return the call. It's something bad. I can tell from the forced tone of her voice, her obvious attempt at neutrality.

The world around me fades in and out as I say my name to the nurse on the other end.

"He is your father, correct?" she asks. Her voice raises an octave.

"He's had a stroke. The doctors are running tests."

### **Background and Purpose**

The purpose of this dissertation is to narratively examine the paradigm shifts (Bochner, 2014; Kuhn, 1970). I experienced an epiphany following my father's stroke. At 24 years old, I became his full-time caregiver and, simultaneously, I accepted a graduate teaching assistantship in a master's program at Central Michigan University. My competing obligations and inspirations (Bochner, 2012) prompted an academic journey in which I initially framed caregiving as a burden, because I believed caregiving kept me from living a "normal" twenty-something life alongside my friends, who were traveling, partying, and immersing themselves in new careers.

At CMU, I delved into the caregiving literature and began to notice a fracture in the identity and storyline I had imagined for myself. I didn't fit into the mold of the caregiver I was learning about, but I also couldn't possibly move onto the life of the graduate student I'd constructed as I was applying for graduate school, before my father's stroke. I was somewhere in between identities, and I found that traditional academic theory and research failed to provide answers or pathways for coping with the increasing complexity of my life. I needed to somehow reconcile three (often) conflicting demands on my life: caring for my father, developing as a scholar and writer, and attending to my own health and wellbeing.

In this dissertation, I write between these identities. I use my experiences of trial and error to explore what it means to be a caregiver, a graduate student, and a functioning human being. I ground my experience of caregiving in narrative because this is the best way I know to provide a complex emotional, psychological, and physical trajectory of human experiences over time (Frank, 1995; Freeman, 1997; Ellis, 2004; Richardson, 2000; Bochner & Riggs, 2014; Bochner, 2014; Bochner, 2017). My goal is to create narrative space for health practitioners, researchers, and caregivers—anyone struggling with family and health—to join a conversation about the practices of caring, and to develop an understanding and appreciation of what it means to care.

In this chapter, I describe the background of my dissertation and its purpose. In the second chapter, I discuss autoethnographic storytelling as a research method. The story that unfolds in the following chapters employs two predominant voices: my native white-girl-from-Detroit tongue, and my academic voice, a second language I've picked up during my graduate studies. I have become bi-vocal as I've moved between the two main worlds I inhabit—that of the young caregiver and that of the graduate student—and as I come to terms with my “divided

self” within the academy (Bochner, 1997). In the final chapter, I reflexively discuss the ways in which the story itself is a negotiation of what I can live with, a rendering of who I am, who I want to be, and what I’ve learned about caring.

### **Caregiving in Autoethnography**

When I first became my father’s caregiver there was a lot I didn’t know. In retrospect, I was finding a new way of becoming “daughter,” a strange rebirth that felt unnatural and left me tearful and alone. I did not know what “power of attorney” meant, or what an “advanced directive” was. Nor did I know how to get the help I needed to soldier my way through the stuff of day-to-day life. In my master’s thesis at Central Michigan University I set out to prove that I had no institutional support, no help, and no currency with which to buy time to enjoy my life. In my thesis work, I wanted to make a statement about *what young caregivers were missing*. I realize now that I set out to make a statement about what *I* was missing.

CMU was the setting for my first foray into graduate education, and though I obtained a master’s degree, I had an inkling I’d mastered very little. I had looked at a lot of literature about caregiver stress and burden, and was unknowingly living a self-fulfilling prophecy (citation needed here) of hating my life. I continued to live the prophecy as I drove my dad across the country so I could pursue a PhD at University of South Florida. The move brought with it another wave of chaos as I struggled to get my dad settled in, find a place to live, and not go completely insane. But the move also catalyzed a series of rebirths—immersions in new bodies of literature, new ways of thinking about and seeing myself as a caregiver and daughter—and a new way of being a researcher that fits me. This time, I am the subject, the participant whose life I have set off to investigate reflexively and autoethnographically in an attempt to understand the

trials and errors of a fledgling academic and fumbling caregiver: That is what I always wanted to do: to *really* write from the source of my own embodied lived-through experience.

At USF, autoethnography (Ellis & Bochner, 2000) provided a means to explore my conflicting identities within the cultural framework of caregiving. The caregiving experience is complex and tells a cultural story as much as a personal one. The diverse ways in which caregiving has been studied and written about over time evince the interdisciplinary nature of the topic, which ranges from medicine and social work to feminism and politics (insert citations). Caregiving is not only a pressing public health concern; it is a relational and relatable matter, and relationships are matters of communication (Bochner, 1984).

As I wrote about my father, I looked at communication literature focused specifically on the father-daughter dyad, only to discover that it is limited and is largely quantitative and theoretical, and none of it is about caregiving as I was coming to understand it directly from the experiences I was living through. Instead, the literature suggested that caregiving was about attachment theory (Punyanunt-Carter, 2007a; Punyanunt-Carter, 2007b), equity theory (Punyanunt-Carter, 2008), predictive studies of relational satisfaction and motives for communicating (Dunleavy, Wanzer, Krezmien, & Ruppel, 2011; Punyanunt-Carter, 2005).

Autoethnographic storytelling operates within a framework of interpretive metatheoretical assumptions, but embraces a radical methodological bend. Few autoethnographic and narrative accounts of caregiving are present in the caregiving communication literature (Ellis, 1995; Ellis, 1996; Bochner, 2002; Bochner, 2014). Ellis (1995) writes a caregiving relationship with a dying partner, Gene, in her book, *Final Negotiations*. She also writes a scene in which she cares for her aging mother called *Maternal Connections*. In *Love Survives*, Bochner (2002) writes of the challenges associated with commuting to care for his mother. In his 2014

book, *Coming to Narrative*, Bochner writes of his turn to narrative writing. As he narrates his journey, he describes the pain and trauma of caring for a partner with sudden onset mental illness.

While such autoethnographic works certainly cover the topic of caregiving, there is currently an underrepresentation of the father-daughter dyad, while narrative research on fathers and sons has a rather strong presence (Alexander, Moreira, & Kumar, 2012; Berry, 2012; Bochner, 2012; Gale, 2012; Goodall, 2012; Patti, 2012; Pelias, 2012; Poulos, 2012; Sparkes, 2012; Wyatt, 2012). Perhaps the father and son dyad is addressed more often because fathers are typically considered gender role models for male children, while mothers are considered gender role models for female children (Wood, 2013). Mother-daughter relationships are depicted in stories by Ronai (1995; 1996) and Ellis (1996). In current communication research that is both narrative and qualitative, one exploration of father-daughter relationship, written by Barbara Jago (2012) has been published. Jago offers moving and detailed accounts of what it meant to her when her father abandoned the family, leaving her without a male role model.

Jago's layered account details the stories of two women whose fathers left them at young ages. When my father had a stroke, I lost the father I had known. He is different now, not himself. A recurring theme in the literature Jago reviews and in the stories she tells is the cultural ideal of the nuclear family. My family was upended long ago. When my parents divorced, I was only six years old; the cultural ideal of the nuclear or "normal" family is not lost on me as I care for my father after his stroke. "What about your mother?" is a question I often get when I describe my family: my ailing father, his therapy dog, and me; the three of us do not exactly conform to the white picket-fence ideal of family life.

Jago depicts the nuclear family ideal as a construction of normative family roles and fatherly identities. Jago cites myriad research (e.g., Amato & Keith, 1991; Fleck, Fuller, Malin, Miller, & Acheson, 1980; Hetherington, 1972, 1989; Hetherington, Camara, & Featherman, 1983; Lohr, Legg, Mendell, & Riemer, 1989; Parish, 1980; Secunda, 1992; Wallerstein & Blakeslee, 1989) that illustrates the socially constructed father-daughter relationship. For instance, fathers are often considered to be the parent responsible for daughters' mental health. Thus, daughters with absent fathers are often pathologized and assumed to encounter difficulties with relationships, moral judgment, emotional detachment, anxiety about sex, development of femininity, intellectual performance, and rootedness.

Jago's layered narrative, sociological, and psychological accounts of academic literature and her own lived experience show the pathologizing frame of the father-daughter, father-absent relationship. This kind of relationship can be extended to the symbolic cultural construction of what it means when a father falls ill, becomes absent as a parent, and a daughter becomes his caregiver. Who my father used to be, a man I admired endlessly—and the ways in which he changed into an often angry, paranoid, and difficult patient—created complicated relational dynamics as I attempted to provide adequate and loving care. “The part hero, part villain,” split Jago writes about resonates with my caregiving experiences as my father and I took on new identities and negotiated his present-absence—in this emotionally difficult negotiation: he became part hero, part villain, and so did I.

Aside from Jago's layered account, much of the current autoethnographic and narrative research is about father-son relationships (Alexander, Moreira, & Kumar, 2012; Berry, 2012; Bochner, 2012; Gale, 2012; Goodall, 2012; Patti, 2012; Pelias, 2012; Poulos, 2012; Sparkes, 2012; Wyatt, 2012). Interesting to me was Patti's description of his father, constructing the role

of “dad” as the hero-trickster (2012). Trickster and villain are similar constructions. “In mythology, the trickster disobeys normal social rules and causes havoc, often unconsciously” (Patti, 2012, p. 158). Patti uses the hero-trickster dichotomy to illustrate the complexity of his father’s role, writing, “...I work to see my father as more than a one-dimensional hero. As my mom reminded me, this story is about ‘John Wayne, the complicated man, not the hero he played on screen’” (p. 158). By drawing on memories of his dying father who fell ill to cancer when he was just a teenager, Patti illustrates his father’s embodiment of illness and, eventually, death. In the event of illness and extreme vulnerability, we are coerced into seeing our parents as human, as fallen (and fading) heroes. “I frame my father in the deepest and broadest way conceivable: *My father the myth. My father the tragic hero*” (p. 154). The idea of the hero-trickster is interesting in the context of the relationship between my father and me because the stroke was a sort of disappearing act, a sudden departure from the role of dad, at times making me feel as if I’ve been had. However, my dad’s story has not ended because he is still alive.

Like Patti’s narrative, much of the current qualitative literature in narrative and autoethnographic form functions to memorialize or reconcile relationships with fathers who have since passed (Bochner, 2012; Gale, 2012; Goodall, 2012; Patti, 2012; Pelias, 2012; Poulos, 2012; Sparkes, 2012). Jago’s (2012) inquiry of absent fathers and Alexander’s (et al., 2012) exploration of resistance and reconciliation with fathers echoes this sense of loss. Sparkes (2012) describes his father’s struggle with clinical depression. His work incorporates a juxtaposition of fatherly heroics and mental illness.

In these evocative stories, writers express what it means for sons to love, hate, lose, memorialize, resist, and reconcile with fathers, and what it means for daughters when fathers are absent. I identify deeply with the evocative content of the current narrative and autoethnographic



literature, and I want to extend these ideas with my own writing, inviting readers into my life as a young caregiver and graduate student struggling to find balance and peace between caregiving and writing in the presence of a father whose presence now is largely an absence that, ironically, is quite present in my consciousness.

## CHAPTER II

### **Storytelling as Method**

To engage in autoethnographic storytelling effectively, I will have to leave the confines of “self” and explore my role in shaping my father’s life, as I tend to focus on his role in shaping mine. Bochner shared this goal in *Narrative and the Divided Self*, one of the stories that inspired me to come across the country to the University of South Florida with my dad: “We’re too absorbed with ourselves. We may use our parents to explain us but we don’t normally dig much deeper into the past; we don’t use ourselves to explain them” (1997, p. 428). In order to explain my father through myself and myself through him, I will need to look back and forth, from past to present, and from the personal to the cultural and sociological, as Ellis (2004) says of the autoethnographic lens.

### **Autoethnography and Reflexive Writing**

Back and forth autoethnographers gaze: First they look through an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experience; then they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations (Ellis, 2004, pp. 37-38).

Reflexivity in autoethnographic storytelling is sometimes an act of resistance to culture; it means looking inward at the self while writing to create a rigorously earned awareness in relation to others. For instance, reflexivity has led me out of a dark, chaos narrative (Frank, 1995) of care—a story of self-pity and loathing—to a quest for enlightenment that examines the degree to

which I am privileged to live the life I lead, breaking the self-fulfilling prophecy I once subscribed to that focused only on burden, burnout, and stress. I have learned to experience life in new ways, though the old ways seep back in from time to time, emerging like ghosts from bleak corners of my mind. The process of “looking back” at old habits and tendencies, at my ways of thinking, is necessary for writing the narrative; it is likely that looking back will reveal the ways in which I have constructed my life and relationships recursively, and reinforce them at times, for better or worse.

Autoethnographers produce an experience of an experience (Ellis & Bochner, 1992). What we seek is to “reveal ourselves to ourselves, allowing or facilitating a perspective on our experience that we did not have before we undertook autoethnographic inquiry” (Bochner, 2017, p. 69). Autoethnography is reflexive because it exposes our vulnerability and enables us to see the cultural stories about others and ourselves that influence the ways in which we see ourselves in relationship to others. As an autoethnographic storyteller I am able to reflexively embrace and illustrate, through storytelling, the many relational paradoxes of having a voice as an academic, a writer, a white woman, and a “caregiver” for my father.

Reflexivity requires a deconstruction of ingrained cultural and social norms, including the normalization of whiteness. My white female identity is a construction that is articulated as relevant to my experience throughout the caregiving literature. Literature on caregivers (Dysart-Gale, 2007; Roth et al., 2015) of other racial and cultural backgrounds puts this “white girl” affliction into sharp relief when compared and contrasted to the massive body of literature focused on white, older, female caregivers and the stress and mental health issues they experience.

For instance, Roth (et al., 2015) examined racial differences in experiencing caregiving as a positive life outcome within the United States. African American caregivers reported more positive caregiving outcomes than white caregivers, while Latin American caregivers were somewhere in between. According to Roth, spousal caregivers who are also white and female were found to have the most difficult time caregiving in comparison to other racial and/or gendered identities. This finding suggests that the identity of the white woman is largely constructed in relation to her spouse and in her ability to care for others in ways that reflect white American traditions and the ideals of individualism (Wood, 1994).

The white female identity in Western culture is an ever-evolving and emergent phenomenon, as is racial identity. These identities are not biological or inborn; they are constructions of culture, reflections of epistemic and ontological belief systems. I have learned to exercise caution against the consistent emphasis of the marginalization of women in academic research contexts, as this practice may reinforce assumptions that continue to construct those identities as marginal or disempowered. Much of the caregiving literature is founded upon the marginalization of white women (Wood, 1994). As I tell my story, it is my goal to deconstruct my marginalization as a woman and attend to some of the implications of my racial identity in the context of caregiving relationships and mental illness.

Clifford Geertz (1973) famously wrote, “Man is an animal suspended in webs he himself has spun;” or, in this case, woman in relation to man. Historically, caregiving was assumed to be “women’s work.” According to the Family Caregiver Alliance in 2016, 66% of unpaid family caregivers in the United States are women. Julie Wood’s 1994 book “*Who Cares?*” was the first in the communication literature to focus on gender inequities associated with care in our culture, asserting that caregiving responsibilities are assumed tasks often foisted upon the female gender.

I understand the importance of acknowledging this experience and have experienced gender discrimination myself, even in relation to my caregiver role. However, it is not my goal to argue that the 66% of caregivers who are female are more significant than the 44% of men who take on caregiving roles.

In *Identity Schmidentity* (Bornstein, 2010), Teyln Kusalik, a mixed-gender person, voices frustration with the ways in which identity constructions divide us. Instead, Kusalik advocates an experiential togetherness, uniting us in our human experiences of suffering and joy, or discrimination and liberation (Bornstein, 2010). I do not want to “gender” care or divide it by binaries that bind us to our suffering and isolate us in our grief. If I do, I will likely make the same kinds of assumptions about gender inequities that create, maintain, and perpetuate gender inequities. I worry that our gendered assumptions often distract us as scholars from other possible truths. Specifically, I refer to subjective truth, through which, as Bochner (2017) observes (citing Behar, 1996; Devereux 1967), “Research becomes more objective when it is done subjectively” (p. 70).

To illustrate the ways in which a focus on gender inequities may enforce a language of oppression (by suppressing the validity of a person’s subjective experience based on her gender identity), I analyze Clough’s feminist critique of Ellis’ autoethnographic novel, *Final Negotiations*. Clough (1997) challenges Ellis’ representation of her experience in a caregiving relationship with her partner and former professor Gene at the end of his life. Clough uses the metaphor of a television screen to symbolize Ellis’ expression of emotion, remarking that this emotional screen protects the author of autoethnography from criticism. Clough goes on to criticize Ellis’ lack of historical context or reflexive discussion of the gendered power dynamics between her and her partner.

I argue that Ellis' choice to write her story without making it about gender is not, as Clough suggests, something to be critiqued. This is not a matter of research ethics or researcher responsibility, but merely a difference in what Ellis wishes to do with her ethnographic "I" and what Clough wishes she would do, or assumes she should do. Ellis expresses a complex relational experience as she lived it, using her voice to demonstrate her perspective, her introspection, and her growth, and creating a space for others to do the same. It is not right or wrong, only different and "true" to how she experienced it.

Including a historical context in caregiver studies is not uncommon in caregiving literature, and studies are made up of mostly (if not purely) female research participants. What *is* lacking in the academic setting is a space to form relationships with readers and with students, although many people have a "feeling" learning style that requires emotional connection (Kolb, 1985). Ellis writes the relationship, and the reader meets her in it. It is in that liminal space between the author of an autoethnographic story and the reader where meaning is made. Clough brings her own lens to the story, where she witnesses Ellis' oppression on screen (Clough's metaphor), rather than her liberation. She questions Ellis' agency within her relationship with Gene, within her choices as an author. This distracts Clough from the paradox of caregiver relationship Ellis conveys, ignoring the complexities and the double binds Ellis illustrates through her writing (Bochner, Ellis, & Tillman, 1998). It is Clough's questioning of Ellis' agency in expressing her experience, Clough's doubt that her story is true to the way she lived it, that constructs her marginalization as a woman. Through this questioning and doubt, Clough transforms the story into one of her own making. It becomes Clough's story of Ellis's story as rendered by or through Clough's consciousness and subjectivity not Ellis's.

The truths I question are the assumptions guiding much of the caregiving research, including assumptions about age, race, and gender, and about how people conceive of care in general. The caregiving statistics suggest that a lot of people *do* (65.7 million in America alone). To assume otherwise is to assume a devastating kind of emotional and spiritual poverty in a dystopian Western culture of care. According to Guberman (et al., 2012) a possible reason for this is the Baby Boomer mentality that they need not provide care for aging family members because doing so would “take away their freedom” (p. 214). These differences in age/generation are important to discuss as they also demonstrate relevant cultural differences.

In interviews with North American professional caregivers, Caribbean social workers, and Caribbean family caregivers, divergent sets of assumptions about cultural values surrounding care emerge (Dysart-Gale, 2007). Dysart-Gale calls these assumptions “ideographs” of care. One Caribbean social worker remarked, “Here we look at it is a shame if you put your parents in a nursing home” (p. 408). In contrast, nursing homes in North America constitute a very lucrative industry. Here, it is expected that when parents are no longer able to care for themselves, family members should put them in nursing homes.

Dysart-Gale (2007) asked caregivers about respite, or getting out of the house. One caregiver simply said friends come over to have beers—respite exists just fine in the house. Another caregiver, when asked if they were the person who gave the most care, said no, that everyone takes turns. When again asked if she led the team, the caregiver laughed, answered no, and said, “Everyone does their share” (p. 410). Dysart-Gale (2007) makes no mention of gender in this study.

Is it necessarily true that caregivers are generally stressed out, older white women at risk for mental and physical illness? Is the average profile of a caregiver in the United States “still a 50-something woman feeding, bathing, and transporting her ailing mother” (Bahrapour, 2015)?

No.

Dysart-Gale’s research sheds light on my experience in important ways, and, in the end, shows white America a different, and perhaps healthier, way of looking at, talking about, and doing caregiving. Autoethnographic storytelling is a way to sort out the chaos that comes along with change, and to understand the nature of relational losses and gains in the context of cultural narratives that may do more harm than good.

To tell my story, I am learning to make order from chaos.

### **The Narrative Arc**

When my story began, I was a different kind of researcher, a different kind of writer. I did not think in ways that demonstrate story, there was no narrative arc to follow. I did not attempt to make sense out of chaos. Things *were* “objectively” true for me for the first six years of my caregiving experience. I lacked financial resources. I lacked social support from my younger peers who did not understand my experience. I lacked skill. I was stressed and stretched beyond my means, and eventually, I snapped like a rubber band. I was diagnosed with mental illness. I was sure I could not participate in a PhD program or move my father to Florida and care for him there, while working on a PhD, while researching caregiving. This was my concrete reality. These were facts.

Eventually I began to question the cultural assumptions that defined my life as a caregiver as burdensome. For so long, I believed my life was factually oppressive, so much so that I wrote an entire thesis that clung to this notion. But I experienced a change in the way I was



thinking about caregiving, what Bateson (1973) calls a change in epistemology. Assumptions are thought patterns; the beaten path in the brain that we take over and over again, regardless of the repeated horrors we face each time.

Throughout my PhD education, I set out to change those patterns, to adopt Buddhist practices of meditation, to be with the fear of death, with grief and suffering—neural paths less traveled. I took classes in social construction, in politics of mental illness, in cybernetics, in communication at the end of life. I practiced yoga. I made dear friends who guided me and supported me as I wrestled with old assumptions and attempted to deconstruct them. I found mentors who challenged the assumptions I made about myself and about caregiving. And, at the meta-level, I saw the conflicts and contradictions in which I was trapped, one double bind after another. I changed the way I thought about learning, and changed the way I learn. I learn best when I jump a logical level, write poetically, write prose; creativity is the only way out of paradox (Bateson, 1980; 1991; 2005).

And I experienced a change in how I knew myself as a caregiver, how I understood what it meant to care for my father, how I came to know the cultural context and language that told me who I was, and how I discovered who I could be: a caregiver, a student of communication, a pleasure-seeking person—a good human being with a good life.

Still, mine is not a story that ties up all loose ends neatly.

Nor is it a story about how caring for my dad at the end of his life became easy—it is hard, it does involve grief, it does involve stress—but that isn't the whole of it, and it does not mean I cannot be content; though, at one time, I fiercely believed it did.

I tend to turn to storytelling and other artistic modes of representation in order to find and express meaning; like Freeman (1997) writes, “poetry, poetic language, rather than entailing the

imposition of meaning, entails disclosure [...] its aim being nothing less than the revelation of truth” (p. 43). Stories in form of poetry and prose subvert the dialectical tension of disclosure; storytellers abandon difficult choices to reveal and conceal information and create new codes of meaning.

Eight years ago, at CMU I was instructed to do my best to remain objective as a researcher, but I knew then objectivity was impossible, especially since I was relatively new to caregiving and was emotionally consumed by the impact of my dad’s sudden array of needs. The emotions I experienced were feelings of loss, injustice, anger, and sadness—they also determined my research questions, which asked caregivers about their experiences with human service organizations (because my experiences were horrible and I had been treated badly) and caregiver stress. My emotions designed my interview guide, and colored my responses to interviewees (who I tended to end up trading shitty-life stories with as if I was not using them for research purposes). My emotions helped code the interview data, driving a focus on the negative aspects of dialectical tensions in caregiving relationships (Scheffels, 2010).

I was determined to tell the world that caregiving was wildly difficult and darkened by illness, turmoil, and exhaustion; I sought out studies that focused only on the negative elements and outcomes of caregiving relationships—the self-fulfilling prophecy I mentioned earlier. This is what Freeman (1997) refers to as narrative foreclosure; sometimes we decide that our stories *are* objective unyielding realities, experiences that will repeat themselves as fact, and remain unchanged. So I set off to verify the troubled experiences I associated with taking care of my dad. In a distant, academic voice, I wrote the results and a discussion section that dispassionately confirmed just how difficult it was to take care of a family member. Not once did I consider other possibilities. In retrospect I see my research approach as a story foreclosed.

Freeman warns that this is often the story we tell in narrative writing as well. Narrative foreclosure may compromise narrative integrity, projecting onto the future a bleak, predestined existence, devoid of reflection. If we foreclose on our stories, we see no possibilities, no other ways in which one's life story might unfold, ways that may be more fulfilling to us and to others in our worlds. Freeman describes narrative integrity in the context of Tolstoy's *Death of Ivan Ilych*, a story of a man "living his life without an ending in mind," (as cited in Freeman, 1977, p. 388), who, on his deathbed, is able to reflect upon his past with dreadful hindsight and ask the question, "What is the right thing?" (p. 389).

Freeman notes that this process becomes destructive when we slip into deep regret and powerlessness over what one might consider doing "the wrong thing" in past relationships. But this process can also be transformative if we participate creatively in rewriting the self. This process is what Freeman considers narrative integrity, "the soundness and depth of one's *ethical*—and, for some, *religious*—commitments, as evidenced by the shape of one's life" (p. 388). Narrative integrity is a process of reflection, of rewriting one's life, and rewriting oneself.

It is always and inevitably an act of self-transcendence; it is an act of divesting oneself of a certain 'blind view' of things; of encountering face to face one's own otherness; and, ultimately, of moving on to a more fully-realised mode of being human. (p. 389)

Through my autoethnographic writing and my studies in communication, I have come to know narrative as an indispensable part of understanding, appreciating, and coping with what it means to be human, and, in my case, what it means to be a "caregiver," not only in this culture, but for me, personally. According to Bochner & Riggs (2014, p. 197), "The human condition is largely a narrative condition" (also see Crites, 2001). My stories about caregiving illustrate how I have evolved; identity is constantly under narrative construction, is multiple, fluid, negotiated,

and never complete (Bochner & Riggs, 2014). I am no more a caregiver than I am a daughter. I am no more or less sad than I am happy. I have hard times and I have good times. I have learned to forge my own way, cobble together my own path in the creation of experience, to tell my own story, my truth.

We are storytelling beings with pasts, presents, and futures, working with nothing more than our flawed memories, memories that encompass past/present/future at once (Bochner, 2007; Bochner, 2014; Freeman, 2010; Hacking, 1998; Kerby, 1991). As such, I find it unnecessary to distinguish fiction from fact:

Autoethnographers must recount what they remember, retelling events and experiences usually in the form of a written, spoken, or performed story. When this occurs autoethnography becomes a storytelling art that can, and often does, merge the real and the imaginary, the factual and the fictional (Bochner, 2017, p. 73).

As I tell my story I work with “a recollection merging into the ongoing business of living” (Birkerts, 2008, p. 6). As time has passed, I have learned to learn differently (Bateson, 1973) and learned to write. I am no longer clutching a series of foreclosed chaos narratives (Frank, 1995) of stress, burnout, and depression in sweaty palms. Instead I live an open, ever-changing story I strive to move with, rather than against, and, in the process of writing as reflection, to encounter my own otherness, to catalyze “an act of self-transcendence” (Freeman, 1997, p. 389). Frank calls this a quest narrative (1995), a narrative that is “as much about the possible as it is about the actual” (Bochner & Riggs, 2014, p. 198). I call it *a narrative education*, a process that carries with it the possibility of epistemic change, a space to make new truths out of the mess of memory and experience, in the midst of paradigm shifts. According to Penn (2001), when we look at our usual narrative mode within a social constructionist,

collaborative frame, the first thing we think about is a concept called “coherence” which means simply: your story has to make sense to you, it has to cohere, hold together for you and for others (p. 37).

It has been difficult to find narrative coherence in my writing in the past. I have only recently recognized the constant change in the ways in which I conceive of care in the context of my own life, and have begun to arrange my experiences into a timeline. I am more content if I tell my story as a coherent quest narrative that unfolds over time, and live it as a spiritual journey (Frank, 1995); it does not have to be perfectly remembered or factual for it to matter. I have discovered that coherent storytelling has therapeutic value (Parry, 1991; Frank, 1995; DeSalvo, 1999; Bochner, 2000; Penn, 2001; Rosenthal, 2003; Charon, 2006; Bochner 2014; Bochner & Riggs, 2014) if done competently and reflexively. According to Peggy Penn, stories have healing power: “When we write...we are no longer being done to: *we are doing . . .*” (2001, p. 50).

Through narrative conversation and reflexivity, I seek to make this dissertation embrace a new ethnography (Goodall, 2000) of storytelling. According to Parry (1991), stories have inventive power, and have the ability to restructure both our lives and our ever-changing worlds. Foster and Bochner (2008) also point to the interaction between the cultural constructs that structure reality and personal experience when they write “...narrative research embraces the details of lived experience, the reflexive relationship between personal interaction and cultural contexts, and the dialogic and dialectical complexity of relationships and communities” (2008, p. 92). Our stories, propelled by language, are analytic glue—they hold us together, connect us to another, and merge the self and society. Through a process of writing my caregiving story as inquiry (Richardson, 2000), I weave in literature to supplement my understandings of self and other, and understand the emerging function of my story within a larger cultural framework. I

live and write to navigate my experiential and formal education as caregiver, to develop as a character in my story, to become a whole person merging different and often conflicting selves to make meaning of a life worth living.

### **Ethical Considerations**

Though I am the person writing this dissertation, this work is not all about me. As Ellis says, I do not alone own my story (2009). My dad and other people I write about also have versions of it that they are unable to tell in a public venue. This is why to write ethically I must write reflexively, examine my own position, and consider the ways in which I influence others.

As Andrew (2017) argues, I should think of the impact my story might have on those I write about. My dad has said he will never be able to read or understand my dissertation, but “to write whatever I want.” This is complicated, because his consent is also colored by his stroke, as is his ability to read it. What is more critical is to consider that he is unable to tell his own story. Because of this, I will work hard to honor his personhood and represent him as the “well-rounded” human he once told me he wanted to be. I also fear that putting my story out there opens it and my life up for harsh criticism.

It’s a real fear and it needs to be recognized and overcome. That’s because there’s no point in writing if you can’t overcome it. There’s no point in writing if you are going to avoid offending, even hurting people. You have to believe in the story. Great non-fiction writers, great journalists—even not so great ones—believe in the importance of the story. The story is its own justification. And the story is their story. The writer owns it (Gawenda, 2013, p. 11).

Another difficult ethical balancing act concerns the ways in which I represent my own character, which will be complex, and in many ways excruciatingly unflattering and

embarrassing. I think this is best done through depicting my communication behaviors honestly without evaluating them too heavily or attempting to justify them explicitly in writing. Though it may seem reflective, a deep evaluation of myself can also become too self-deprecating, too negative or too positive, and this denies the authenticity of my character. But if I depict my behaviors honestly, readers can decide for themselves what sort of person I am. As Andrew (2017) suggests, I will enhance the writing of my “self” or, better yet, “selves,” honestly by asking my writing partner, Lorraine, to read my work and show me where hidden motives might be in my writing, make me aware of them and, as a result, able to represent the truth more authentically. Though Lorraine is my closest friend and she knows my story well, she also knows my blind spots, evidenced in her consistent ability (throughout our friendship of four years—four years with the promise of forever) to show me things I cannot see (usually because I look too close).

Though narrative inquiry asks a lot of its writers, it also asks something of you, my reader. I am writing with hope that my story is a truthful emotional experience that elicits laughter as well as tears, and, in the end, gives you something to take with you. Though as Andrew says (citing Dhal, 2009), we have both clean and dirty pain, and I will portray both and bring both out in the reader. Clean pain, he says, is sadness, but dirty pain is “rage, self-righteousness, or judgmentalism” (2017, p. 33).

So be warned, by the end of my story, you may feel one or both kinds of pain. I am asking you to go back in time, to live with me for just a little while, to be a part of me. It might not always be fun, and it certainly will not be clean.

## CHAPTER III

### Everything is Not Fine

Clinton Township, Michigan: the year is 1989 and I'm little and feeling shitty. I writhe around on the floor of the downstairs bathroom at my mother's feet, clutching my stomach in the square foot of space between the wall and the toilet and sink. My little red sweat suit creeps up my back. The crusty old brown carpet smells like corn chips. It's giving me rug burn. My mom is putting on lipstick for her Christmas concert in the Clinton Township community choir at the old folks home just outside Detroit.

My dad waits by the door. He is always ready to go. She is never ready to go.

"My stomach hurts, mom. It really hurts. I don't wanna go."

My dad walks to the bathroom door and stands over me, 5' 10", a giant hovering over my tiny crumpled body, his hair wild around his head, his wire-rimmed glasses perched at the tip of his nose.

"I think she's really sick, Carol," he offers, "I can stay home with her if you want."

"She's six years old, Klen, we can't let her run the show. She'll be fine." She turns to the mirror for one last look, her short, dark hair cropped closely to her ears. She's pretty and knows it. Faux pearl necklace draped around her neck. Matching earrings dangling from her earlobes. Hunter green silk blouse. Skirt. Heels. Olive skin and red lipstick. Her hazel eyes are green tonight.

She helps me up from the carpet, pulls my sweatshirt down to meet the elastic of my sweatpants and pats my back.



“Come on, girl. You’re alright.”

We get in the old wood paneled station wagon and my dad starts it. We’re coasting into our first turn when the bubbly brown sickness rises up and out of me in a river, washing over my red sweats, onto the backseat, the floor.

That night my mom skipped her concert to carry me into the house and pet my head. I sobbed and soaked her nice blouse in vomit. My dad’s eyes met mine as we walked inside.

“I thought she looked sick,” he said.

### **Terriers, Ravioli, Divorce**

The snap-crackle-pop of my dad’s beer can ricochets off the living room walls.

“Every time I hear that sound, I feel sick,” my mom growls as she marches past us.

I am in the living room with my dad and his Budweiser. I look down at my little kid hands for a while and then sandwich them between my legs and the orange and brown plaid couch. My nightgown—an old Charlevoix, Michigan T-shirt of my dad’s—covers my knees in worn gray.

My mom stomps around the kitchen, back and forth past the white plastic table with the bucket seats and the broken dishwasher. Her slight silhouette dapples the yellow kitchen light and blurs the brown plaid cornucopia wallpaper behind her.

My dad picks up his beer for another swig. His face twists, kaleidoscopes.

My mom’s growl crescendos to a shout:

“I’m not gonna to do it anymore, just not gonna do it!”

My dad gets up from the couch and marches into the kitchen and around the corner. I sit still.

More yelling.

A thud.

My mom is crying. My dad walks behind her, has his hands around her shoulders, keeping them a few inches away as if she's a plane he's trying to land. He ushers us all toward the front door without touching her.

"We have to go to the hospital," he says. "Your mom is fine but her wrist—"

"It's broken." She says with a whimper. "The neighbor, Sharon is gonna watch you for a while."

The aluminum screen slams shut and I'm carried to the edge of the cul-de-sac from our townhouse in the center. The red bricks and matching shutters bleed together. Through blurred, glassy eyes I can't tell which one is mine anymore. We've arrived on Sharon's front stoop.

The door jams then breaks free with a snap as she opens it.

"Come on in," she says. Her two Boston terriers surround all three feet of me, sniffing, panting, barking.

My dad thanks her.

"Of course," Sharon says as she closes the door on him.

It's dinnertime. Sharon makes a can of Chef Boyardee beef ravioli for me, but I don't have an appetite. And I don't like meat. Especially the little brown granules of god-knows-what all clumped together in a too-soft-for-comfort noodle-bed.

I stare at it when she sets the green plastic bowl in front of me. The kitchen is dark. The table is dark. I'm the only one at it. In a booster chair. I poke at the ravioli with a yellow Spork and hope for the opportunity to slip some to the terriers who circle below like piranhas. Sharon is on high alert. She catches on. Her face turns as red as her close-cropped hair. Her veiny arm juts out before me and snatches the bowl.

I sit real still.

She throws the green bowl at the sink. It crashes at the edge of the counter. Red meat sauce spatters the cabinets and floor.

“Fine, don’t eat it,” she barks.

Tomorrow, my parents will tell me they are getting a divorce. In a week, my dad will move out.

## **Bars**

Freshly 21 and I’m drunk and driving down Hall Road. My dad is waiting at the bar for me, the one with Abe Lincoln’s face painted on the cement wall in black and white. He lives less than an hour away, but he mostly looms large, silent. I see him in the distance, unblinking, constant: the Northwest Star that gives me directions over the phone.

I’ve been drinking with friends half the day—I never would have found it on my own. I pull into the parking lot and rush out of the car, my hoodie catching in the door. I yank it out and it rips a little. I’m late.

My dad is early. He’s always early. I grasp the metal handle and open the heavy door with all my might. He’s at the bar alone, hunched over. I take the seat next to him and swing my barstool into his.

The bartender sets a beer down in front of me.

“Notice how bars never have windows,” my dad says.

“I’m 21, dad!” I bubble over. He looks serious.

“Sorry, sorry. Why don’t they have windows?” I ask.

“It’s because the people inside are ashamed,” he answers, staring into his beer.

## **Imperfect Symmetry**

“That tree is perfect,” my dad says, staring softly in the direction of the front door he was exiled from some sixteen years ago. Red bricks. White siding. Red shutters—their rust color the only thing that separates one condo from the next, aside from his tree.

“I planted it when you were born. You never know how things will turn out, but it grew in so straight,” he says.

Beer belly, graying hair, thick with wiry curls. Wire-rimmed eyeglasses. Double XL golf shirts. Slacks and a hat from the Goodwill. His blue eyes twinkle, glazed.

After 22 years, the little, flat-faced condominium is dwarfed by the pine’s perfect symmetry. The windows are hidden from view.

He’s here to see me off.

I’m goin’ to Mount Pleasant, Central Michigan University. Got my shitty grades up and got a loan to get the hell out of Clinton Township. Say it. Just like it sounds: Clinton Township.

Strip malls, dingy buildings, decay—gray, gray, gray. Everyday, the same roads: Metro Parkway, 15 Mile, Gratiot, Groesbeck. Patches of blackened snow scatter the streets. Greasy, lame granules that were once soft, pure, driven.

But I always look forward to the summers. The carefree, easy breaths that escape my mouth and become one with the wind that whips in and out of all four open windows of the red Grand Am.

## **Switchblades and Bowler Hats**

It’s my first year of undergrad at CMU and I’m in a band.

*Score.*

I am wearing a leather jacket and holding Jon's guitar, my fingers rest on power chords below a tiny gilded star encircled by a crescent moon, dotting the neck of his guitfiddle. Jon is wearing a bowler hat and biting down on a switchblade, the white tips of his straight teeth scarcely visible between the metal and his upper lip.

Tonight we are snorting cocaine.

Black "Krackle" nail polish is shattered in matte bits across a shining rainbow I painted on the tips of my fingers. My hair is gold and broken and curled in loose spirals, crowned by a pouf of wispy frizz, blue eyes shielded by mauve wire-rimmed glasses, lashes coated in cheap, thick Maybelline mascara.

Jon is wearing sunglasses that make him look like a dorky, white, talentless Ray Charles. Fuzz and scruff frame his mouth and strong chin and my leaning toward him makes it look like we have the same jawline.

We don't.

When my smitten girlfriends fawn over him I always say, "I know he's handsome but I can't find him attractive because I *really* know him."

Jon's hand rests behind my back as we snap a selfie. We are at his most recent rental house getting ready to hit the bars in downtown Mount Pleasant, population: us and about 100 or so town alcoholics.

When my dad visited and met Jon, he was impressed; Jon had always possessed an entrepreneurial mindset and had the youth and good looks to make it seem possible to go for your true American dreams. He was a kid who won the science fair every year, but lacked discipline after his parents' divorce and ended up in jail for his third DUI in his late teens.

## **The Call**

My hand grips the steering wheel as I press play on a voicemail from St. Mary's Hospital in Livonia, Michigan and drive to my apartment from aerobics class in cigarette burned Central Michigan University sweatpants.

That's when the woman on the message recording says it: "This is about your dad, Klen Scheffels."

My hands shake as I return the call. It's something bad. I can tell from the forced tone of voice, her obvious attempt at neutrality.

The world around me is fading in and out as I say my name to the nurse on the other end, as I say his name to her.

As she tells me "he had a stroke," and that "the doctors are running tests."

I guess she doesn't know much else about it.

Two weeks ago I got a much different life-altering phone call announcing I was admitted to the graduate program at Central Michigan University. I was thrilled and had been partying and calling everyone I knew since.

My dad was the first person I called. He was wonderfully proud.

I didn't just get into the graduate program, I also got a teaching assistantship that meant I didn't have to pay for school, that I got to be a college professor...sort of. My senior year of college I decided this was an excellent path when the professors in my department began to take a serious interest in me, commending my writing and thinking, asking what I wanted to do after I finished my degree. It was as if a rewarding and fun career path had suddenly materialized before me.

For the first time in my life, I'd felt lucky.

Even as an undergraduate, I was seduced by the romanticism of the academy; everyone digs a professor. The elbow patches. The glasses. The assumed wisdom and absentmindedness. All things students find endearing, mesmerizing even, as if professors could be superhuman. I also suspected that somehow being a professor enhanced one's perceived physical attractiveness.

And in the midst of all this celebration of the accomplished, attractive, possibly superior person I could one day become, my glimmering future fades into the background as I'm faced with the second call. I thank the nurse, hang up the phone, stay in the car, and drive the four hours to Livonia to see my dad.

When I got into that damn graduate program, he wasn't just the first person I called; he was the first parent. I called my mom later. I won't call her now to tell her about the stroke. I never call her when bad news comes because she takes it worse than I do.

I chain smoke cigarettes. I try to catch my breath. I roll the car windows down and let the harsh February air whip in. As if the frigid shock would wake me. As if I would suddenly be warm in my bed, the wisps of my curly, straw hair tangled in thick drool across my cheek as I lift my head and blink my way back to a reality safer than this.

When I arrive at St. Mary's, I park my car a few spaces down from my dad's dark green Buick LeSabre—the big boat is parked sideways, taking up two parking spaces. The driver side door is cracked open. I slam it shut and turn toward the hospital entrance.

“Intensive care unit” is where the woman on the phone said I could find my dad. It sounds so bad, like a virus or something invasive has taken him. I am lightheaded, shoving one foot in front of the other to walk in. My dad is in room 9, so an elevator ride, a left turn, a right turn, and there it is.

I stand outside the propped door a few minutes before walking in. His eyes are closed, face droopy. He's slumped over in the hospital bed. I stare intently at the heart monitor, watching for his faint little heartbeat to blip the radar. He looks much older than when I saw him last, just a few months ago. Apparently, a stroke will make you look like you just served two terms as President.

My breath catches and I hiccup loudly.

Then his eyes open and he turns to look at me through squinted, fleshy lids.

"Don't cry, Erin. I'm not dead yet."

The next morning I stand in a narrow kiosk of an office in the ICU meeting with Carol, a middle-aged woman with cat eyeglasses. Carol is a social worker of smallish stature, with brown hair and long, manicured red fingernails. Her name is the same as my mom's and I think both of them are irksome, faux-calm strangers in a crisis. Well, in my mom's case, faux-calm is "calm" until the inevitable full on flip-out I fear comes out from behind the curtain of forced, distant composure.

"Your dad has no health insurance," Carol says gently. "You'll have to apply for Medicaid and the St. Mary's Hospital Waiver Program as soon as you can."

She hands me thick booklets of paperwork.

"I don't know where to start," I say, eyes watery, brow furrowed.

"Start at your local library. They have the state sanctioned forms you'll have to fill out with your dad to become his Power of Attorney. You'll need to get them notarized before they are valid."

I try to look her in the eye as I respond with a pathetic sounding "okay," but quickly divert my gaze and walk back to Room 9 where my dad stays. A nurse is just leaving with her



rolling cart as I go in. I force a sad, awkward smile at her. My dad turns to me as I enter. His eyes are both lazy, taking a halfhearted stab at moving in my direction. He takes a minute to show signs of recognition. His mouth gapes, the whole of it droops sideways.

“I don’t like the waitresses around here,” he says.

I let out a little laugh. *All of this is absurd. What the fuck is Power of Attorney? What do those words mean? Am I old enough to be one?*

## **Mom**

My mom stands at the door of the old townhouse I grew up in. She looks at me with big, sad eyes, her head cocked. She pulls me in for a hug, Oil of Olay emanating from her pores. Her olive skin looks good for her age. Her short, dark hair is cropped closely to her ears. She doesn’t wear much lipstick anymore, just sweatpants and t-shirts that look like all the ones I’d pass up at Goodwill, or buy to be ironic because I think of myself as a cool young person with a clever message to send. She’s still thin, a natural result of a metabolism my dad’s blood could never afford. I take after him.

I took the easy way out before I came here: I told her over the phone. But I could never come back into town with a crisis like this on my hands without returning to that old condo.

“Come home,” she’d said before we hung up. So I did.

“I’m not staying long,” I say now, pulling away. “I have to go to the library, figure out the forms.” She pulls me close and pats my back.

I don’t tell her how to take care of me. I guess I never have.

## Survivors

Two weeks go by before my dad is released from ICU at his demand, after a slew of paperwork he signed to relinquish St. Mary's Hospital from the liability of what was now his precarious life.

"What's going to happen? Is he going to be okay?" I ask the doctor, his white coat washes him out in the background of the hospital walls. My eyes start to blur.

"It's hard to say with stroke victims," the doctor says. "Sometimes they bounce back, sometimes they don't."

A large, Indian man in green scrubs wheels my dad out and I walk beside them, eyes twitching to a strange, offbeat cadence. When we get to the car my dad rises from the wheelchair and gets in with ease. He's still strong, strong enough to not be stopped when he decided to leave that hospital bed.

I drive him to Parkway Heights Apartments where he's lived for nearly a decade in unit 1A (MANAGER). The place is populated by furniture scored from dumpsters and the vacant apartments of dead people; I occasionally brag about this to my friends. He sits down in a kitchen chair at a recently added glass dining table. I don't ask this time where he got it. I run my fingers along the lines of a V forming between my eyes, a wrinkle I anticipate will get deeper with time.

He looks at me quickly then turns away.

"Go home," he says. "I'm fine."

I take the bait and get ready to go back up north to school. I'll just wait there for him to bounce back. He will.

A few of the lingering residents come to greet him upon his arrival and ask enough questions to realize he needs looking after. His boss, Joe, owns the apartments and says he will keep an eye on him, too.

It takes a community.

I am driving to class with the windows down to let in the spring air, to breathe. There's a ceramic coffee cup perched in my lap that spills as the phone rings. I jump out of my skin at the sound of it. I glance at the caller ID on my Motorola Razr, and JOE flashes across the screen. I'm shaking. I've been so anxious, having nightmares befitting a Stephen King novel.

*It's his boss. My dad's dead.*

I let it ring four times before I answer it.

"Hello?"

"Hi Erin, it's Joe. You doing okay?"

"Yeah, I guess...what is it?"

"Look I'm calling because, you know, your dad...I've given it a few months and, well he just can't do his job. I'm so sorry. I'll give him \$2,000 dollars in severance so you can figure things out. I'll keep in touch to see how you are doing."

And for a little while, he did.

## **The Purge**

My dad is walking to the dumpster and chucking dishes in as I pull up to the end of the parking lot where the sliding door to his apartment is.

"Are you sure you want to get rid of all your dishes?" I say.

"Yes." He's off balance, manic, shaky.

I found him a one-bedroom summer rental in Mount Pleasant. The Central Michigan college town is dead over the summer, so it only costs \$600 dollars for two months' rent. Hopefully there's enough time to get him something else that's decent.

I load up my car with boxes of stuff Joe helped him pack up. An old bust of Beethoven painted brown, its glaze barely covering the white porcelain, upside down and jammed in between the other stuff that made the cut. Beethoven is the last composer left, the only one that didn't get broken when I was a kid; he used to have four porcelain composers, a whole set with Brahms, Bach, and Mozart. A few framed photos of his parents are sandwiched in. A few of me. Old checks he's saved from paying the Friend of the Court child support—proof he paid it so my mom wouldn't get him thrown in jail. A Polaroid of him in jail, his face between the bars, standing next to a brown-skinned man I don't recognize. I wonder what story lurks within that old photograph. I don't ask. He probably doesn't remember anyway.

### **Lesser Evils**

*The drive north could not be longer*, I think, as I glance nervously at my dad every two seconds. He sits slack jawed in the front seat of my car. That's sort of his look these days, but it always feels new and scary, like when I was little and he would suddenly shave all his facial hair.

Now he's pale and gray in the face, his white beard forming a five-o'clock shadow around his sagging chin, I realize he hasn't eaten. Taco Bell seems to be the healthiest highway option, the lesser of evils. I pull into the drive-thru and roll down the driver's side window to shout our order into the speakerphone through gritted teeth.

“Four chicken soft tacos, fresco style and two waters.”

I glance at my dad, twisting my hands in my lap.

The doctors say that about half the time stroke victims bounce back and I can't help but think we are looking at a half empty glass. *Or in this case, I think as I take the food and sweaty waters from the man on the other side of the window, a half empty wax paper cup.*

## **Public Assistance**

I sit in a plastic chair scanning the walls of the cold and sanitized Department of Health and Human Services in Mount Pleasant. I'm staring down at the thick grip of blue paper in my hand. The application for assistance is more like a book. Pages upon pages of white grids, empty fields to fill, each one a question I don't know the answer to. I don't know what my dad's assets are.

*Does he have any still? Did he ever? What counts as an asset?*

I waited in line for over an hour to get to the clerk's window.

"I need an application for public assistance, my dad had a stroke—" The clerk ignores my tears and cuts me off mid-sentence:

"Applications are over there." She points to the brick wall covered in thick, glossy beige paint on the other side of the lobby and turns away. I feel paralyzed, and she's clearly annoyed when she turns back around and I'm still standing there. She points again and I zombie-walk over to the wall of pamphlets and booklets.

I sit in a plastic chair and stare at the application for half an hour, hiccupping quietly before forcing myself up, staggering toward the exit, and pushing the heavy metal door open to leave.

I was supposed to be a professor this semester...sort of.

I was supposed to start something else. Not this.

I was supposed to be somewhere else.

I get in the car and start the engine and feel myself going numb as it revs, as I put it in reverse. I don't remember driving back to my apartment, getting into the wine, sobbing. But I wake up with a soaked pillow and a pounding head.

I just want to forget everything, wake up a different person.

Like my dad did.

## **Aliens**

“So what happened when you talked to my brother? Did you learn anything? Did he tell you anything about the aliens?” I am at my dad's place at 8:00 a.m. to fill his meds. This is the first thing he asks at the new apartment I've moved him into at Cranbrook Terrace. It is freezing cold today in Mount Pleasant, and this early hour is not my finest. To make matters worse, it appears he didn't take his meds the day before.

Today he asks me to help him with his laundry—a rare and subtle admission to illness. As we walk out his apartment door, laundry baskets in hand, his non sequitur breaks the silence. “I've always had high blood pressure,” he says. “It's just a part of my personality.” I stay quiet. We stop in the community room for a necessary free cup of coffee before we wait for the elevator to take us upstairs to the laundry room. A sign in the lobby reads “Ice Cream Social, Tuesday, May 17, 2:00 p.m.”

“You going to the ice cream Social, Dad?” I ask, knowing the answer already.

“Well, I do like ice cream...”

“Yeah, it's the social part that isn't up your alley. If the sign simply said “Ice Cream, Tuesday, May 17, 2:00 p.m.” they might be able to expect you.”

He laughs loud. “That's funny, Erin.”

I love his sense of humor, great and billowing. When he laughs, his face lights up in the best way. His eyes grin more than his mouth ever could, and this gives him a childlike look, full of wonder, transcendental, happy. No joke I tell is ever lost on my dad, something that sets him apart from all the rest.

We get to the top floor, step out of the elevator, and walk down to the brightly lit laundry room. A woman and a man are inside doing laundry. I watch them look at us, smile wryly, and whisper something to one another. It's then I realize my dad isn't just paranoid about the people in the building talking about him behind his back.

My dad lurches over to the line to stand behind the woman, teetering and waiting to get quarters from the machine. When she realizes he's there, she glances at him and moves away. As he puts the money into the machine to get quarters, I look him over. His baggy blue jeans, white tennis shoes, red, white and blue striped polo shirt, and unsteady gait give him the appearance of a little boy; sweet and innocent. *I love him more than ever right in this moment.* I decide right then that I also despise most of the people who live with him in this building.

"The dog made a mess in the bedroom," my dad discloses to me, in front of the glaring woman.

"Did you spray anything on it?" I ask, awkwardly.

"No. I didn't."

"Well, we will clean it up when we get back." I assure him, and the glaring woman. I imagine her ratting him out to the management, and, propelled by my own paranoia, dislike her more.

Right after the discussion of the sullied apartment carpet, the woman leaves, and I sit in a plastic chair with a bucket seat, waiting for the washer to finish its final spin. The magazines on

the table next to me are tabloids called “Globe” and there’s a whole pile of them. I look at their covers contemptuously. The first two are about prominent Black Americans being on crack cocaine (first President Obama, then Oprah). The third cover story is a small piece about Whitney Houston’s 18 year-old daughter—also on the crack. Then there are the stories about female celebrities and their supposed failing marriages.

Once the laundry is finished, we go downstairs to clean up the dog’s mess. My dad grabs the shop-vac and starts vacuuming around the already dried urine. This is not going to be effective. I grab some cleaning solution instead, and a scrub brush from under the sink and get down on hands and knees to scour the yellow stain. My dad vacuums nearby with no attachment, flailing the black plastic accordion of a hose around and occasionally pulling a bed sheet or an article of clothing from its grip.

It’s in that moment that I decide to use the morning to clean his whole apartment.

When I’m done with it, my dad says, “Wow, Erin! Look how nice it is. I can’t believe I live here!” I laugh and hug my dad. “I’m glad your mother had you,” he says.

“Me too,” I said, “life is kind of funny I guess, when you think about it.”

“Yeah, except for all the problems,” he says.

### **Jon’s America**

The dim yellow glow of Tony’s Tavern illuminates the laminate bar top to reveal circles of condensation—overlapping O’s that resemble Olympic rings. I trace the trails of water into the shape of a heart, hunching over the bar, shoulders sunken. My dark blonde hair is black with sweat around my hairline. Spandex wraps all 5’2” of my small frame. I ran past Tony’s at first, but I came back.



Jen rushes past, rooting around for a rag. This is Jen's bar. Her red ponytail sways by the logo on back of her purple "Tony's" t-shirt as she extends an arm, pale and slender. The rag weaves across the bar to wipe away evidence of graduating daughters, heartbroken divorcees, date nights, and layoffs from work who drink on house credit and go home smelling deep-fried.

The jukebox is quiet now, but soon gangster rap will blare from the speakers, \$1.50 a song. Later, country music will bring in the big bucks, playing the old American hits over and over until closing. Tony's is a country kind of bar, situated in the right ventricle in the heart of Mount Pleasant. It's only 8 p.m., and the family side of the bar is still buzzing with nine-year-olds running, shouting, and circling the pinball machine.

Jen flashes a straight, white grin my way and glances at Jon, who is talking frenetically at me, something about the oilrigs and fracking this or that. Jen and Jon are dating. He's on beer number four. I nod at him, but my replies are clipped, my tone slightly shrill.

Jon's short brown hair juts past his forehead, the strands glowing like embers in the yellow light. He's tall enough for his booted feet to rest on the sticky black and white checkered linoleum if he leans a little. His blue jeans expose white socks when he sits, his red flannel shirt rolled up to his elbows.

Each time Jon misbehaves, Jen says, "Pretty ironic, my family owns a bar and my boyfriend is an alcoholic." But she always lets him come back to Tony's, where he sits near the waitress station, behaving himself, for now.

Jen hears him doing his oil-drilling bit and rolls her eyes at me.

My purple Reeboks dangle helplessly from the steel barstool. Jon props his head behind his hands and gives me a sidelong prom king smirk, pleased with himself for getting me to meet up with him. The usual "you never hang out with me" guilt trip got me this time.

“So how are you doing?” His s’s are starting to slip into sloppiness, and he stresses the “you” mockingly.

I take a few gulps of the bribery beer he bought me, using both hands to grip the wet mug because I’m not strong enough to lift it with just one after a four-mile run.

“I’ve been better,” I say, staring into the mug, cupping its cold shape in my burning hands.

“Stuff hard with taking care of your dad or whatever?”

“So fucking hard. You don’t even know, Jon. The state took away his Medicaid.” I look down at the bar top, down into the beer, down at my swinging feet. “I just don’t know if I can do it anymore. The constant waiting in lines and fucking calling and waiting on hold and getting nowhere. I’m only fucking 24. I’m supposed to be a grad student. I need help from somewhere! I just don’t understand why it’s gotta be so hard to get help. I don’t get it.”

Jon stares blankly in my direction before turning to Jen. He motions for another beer and she reaches into the cooler for a new mug.

“Well, that fucking sucks,” he says, “but if you think about it, it’s good. You’re doing what you’re supposed to be doing.”

Jen puts the beer down in front of Jon, the mug frosty and still steaming from its collision with the warm bar air. He hardly looks up but takes the mug and tosses three gulps of it back.

“What is that supposed to mean?” My heart thumps in my ears and I grit my teeth as I look at him. “Jon, what does that mean: *What I’m supposed to be doing*. Supposed to be doing what? What exactly am I supposed to be doing?” I lean forward, inches from his face. My wide eyes try to meet his half closed, glazed pair. Jon leans back in his chair.

“You know, taking care of your own. That’s what we need in this country: take care of your family so the government doesn’t have to.”

“Jon! I can’t believe you would say that! I’m barely alive—as in I really might die, like, kill myself. As in I really need outside help to survive. It’s not like I have money to hire someone. I can hardly afford my own bills much less my dad’s. So why shouldn’t I have help from somewhere! Even if it is the stupid government. I’d think—I would think that as my friend who cares about me—you’d want me to be okay.”

“You are okay. You’re sitting here, aren’t you? So your dad had a stroke. You’re handling it. In America, beer in hand. I’d say you’re doing just fine, goddammit.”

“I’m not fucking okay,” I say. I slam my beer down on the soiled, sweaty bar top, spin the stool in the opposite direction, jump down, and march off. *I’m too busy for this shit anyway. I’m trying to work on a goddamn Master’s degree.* I stomp the whole way home, grumbling and crying and thinking about the ring my glass left behind.

## **Master of Nothing**

The corridors of Moore Hall are lined with brick and a thick coat of beige paint, the carpet gray and stained in big dark puddles, probably remnants of piles of vomit I guess. Moore Hall was built in the year nineteen hundred and seventy one, a fact I memorized standing outside by the engraved brick, which sits just above the grass at the building’s foundation, and just below the ashtray where I suck down cigarettes every day.

My classes are on the third floor and the fluorescent lights that illuminate the hallways are unflattering. And, even though the hordes of new CMU appareled students milling about make me want to turn my head away as they walk by, there is still a strange warmth to all this, a sense of affection and protection from my mentors that surrounds me like a ball of soft light. I

just feel so different from the undergrads—their freedoms, their fantasies of futures full of joy and success.

Meanwhile, I am elsewhere, a novice player in the next level of this game of “higher ed,” but I can’t help but wonder if I’m losing it. Still I try to understand the communication research methods available to me in my Master’s program. I prepare thoroughly for class, memorizing and synthesizing mountains of complicated literature for written exams. And when I’m not in Moore Hall doing all this, I stand in long lines at the Department of Human Services (for financial assistance and food stamps), wait at doctors’ offices (for evaluations and rehabilitations and labs), and wait with my dad for our number to be called at the Social Security Office (so we can secure some form of income for him).

It’s my second semester as a graduate student here, and recently I wrote a paper about caregiving for my qualitative research methods class. I started the paper with a story, and felt confident the essay would be a big hit. I was wrong. My professor assigned a “B” on the paper, basically “a fail” in grad school. In his comments he said, “*Never* begin any research project with a personal narrative.”

The rejection of the little story I wrote shook me. I got a bottle of red wine to ease my thinking and sat at my kitchen table to drink about it instead. *This is stupid*, I said to myself. *Get over it and just do what the fuck you’re told, that’s your job if you want to succeed in the end.* I’d naively hoped I would find some answers here, in this academic mess, which nonetheless feels far preferable to the disaster area I now call my life outside of class.

*I am trying to help my dad and also get this degree, how could my story not be a part of my research?* After all, I am living daily life in the midst of a family crisis that occupies my every thought, but am unable to address this in a way that makes sense to me, unable to address

it subjectively. Instead I am told to search for literature on the subject, to cobble together a line of logic, to hide between and behind pages and pages of academic writing and mimic the research of the past. No stories allowed, not back then, and apparently not now in the new millennium either.

I'm lucky enough to be led by my wonderful mentor Dr. Miller in a direction that makes sense to me; she understands that I want to tell a story about what I am living through, and even if I can't tell *my* story, I *can* ask other caregivers to tell me theirs. With the help of her love and encouragement, I buckle down to write most of my thesis in a dimly lit coffee shop in our small, sleepy college town where the gray, bleak winter seems to last year round.

On the overstuffed Kaya Coffee House bulletin board, there is a newspaper article I read again and again. The CMU community announcements are a way for me to periodically walk over and stand and stare at something other than my computer screen. The article (published in the student newspaper) has been cut out and pinned proudly to the center of the board. It's about a young white girl who is probably about my age and has dreadlocks. She used to work here, but left both the university and her job as a barista to "become a student of life."

I roll my eyes at her, a girl who, in my head I've condescendingly dubbed 'Dreadlocks.' But the truth is I envy her as I sit back down at my tiny bistro table in the coffee shop she abandoned, feeling left behind, searching the worldwide web for caregivers to interview, mining data in my tie-dye t-shirt and glancing nervously at my phone to make sure I don't miss a call from my dad. Dreadlocks' new life seems full of adventure, freedom, and possibility—things that many young white people feel entitled to during our early twenties, when we're just "trying on" personalities (or in Dreadlocks' case, culturally appropriating them).

Meanwhile, here I am, 24 years old, holding a quite different set of things that are not my own—the mistakes my parents made. My big dreams of becoming a cool, young professor don't really seem to fit so well with the tragic loss of my doting father and sudden gain of a 59-year-old, 200-pound little boy. And as I sit in this damned coffee shop day after day, reading through literature about caregiver stress and burden, I feel more alone and alienated from what I want than ever before.

The barista refills my coffee cup and sets it in front of me.

Nonetheless, I keep at this shit and dive head on into my studies, which have become a place to be still. I have great friends, and my dear mentors love me like a child; a kind of care I am desperately missing now. But, aside from some of the theory I learn in my classes, the material I study here is bland. The research methods taught in my program seem to contradict the brilliant theories and philosophies of meta-theory that are assigned in class. The ways in which we are methodologically sanctioned in our discipline to pursue “knowledge” leave little room for creativity and self-expression, and my intense lifestyle outside of the classroom churns inside me like a heavy meal.

If, as Thomas S. Kuhn says (currently we are studying his seminal work in my Communication Theory class), *intuition* is the key to revolution, to seeing a planet that was once flat blossom into a sphere, then why is my intuition to bring the honesty of experience into my research rejected (1970)? Kuhn says the scientific community tends to rally against revolution, suppressing it. As I pursue my M.A., I am taught that much of the current qualitative caregiving research is what is called post-positivist research, existing within the paradigm of a “scientific” study of social behavior and human relationships. I am taught this is the only way to both do qualitative research and gain scholarly respect.

But this is no critique of my professors or mentors; they are doing what they know to be best for me, and my future success as a professor. And I dutifully feed the paradigm they were once socialized into, doing research from within the disciplinary matrix of post positivism (Kuhn, 1790). Post positivists are researchers “who value a scientific approach to explaining social phenomena, but who also accept many of the criticisms of the different positivisms, and have developed positions that transcend them” (Corman, 2005, p. 21). And so my thesis project utilizes an “X is the opposite of Y” formula for coding dialectical tensions described in caregiver interviews about their relationships (Scheffels, 2010), a post-positivist method. Interviews and thematic analyses wherein researchers code data are also post-positivist methods (Tolliver, 2001; Whetje-Winslow, 2003; Dysart-Gale, 2007a; Yedidia, 2008; Institute of Medicine, 2014; Sun, 2014).

Truthfully, I am bored by post-positivism, but I drag my feet through my thesis anyway, weighted with readings that dominate caregiver studies but don't interest me in the least until I reach their conclusions: caregiving is stressful, like, really fucking stressful (Kane & Kane, 1982; Smith, 1985; Brody & Schoonover, 1986; Hofland, 1988; Pilisuk & Parks, 1988; Pearlin et al., 1990; Wood, 1994; Davenport, 1999; Blankemeyer & Pinkard, 2000; Musil et al., 2003; Wehtje Winslow, 2003; Baus, et al., 2005; Malhotra, 2006; Dysart-Gale, 2007a; Frank, 2008; Yedidia, 2008; Burgio et al., 2009; Robinson & Tian, 2009; Roscoe et al., 2009; Centers for Disease Control and Prevention, 2010; Butler, 2013; Institute of Medicine, 2014; Family Caregiver Alliance, 2015). So much so, it drives folks crazy—fucking crazy. But the work I read now never speaks in a human voice, never says anything with soul or color, and definitely never says the word “fucking.” I get tired of reading this kind of literature pretty quickly and decide I never want to pursue a PhD—especially when, upon asking how difficult it is to achieve the title of

“Doctor Scheffels,” a male mentor of mine at CMU says, over beers one night at The Cabin, that a thesis is “a children’s coloring book” by comparison.

“And with that I’ve heard enough,” I say. “I’m all set on the PhD. More like Ph-don’t, am I right?” That one gets a good laugh. I’ll remember that.

Of course, interpretive methods are taught in my program as well—I should not fail to mention this—but they are taught usually as more of an idea than a practice. In practice, the interpretive methods the professors in my department use are post-positivist; riding the line between interpretive and positivist methods is a way these researchers to achieve acceptance, a way to combat what Kuhn (1970) calls “incommensurability,” or the inability to communicate across divergent research paradigms within a field or discipline.

I hear an acoustic guitar strumming in the background, a John Mayer cover. *Fuck, it’s open mic night.* The barista grinds coffee beans, drowning out the sound of the guitar. “TURN THAT FUCKING COFFEE GRINDER OFF!” My head snaps up and I see a red-faced guy with a guitar on stage, swaying, drunk and full of rage. Startled, the barista shouts back, “IT’S A COFFEE SHOP, ASSHOLE.” But the guitarist won’t be stopped. He goes back to playing.

In the 70s and 80s, communication researchers, among others in the human “sciences,” took what is now referred to as “the interpretive turn” (Lindolf & Taylor, 2011), which, thanks to the lure of positivism and fear of expulsion from the discipline, is often more of a merge than a 180-degree spin. The overarching meta-theory of interpretivism embraces multiple realities and focuses on the reflexivity of researchers and the roles they play in knowledge creation. All of these concepts are covered in my program, but I know it’s still not enough for me, that there’s still no room for scholarship that is creative enough to entertain, intrigue, and *really* teach me something that people go through.



But one day, to my surprise, I stumble upon what I'm looking for. It's the first week of my Interpersonal Communication Graduate Seminar with Dr. Shelly Schaefer-Hinck, and we are assigned a book with the not so enticing title: *The Dialectics of Studying Personal Relationships*, edited by Baxter and Montgomery (1998). As I flip through the table of contents, I come across a chapter called "Mucking Around Looking for Truth." This is the closest thing to the word "fucking" I've found in academic writing and I'm instantly attracted to whatever this is. Each of us has to choose a chapter from the book to present to the class and I prematurely volunteer to present this one, staring at the other students who get to choose their chapters before me, as if a well-executed stink eye could protect this little treasure I found.

Compared to other researchers in the Baxter and Montgomery book, in "Mucking Around Looking for Truth," Bochner, Ellis, and Tillman (1998) reject positivism in search of other epistemic possibilities, straying away from absolute Truth (with a capital T) and moving in the direction of postmodernism, which "does not designate a systematic theory or a comprehensive philosophy, but rather diverse diagnoses and interpretations of the current culture, a depiction of a multitude of interrelated phenomena" (Anderson, 1995, p. 19), in other words, multiple truths. In the chapter, Bochner, Ellis, and Tillman embrace multiple truths, introducing autoethnographic storytelling as a way to examine dialectical tensions as they look and feel in the context of lived relationship experiences (1998). Dialectical tensions merge two opposites, opposites that contradict themselves and illustrate paradox, and the authors argue that the most effective way to illustrate something as complex as paradox is to *show* the reader how those tensions shift within real relationships with a method called "autoethnographic storytelling."

The relationship depicted in the chapter is a caregiving relationship between Ellis and her partner, Gene, who is dying of chronic emphysema. Ellis experiences dialectical tension in an

excerpt the authors pull from her book *Final Negotiations* (1995), which is discussed in the chapter as an example of how she is able to illustrate her truth to the reader through storytelling. She is attached to Gene, but that attachment is tempered by loss “as she and her partner wage their insatiable appetite for life against the relentless progression of his disease” (p. 56). As I read the chapter for the first time, I get the sense that the authors are truly “Mucking Around Looking for Truth,” and that I am too—it feels real, right, and I know now that I have to be able to do autoethnography if I am ever going to go on to pursue a PhD. The guitarist persists with his John Mayer covers:

*I just found there's no such thing as the real world, just a lie you've got to rise above.*

## **Professors**

I snap a picture as Dr. Hinck leans across the pool table in a black blazer and khaki slacks, her dark shoulder-length hair framing her petite face. She taps the yellow one ball. It misses the pocket and has her swigging a glass of red wine and shouting, “darn!” in her cute, signature high pitch voice.

Shelly. Shelly Schaefer Hinck. Dr. Shelly Schaefer Hinck. Her husband is Dr. Edward Hinck who most people automatically call Dr. Hinck or Dr. Ed Hinck, while still referring to Shelly as just “Shelly.”

*No respect these kids*; I think when she tells me this. But grown-ups do it too. Everyone, unknowing misogynists.

We are at the best bar in Mount Pleasant, “The Bird,” where my dad used to hang out and drink Coors Light with his band buddies back in the 70s. This is where we hang out after long weeks of class. On some nights, to the delight and surprise of us grad students, our professors join us.

I brought my dad here once when I was still an undergrad and he was still okay. We got pizza and beers at the joint next door called “Pizza Planet” where the pizza is acceptable at best. “This wasn’t here when I was here,” my dad said, looking around at all the chrome and red. He’d helped me move that day, hulking furniture and boxes full of laundry into my new apartment as I bragged about it to my friends via text.

“My dad is such a badass,” I’d said.

The other day my friend, and Co-Assistant to the Basic Course Director Betsy, and I got lost and she’d called her dad to ask him where to go.

“He always knows his way,” she told me confidently.

Dr. Hinck had asked Betsy and me to work with her on a research paper that analyzed written reflections from graduate students who went to work with men who were doing time in a local prison (Hinck & Scheffels, 2015). The paper is about service-learning projects that take place outside of college classrooms and is specifically concerned with prison as a site of learning. It was clear to us then that as the students talked to the men and made friends with them they discovered, to their chagrin, that these men, though incarcerated, are also human beings.

Some of the students wrote that the anger and fear they’d started the class with had been imposed upon them, that they were lucky to be on the ‘right side of the system,’ that these people, most of them poor and black and locked away, should remind us all to behave and value our freedom. The project made me think that perhaps white people see their liberty most clearly through the eyes of oppressed black people.

Dr. Hinck balances her pool cue against the wall and I walk over, my hand poised for the high five.

“Hey not a bad shot anyway. Next time!” As if I have anything useful to say on the subject.

“Yes!” she says, high fiving me back, always optimistic.

“So how’s your dad?” She takes a sip of red wine from her glass, looking upset after she says it.

This is a question I get often and from everyone, but somehow it feels good instead of exhausting and prying when Shelly says it.

“He’s...okay...I guess. He is really upset about his pension. Keeps asking about it. Well that and the aliens. He’s always asking about the aliens.” My dad repeatedly tells me the government is hiding the aliens from us, covering up their existence. The reason we don’t know about them, he claims, is because the aliens are too smart to have any use for us, or our sad little planet.

There is probably some truth in that.

“Well what about you?” she asks. “How are you doing with all this? Betty Jo said you’ve been having a hard time with him.”

She’s not wrong. I’m so wrecked emotionally that I’m starting to annoy even my best friends. I go to Betty Jo’s office or house often to cry like an infant. Dr. Betty Jo Miller is the reason I’m in graduate school to begin with. She was impressed with a weird theory paper I’d written for the dreaded undergraduate COM 301 class, Research Design and Methods. A lot of students couldn’t pass. She suggested grad school and I applied for a teaching assistantship. I didn’t know what I was going to do with my life anyway.

I didn’t have other plans.

Betty Jo has a daughter who wants to kill herself. She calls sometimes and tells her mom about it. I was also an almost-lost kid, but the difference is that Betty Jo has no reason to feel guilty about my agony. And I desperately need a friend who can both put up with me and try to understand.

Betty Jo never comes to the bars with us. Her ex-husband is an alcoholic and she doesn't drink. But Shelly and Ed like to party and I take every chance I get to hang out with them. Sometimes, I'll pretend they're my parents. That their daughters Alex and Ashley and son Robert are my siblings. That we all have a great friendship and that nothing about my life now truly exists.

### **Orientation Day**

It is my first day as an instructor at Central Michigan University and my dad's apartment is covered in shit and vomit. A little black dog lies on his side in the corner.

"I don't know there's just something wrong with him," my dad says. "He's sick or something."

I am on my way to orientation, which starts in 15 minutes.

My brand new, black Mercury Milan is in the parking lot, its insides pristine, unlike the grime covered red Grand Am I'd finally gotten rid of. My pulse quickens as I walk over and kneel down, hovering over the sick dog. His name is Sky. Because he's black and because that is the name he came with when I took my dad to adopt him from the animal shelter a few months back. He'd almost adopted a different black dog, but the apartment complex said it was too big and we had to take it back. The reason he was able to have any dog to begin with was because his neurologist prescribed it. And though the dog made things more challenging, he made my

dad happy and lowered his blood pressure, and that was enough for me to tolerate the arrangement.

I touch Sky's nose. It's dry.

"I think I should take him to the vet," I say. "Be right back. I need to call Jon, maybe he can help me with it."

I can't risk putting the dog in my new car or getting dog shit and vomit on my pantsuit before my big day even starts. So I go sit in the driver's seat and call Jon because he has a big truck bed I could put the leaky dog in.

"Hello."

"Oh my god Jon I really need your help. My dad's dog is sick and I need to take him to the vet but I don't want to put him in my new car and I'm all dressed up on my way to orientation. Can you help me with this? Put him in the truck bed and I'll go with and just be a bit late for it?"

I wait but don't hear anything on the other end.

"Hello?"

"Yeah I can't do it. I have other plans," he says.

"But, but...I need help. This is important." My voice starts to crack.

"Sorry," he says.

I listen for something more but there is only silence on the other end. My throat tightens and I bash in my steering wheel with my fist. The horn honks a tiny honk so I hold myself back from doing it again. I'm trying to breathe.

I can't believe Jon would do this. Wouldn't do this. Whatever. What a dick. I collect myself before I go back in there to be kind and reassuring to my dad and the dog.

Before I go back in there and try to avoid getting the mess on my First Day Outfit.

Before I put a blanket down and carry the dog to the backseat and take him to the vet, only to learn (\$100 later) that changing his food too abruptly did it.

Before I miss the first day of orientation and am drinking and writing apologetic emails and smoking weed and watching *Lost* and feeling like actual dog shit.

## **Lost**

I scan the sidewalk for signs of dad. My foot is heavy on the gas and hard on the brake.

The Grand Am whips around neighborhood corners, past abandoned frat houses, where corpses of red solo cups litter the lawns like fallen drunkards. The sorority houses remain pristine, their lawns cornered by large rocks, spray painted with pink and white Greek letters, mantras written in neat cursive.

I have to go to class. I can't find him. I was just here a few hours ago for his first dose of blood pressure medication.

I have to get to class. And that's where I am when the police officer calls, my dad's meds and groceries in my car, my heart in my throat.

I need to excuse myself from class.

"Hello?" My voice shakes.

"Hello, is this Erin Scheffels?"

"Yes."

"This is Officer Lauria with the Mount Pleasant Police Department. Your dad wandered over here. He seems confused, said he was looking for you."

The air rushes from my lungs.

"Okay, I'll be right over."

I need to leave class.

My dad is standing outside when I pull into the parking lot. I get out of the car and hug him.

“I didn’t know where you were,” he says. “I was worried about you.”

### **Poor Choices**

I am driving and it’s dark and cold outside but I furiously dial 794-8134 with my cellphone, my fingers burning. My mom’s shrill voice comes through the other end and I know she doesn’t want to talk to me, unless it’s only her talking and it’s something about her and her church friends.

“Hello?” Her greeting is classic telephone singsong but slow and tentative, her tone stiff with the sting of an all too familiar defensiveness.

“Hey,” I say, my voice cracking on the other end. Before she’s even able to start talking about some church thing she did with her friends I get right down to it. “Why? Why did you have to divorce him? So he drank, big deal! He was still awesome. You could’ve helped him. You could’ve been his wife and he would’ve stayed forever and none of this would have happened. You’re the one who chose him to be my dad. *You* chose him and now he’s crazy and I’m going crazy too. I can’t do this on my own, mom! You should be helping me,” I gasp to catch my breath.

She pauses before venturing in carefully, her voice clipped. “Erin we all make choices in life. I chose to get divorced because it was the right thing for *me*. *You* chose to take care of your dad even though you were starting graduate school. You *chose* that. I’m sorry it wasn’t the right thing for you right now, but it *was* your choice.”



“My *choice*?? I didn’t choose for him to have a stroke! I didn’t choose to be the only one to take care of him! I do it because it’s not a choice. And you know what, fuck you, I’ll be sure to remember your “wisdom” about dad when you’re old and sick on *your* deathbed!”

***Jon Anderson***

***12-19-85 to 9-19-2016***

Jon and I are drinking and driving down dirt roads in the backlands of Isabella Township. I sit in the passenger seat and his little black dog Juniper ‘sits bitch,’ a slang term used for whoever has to sit the middle seat in a two-seater truck; it’s fitting for a female dog since she requires no legroom. It’s less fitting for a human woman, which is one explanation of the origin of the term. Urban Dictionary’s definition is: usually the smallest person or only female in the group will have to “ride bitch,” so that the guys don’t touch each other (irrational male homophobia).

The steel cage of his F250 jostles me.

We are here because he is trading me a Xanax for some weed. It’s late and I’m in my pajamas but I can’t sleep.

I let the Xanax dissolve some under my tongue and wash it down with a pull of Budweiser that sits open in the cup holder.

“It works faster that way,” Jon says with tight, smoke-filled breath, barely finishing his last word before the coughing fit. My heart rate quickens in my heavy chest and his choke drowns out the radio and country music hits. I fix my nervous gaze out the window and on a blurred swath of leafy darkness hoping he’s not going to be sick.

“Hi my name is Jon and I’m a cross-addicted alcoholic,” he recites, passing the joint.

“Man, we are so fucked up,” I sputter. “Shit we’re sad.”

Jon throws his head back and laughs before guzzling more beer. He has three DUIs and just got his license back after years of hitching rides.

“How’s that Xanax treating you?” he asks, passing the joint.

“Good. Starting to feel it.” I take another hit and exhale slowly. “It’s like a light breeze inside my head. Like it feels good, but it just covers up shit. Doesn’t fix it. Like a shit pile sprayed with Febreze.”

“That’s so fucking brilliant,” he marvels, trailing off. “Brain Febreze!”

“Oh my god fuck yes!” I say as he guns it and we congratulate each other and laugh.

Today, Jon is buried in a small clearing on his family farm a few back roads away from the place where he fell off the ATV drunk and crushed his spine. A few roads away from the place where we expertly coined the term “Brain Febreze” that night.

All along we’d planned I’d write a book about Jon from the perspective of his little black dog, Juniper. He and Juniper hitchhiked across the country together and Jon was always doing something crazy, some whacky or wicked thing. And though my memory is too shitty now to write about his stunts in detail, I can still talk about him here. Mostly he exists as a lump in my throat, but I can still write his name.

On the way to his funeral on September 23, 2016, I stopped at the mall to get a drink and wrote him a note on half a torn envelope. Later I slipped the note I wrote at Macy’s restaurant into the wooden box with the last of him in it.

I wrote how he told me I was the smartest one. That my singing voice was like butter. How he bragged about me. I only brag when I’m drunk. But he was often drunk. And he bragged.

Long after he and bartender Jen broke up, I met his wife, Angela, for the first time as we stood over his dead body next to the open casket. I had not made it to their wedding. I was poor and in Florida and Jon understood. At the funeral Angela was pregnant again and holding their two-year-old son Ethan. We did not get coffee. I am certain this is my fault. But we already knew each other; Jon had made sure of that. I read her the note before I put it in the cold hand of the empty vessel we pretended was him.

He was silent. Not being himself. Never quiet unless he was passed out. But I saw his smirk through that painted fake mouth and I ordered a vodka soda at the shitty mall to write to him.

How else was I supposed to meet him somewhere?

Jon died on my 33<sup>rd</sup> birthday, September 19, 2016. He had been drinking with a buddy of his and fell off an ATV on the back roads of Isabella County. The ATV bounced before landing on top of him and crushing his spine.

*Dick move, Jon. Selfish, really.*

He'd laugh so hard at the irony of me calling him selfish because he died and ruined my birthday.

At least he'd called to wish me a happy birthday that day. I don't remember in any real way because I was drinking too, but I doubt I picked up. Selfish. Suffice to say, my birthdays to follow include the same amount of drinking as always, but a lot more sobbing and more minor bodily injuries. But Jon always did have a way of staying with me no matter where either of us was. He had a knack for forging strange legacies.

Jon was hired as an engineer fresh out of graduation. He worked for big firms that ran oilrigs in North Dakota. He said the hookers and the people who work at McDonalds make the

same wage there, and it's better than the wage I make in Michigan as an instructor at a university. By a lot. Jon was good at reminding me of the futility of work in the public sector, of dismantling my idealism and replacing it, if only temporarily, with a complete lack of "give a shit."

Once he came home with a broken leg after working "three weeks on, two weeks off" in North Dakota. He'd been pulled from the passenger seat by the throat by someone he'd insulted and ended up in the backseat with his foot caught in the steering wheel. In one tiny alteration of that scene, everyone in the truck could have been killed.

Yet somehow he was invited back to keep starting shit. No one could do what he did. He'd invented engineering software for the oilrigs, a system for measurement I could never truly understand or quite believe in, because I wondered if he was telling tall tales in an attempt to impress and entertain me. But he actually did it. It took me a long time to realize that.

After getting my own diagnosis of mental illness (Jon's father was a psychologist so the kid always had plenty diagnoses to work with), after moving away to Florida, after losing touch, once he was gone forever, I realized what I hadn't done.

I never told him I was proud of him until I stood and spoke at his funeral. I never told him he did his very best.

It's so easy to assume people are untouchable, invincible, or immortal.

Then in a flash, your powerful heroes, villains—your complex characters—they fall to illness, come crashing down in death.

## CHAPTER IV

### Don't Kill Yourself

“Okay, this has to happen,” I tell myself for the 19<sup>th</sup> time this week as I hover over the phone at my kitchen table, looking out the window at the snow again, dazing off as if to prevent myself from paying attention. I’d successfully ignored the nagging voice in my head until now.

I pick up the phone and call my family physician, Dr. Gall. Joan, the receptionist, answers.

“Dr. Gall’s office, can I help you?”

“Yes,” I pause, stammering. “I need to make an appointment.”

“Sure, what is this regarding?” I try to take a deep breath to squelch the crying as Joan chirps back at me. It doesn’t work.

“I...I’ve just been having a really hard time lately, uhm, getting through the day.” My voice cracks. The tears are spilling now and I feel stupid. I try to catch my breath, which comes through me in short, urgent bursts. I kick myself under the table, using one foot to inflict pain on the other. I consider throwing the phone down. Instead, I shake it violently toward the sky as Joan chatters on about available times and days.

She continues. I bring the phone back to my enflamed earlobe. “How about tomorrow at 3:30?”

“Okay, we’ll see you then.”

The table in the exam room in Dr. Gall's office comes up to my chest. Daunted, I slosh my body up against it. I grasp for the edges and hoist myself up. The vinyl makes loud popping sounds as my nearly dead weight collides with it. The paper crinkles beneath me as I adjust. The noise is deafening. I freeze, wishing it away. "Whoosh," the cushion sighs in response as it compresses beneath me. I vow to stay still until the doctor arrives. I can't handle the noise of the paper I'm sitting on; it gives me chills, painful chills. My skin hurts. "Just freeze," I tell myself. I'm like a lab rat playing dead, uncomfortable and on display, afraid of what they will do to me.

"You need help," I remind myself, trying to silence the stubborn voice inside my head urging me to try to survive this on my own. I wait on the table to be examined and tagged, my troubles noted in my chart. The chart sits on the counter before me in a bland manila folder. A bright red tag denotes the first three letters of my last name, *my criminal medical record*. My thoughts are interrupted by two quick knocks on the door. It swings open. Even if I wasn't ready, here she comes. Why bother knocking?

"Hiiiiiii, Erin!"

"Hi Dr. Gall." She's always so smiley and sweet; she talks to me like I'm a little kid who's afraid to be immunized. I half expect her to promise me a sticker or a lollipop. "How are you doing?" she says, her voice lower now, her usual gushing turned to gentle concern. She knows why I'm here.

"Not so good..." I begin. Tears well up in my grey-blue eyes. I try to keep control.

Her face wrinkles up with so much concern that her lip starts to curl, making her expression border something else, something like contempt or disgust. I want her face to stop looking at me like that, so I keep talking.

"I take care of my dad, ever since he had a stroke five years ago," I say timidly.

“That has to be difficult,” she replies. As soon as she says the word difficult, I start to cry. Support of any kind can cause open sobbing at any time, simply because it suddenly feels like it’s okay to be sad.

“It’s been really difficult lately. His dog, Sky, has been sick and I’ve been going to his apartment three times a day to give him medicine. My dad doesn’t like me coming over so often. He doesn’t want me taking care of him and the dog. He wants to be independent, but he can’t be!” I say this defensively, though nobody is challenging me, and then continue to explain. “He doesn’t want me there, and I don’t like going. Every time I make the trip, I get so nervous I feel like I can’t catch my breath. His health is getting so bad that I’m terrified I’ll find him dead.” I force the words out through the sobbing in little chunks.

Dr. Gall cocks her head and starts back in on me with the sticker and lollipop voice. “Sometimes when things get really hard, like what you’re doing for your dad, people need a little help getting through it.” She pauses. “Have you been having suicidal thoughts?”

“Yes...” I admit reluctantly.

“How often?” she asks. I pause to think about my response.

“Just, sometimes...” I say, lying. I can’t tell her anything else. What if she institutionalizes me? Who will help my dad then?

“Well Erin, that’s not something that can go untreated. There are medications that work wonders to eliminate suicidal ideation.” After she parrots a lot of jargon-filled medical talk at me and I refuse her offer of Prozac, I walk out with prescriptions for Wellbutrin XL and Xanax, but with no stickers or lollipops. I’m all grown up now.

I feel more depressed than ever. But I'll get through the next year, here in Michigan. I will adjunct at Central Michigan University. I will take the GRE. I will move forward. To South Florida? I remember talking to Art Bochner and Carolyn Ellis.

They seemed to like me.

### **Stay in School, Forever**

In 2011, one year after my graduation from Central Michigan, I attend the 97<sup>th</sup> annual National Communication Association Convention in New Orleans. Upon learning about a session called "Scholars' Office Hours," I decide to find Drs. Art Bochner and Carolyn Ellis and talk to them. The session invites students to meet and speak with the biggest names in the discipline, and, nervously, I go and wait my turn, finding Art Bochner's table first.

When he stands up from the table to shake my hand I think, "holy shit he is tall." He sits back down and I sit too, facing him, knees knocking, pushing my red-rimmed glasses up the bridge of my nose. His hair is wild, whitish, and dark like Einstein's, his smile broad and tall, like him.

"I read 'Mucking Around Looking for Truth' and love it," I say. "I didn't know you could do research like that."

Art Bochner chuckles. "A lot of people don't," he says in a gentle tone.

"I take care of my dad, so the story really got to me, and now I know that's what I want to do," I tell him, twisting my frayed blonde hair and looking down at my bird printed dress.

"I'm just nervous about the GRE. I'm really bad at math and I know PhD programs look at that."

Again he lets out a little laugh. "Not our program," he says with a grin. "If we get an application with anything quantitative in it, we reject it. You know, I should introduce you to Carolyn Ellis. Come with me."



*Did I do or say something right?*

He stands to walk me over to Carolyn Ellis' table. "This is Erin," he tells me with a grin. "You two should talk. She's a caregiver for her dad and is thinking about a PhD at USF." Carolyn wears a flowing, bohemian blouse, her face framed by wire-rimmed glasses and curly hair.

I tell her my story, welling up with tears.

"Oh honey," she says, passing me a box of tissue.

"I'm sorry," I blubber, taking one in my hand.

"It's okay. That's what they're there for," she says.

I am at NCA this year looking for inspiration to move forward in academia, like Dorothy looking for Oz, only without all the magic and cool shit. And even though they didn't do any magic tricks for me, Art Bochner and Carolyn Ellis were forthcoming with their humanity, their experiences and flaws—unlike Oz, who turned out to be no wizard at all. And so I tell Carolyn about my dad, about my friends and mentors in Michigan, about my thesis.

"It sounds like you have a really great support network there," Dr. Ellis says. "Would you be okay in a new place, would you be okay if you left them?"

I think about what she asked me long after we say our goodbyes. I am protected at CMU, planted in Michigan, but maybe I've stopped growing. *Is it time to move on? Will I survive an uprooting of all I know? Will I be okay if I leave my support system?*

It doesn't take me long to realize I will only be okay if I do.

## **Moving**

I apply to USF in 2012. I summon the courage to take the GRE, which is basically a four-hour long torture session that, if endured at all, is something to commend. Happily, my verbal

score is in the 77<sup>th</sup> percentile—which isn't simply the 77<sup>th</sup> percentile (which would be like a C+), but the 77<sup>th</sup> percentile in a group of people that all suffered through that horrible test of mental fortitude and intellectual character just so they could continue their studies and keep learning (so it's really like an A-?). My math score is abysmal (7<sup>th</sup> percentile, embarrassing, though to be fair I flew through that section clicking answers randomly: my only defense), and during the math portion of the test I am thinking of what Art Bochner said when I met him at NCA: *If we get an application with anything quantitative in it, we reject it.*

It's my GRE mantra.

In the end, I make it through that damn test and apply to three schools, but only one of the "Statements of Purpose" I write for any of them starts with a personal story:

*The year I began the master's program at Central Michigan University my father suffered a debilitating stroke. The stroke robbed him of his working memory, his strength, and his job. He had no health insurance or place to live. With \$2000 from his previous employer and a heavy heart, I became more than a graduate student and more than a daughter; I became a caregiver. I am determinedly chipping away at the mountains that lie before me. This process, albeit arduous, has led me to a path of study that is both meaningful and rewarding.*

*I was first introduced to narrative as methodology, and to University of South Florida, as a graduate student at CMU. Narrative inquiry excites me because I am able to feel with the stories that are told. Narrative opens a doorway to the life experiences of others, and I find this extraordinarily valuable in stimulating self-reflection. For me, the humanistic qualities of narrative provide for a wonderfully atypical methodology that gracefully departs from the traditional paradigm of social science. My continuing*

*investigation of the University of South Florida, the communication faculty, and the work you produce has revealed your investment in alternative avenues of communication inquiry. The opportunities to develop my skill in narrative work would extend the research skills I developed in my Master's program.*

*I want my research efforts to reach caregivers. I have been wondering how exactly I am to accomplish this when, from the "ivory tower" of academe, caregivers seem so far away. Reflections concerning my experiences as both a caregiver and researcher have made me uncertain of my ability to provide other caregivers with viable solutions when I often find myself in the midst of problems that seem unsolvable.*

*I believe that my future research will be most productive in narrative form. This method best reflects my interests and abilities and has the utility I have been searching for. My own experiences as a caregiver are distinctive because of my relatively young age and my intersecting personal and professional roles. It is my understanding that narrative research is an expose of the subjective experiences inherent in the human condition. I find that people are easily engaged by and respond passionately to these kinds of experiences; they are powerful tools for teaching theory to undergraduates. Therefore, I would like to continue my work as a caregiver and scholar by authoring a personal narrative. An autoethnography will allow for the depth of self-reflexivity that I desire and make my work more accessible to students, colleagues, and caregivers alike.*

*My time spent at Central Michigan University has been an enlightening period of both self-discovery and growth. I have grown as an academic and a teacher. I have discovered my scholarly voice. I want to use that voice to sing and shout from rooftops. If*

*I am afforded the opportunity to pursue my PhD at University of South Florida, I know I will be heard and not hushed.*

Art Bochner calls me on February 17, 2013, at 5 p.m. to confirm my commitment to the program. I think I am still being interviewed. I call it “what may be the most important phone call of my life.”

When I hang up the phone with Art Bochner I jump up and down in my living room. It had gone swimmingly! I can feel it! I’m so lucky to be surrounded with love from my friends and mentors, and for the first in a long time, I feel like there’s hope for me.

On February 27, 2013—ten days later (felt more like a decade)—The Graduate Director at USF, Dr. Jane Jorgenson, called to tell me I had been accepted to USF with a full teaching assistantship. I had to announce it to the world, so I opened my Facebook page, wrote “I GOT ACCEPTED TO USF \*TEARS OF JOY\* I CAN ONLY TYPE IN CAPS & MY HEART MIGHT EXPLODE!!!” and clicked “Post.”

I was sad to leave CMU—that was where I had found my people, my passion. But it was time for a move—time to forge an old self into someone new. On the first day of March, I sat in my cold bedroom thinking about the not-so-glamorous Spring Break I would spend in freezing cold Michigan. One year from now I’ll be doing that very same thing, but at least I’ll be warm.

### **The Storage Closet**

It’s one in the morning and the apartment is dark and empty, built brand new with sterile, white walls, the old folk projects; income-based living for Tampa’s seniors, ages 55 and up. I approach my dad’s bedroom door cautiously and peer inside. Teetering at the threshold, I listen for breath until a deep snore erupts from within.

Still alive.

I creep backward one foot at a time and open the closet door. A twin-sized air mattress is wedged between the wall and air conditioner: my only place to live and sleep. I collapse into it and wrestle with my phone for its flashlight, shining it into my purse to find the one-hitter pipe that stares back at me between my Nancy Drew wallet and King Parliament Lights, my closest friends here in Florida.

I untangle a stick carved of zebrawood from my up-do. My messy curls tumble down and cloak my face. I pull the pipe from the depths and reach back in for a blue lighter, sliding the wooden lid of the one hitter open and lighting the metal cigarette shaped pipe, inhaling the sharp smoke and holding it tight.

Since the stroke my dad lost his sense of smell.

*I should still smoke outside. What if a fire alarm goes off? I should go out on the balcony, but someone else might catch a whiff and I'd be busted. We'd be busted: no smoking permitted on the premises. If he gets evicted, we're both homeless.*

The balcony is five floors high. I could just jump—end it all. But then, knowing my luck, I'd probably survive and just wind up with a spinal cord injury.

The closet is better, the air mattress, the air conditioner, the glow of my iPhone.

I guess. This morning was pretty bad. We got to Tampa after a 24-hour drive from Michigan with no sleep, and my dad promptly accosted me.

“Why don't you just get out of here?” he'd shouted, his face red, his left eye blue and droopy. “Get out of here. Get out of my apartment!”

“But you need to sleep, dad! You look bad. It's scaring me. Please, just let me blow up the air mattress.” I'd gotten two twin air mattresses to sleep on, one for him, one for me, until I could salvage some cheap furniture.

He grumbled and glared at me with contempt. I dragged his air mattress to him where he leaned against the wall of the empty living room, his posture looking involuntary.

“I’m just going to get you a pillow,” I said.

“I don’t know what’s so hard to understand. I don’t want anything from you. Get out of here! Hit the bricks! Don’t come back.”

His face got redder. A warning sign?

*He’ll have another stroke because of me.*

So I stomped out, letting the door slam before tears hit my ruddy cheeks. Now I’m back after I literally did hit “The Bricks,” a bar in Ybor City where I sat drinking alone, talking to no one. I wanted him to be asleep when I got back.

I wanted to be able to sleep when I got here.

I sit up on the air mattress. The concentration of weight puts my body in touch with the hard floor as my eyes adjust to the darkness. I inhale another puff of smoke and choke on it, shoving my face into the pillow to muffle my cough.

He told me to get out so I did—after I got him his pillow and went to the bar, like he used to, like he would if he could. The air conditioner roars in my ear. Beer, weed, white noise and I’ll sleep in his black closet forever. I’ll sleep when he gets up at five in the morning. I’ll sleep when he watches TV at one in the afternoon.

I’ll sleep all day.

## **Broken Brain**

It’s 10 a.m. and I’m in bed in my apartment, the only one I could afford a deposit on. I have a stranger for a roommate, but that beats my dad’s closet. My pill reminder goes off, and the words “don’t cry, be happy” flash across my phone screen as they do each morning, urging

me to take the Wellbutrin I've been prescribed. I know it's affecting my brain chemistry. If I forget to take it, I sink into a dark place a few days later and lose control of my thoughts. Since the Wellbutrin began working, thoughts of suicide have nearly vanished. I swallow the pill, have a cup of coffee, and get down to this business of graduate school.

It is my first semester at the University of South Florida. I look at the readings that are due Monday for my "Social Construction" class taught by Dr. Art Bochner. I'm immediately drawn to "The myth of mental illness," an article by Thomas Szasz (1960). Szasz suggests that mental illness is a psychosocial phenomenon rendered by judgment. "Illness, whether physical or mental, implies deviation from some clearly defined norm" (p. 114). Norm deviations are fodder for moral judgment. As a result, norm violations typically lead to social marginalization, stigma, and maltreatment (Goffman, 1963).

"While treatment has improved considerably over the years... it is doubtful that people really regard the mentally ill in the same way that they view the physically ill" (Rosenhan, 1973, p. 130). Although people diagnosed with mental illnesses are responded to differently than people who are physically ill, mental illness is commonly treated as a physical ailment, a malfunctioning of the chemistry of the brain, which is weird because no one knows where mental illness is located, exactly. You can observe a broken arm and say, "yep, it's painful and it doesn't bend or rotate," but what do you say about a "broken" brain? The psychological pain, the anger, the paranoia, the anxiety, the inability to rotate or move your brain in ways that help you along socially is a condition that is inherently invisible, so it's easy to say a person is just bad, faulty, and unworthy. Maybe all of us who are considered mentally ill should quit taking the drugs and wrap bandages around our heads instead so people will ask "Oh my god what happened?"

The truth is if it doesn't involve a funny story about falling down a flight of stairs, they probably don't really want to know.

Our accepted medical narratives of mental illness and subsequent medical treatment suggest that mental illness occurs inside the body, in the brain. Mental illnesses like depression and anxiety are usually diagnosed from a classic checklist of symptoms: *Do you feel guilty, worthless or, helpless? Have you experienced a change in eating habits, and/or weight changes? Do you have problems concentrating, remembering, or making decisions? Are you having problems sleeping? Are you easily angered or irritable? Are you spending most of your time alone?* (Beck, 1961).

The only marker of the illness, however, is the diagnosis, crudely crafted from doctors' inferences from the checklists. What we know about the brain, and the effects psychiatric medications have on them, is limited (Whittaker, 2010). Hacking (1999) points to the interaction between the brain and body. According to Hacking, there are two conflicting schools of thought about mental illness. The more popular one claims that it's an embodied, biochemical disturbance. The other one views madness as something that is socially constructed and brought to life in language, imagination, and socialization. Hacking argues that there is a missing link here that the biochemical claims affect the social experience—the two are interactive. The symptoms of depression, as checked off on a list to label a patient depressed, are perpetuated by the diagnosis, which essentially says to the patient, “you are too sad, something is wrong with your brain.”

When I was diagnosed with depression three years ago, the interaction between Dr. Gall and I focused on a troubled relationship, not a malfunctioning brain (Szasz, 1960), yet we decided on a biochemical diagnosis and treatment as per the convention. When the treatment



worked, it confirmed the assumption that there must be a biochemical cause to my struggle with sadness. Protected by the cloak of doctor-patient confidentiality, Dr. Gall and I determined what kind of person I'd become and what kind of person I could be in the future (Hacking, 1999). To make sense of the diagnosis and treatment of my depression, Dr. Gall and I negotiated our own private little world, the way Berger and Kellner (1964) describe the experience of building a joint reality with a relationship partner. Together, we co-constructed a medical solution to an interpersonal problem, a problem that exists in the mind and body on a loop (Hacking, 1999), and is both made up and completely real at the same time.

If our solution had really worked, everything would be fine.

Still, I can't help but question our tacit agreement. By taking medication, I was agreeing that sadness and fear are "symptoms" of disease, when, deep down, I know that they're natural parts of the human experience. By treating these "symptoms," I must be submitting to the idea that my heartbreak is disturbing my brain, or some such thing.

Do sadness and fear and stress need to be treated as mental illness to become natural? And still, if there are so many of us diagnosed with myriad versions of this, why does it seem nobody wants to help in any way that goes beyond a topical solution like Wellbutrin?

Rub one of these on your frontal lobe and call us in the morning!"

Although what the readings for class by both Szasz and Hacking suggest make perfect sense, when I return from lofty theory to the places I live and work, to the difficulty of functioning with overwhelming fear and sadness, taking medication makes sense too. And if I'm to be practical, if it works, I should do it.

I stop reading to look at my phone and realize I have two consecutive missed calls from my dad, complete with voicemail messages. I stare blankly at the screen and press play as if the

fuzzy little triangle might explode from the warmth of my finger. Through the crackling, distant speaker of his ancient cell phone, I hear the voice of an alien who has landed on a planet that does not support his life form. I freeze in fear.

“Hi Erin, this is your dad. My feet are swelling. They’re too big and I can’t put on my shoes. I don’t know what’s going on but I thought you should know. Okay. Bye.”

My heart is pounding out of my chest, and each erratic series of beats seems to shout, “Emergency! Emergency! Emergency!” I press the play button on the second message bravely.

“Erin, this is your dad. My foot seems to be a little bit better. Maybe it’s the dog licking it. I don’t know but I’ll see you later. Don’t worry about me.”

I call him back immediately because I am worried, so worried that my eye is twitching hard, like a small insect has burrowed its way inside and is struggling to get out.

Maybe he needs to go to the ER.

He answers the phone after five rings, each of which seem to take an hour.

“It’s okay Erin, don’t worry, my feet are swollen but it’s not too bad, it will probably go away. I really don’t need to go to the doctor. Really, I feel fine.” His vocal pitch diminishes at the end of each sentence, as if he is an exasperated racecar, clunking its way into the pit.

“Well, maybe we should visit a doctor. We need to get your medicine refilled anyway, and it would just be convenient to ask about the swelling.” I calmly reply, but in my mind I’m racing around like a pit-crew mechanic. “I’ll make an appointment for tomorrow in the morning and call you as soon as I have a time set up.”

“Okay...” he says, his voice laced with resignation.

“I love you!” I rush this in before we hang up, and it comes out forcefully, as if I can somehow save myself from feelings of guilt and infinite loss with these three words.

## **If You Ever Need to Get Tested**

Last night I set my alarm to go off at 8 a.m. I stayed up past 1 a.m. worrying and when it goes off I don't want to move. My dad always says, "don't worry about me," but when he says not to worry, I worry more. I recall his wisdom on one of our trips to the doctor: "Don't worry, Erin. It's just life," he said, his voice buoyant and sincere.

I drag one arm through the sheets. I'm dead weight. I hit snooze. Ten minutes later the alarm rings again; I hit snooze again. This cycle repeats until after 9 a.m., when I finally convince myself to get my ass up. Then, I notice I have a missed call that came at 5:19 a.m.

It was from my dad.

My heart races out of its resting place so quickly it palpitates. I gasp for air, and then hold my breath as I press play on the voicemail he left—20 seconds later, relief. He tells me his feet aren't that bad and to go ahead and sleep in. I collapse into the pillow. It feels good, nurturing.

After lying there in vain for 20 minutes, I get up and start looking for a free clinic. First, I have to find the list of clinics the social worker gave me. I drag myself across the room to my desk to sift through the piles of paperwork that cover every inch of it. I finally find the list; it's on the bottom of the only untouched pile of shit.

I make the first call and get a friendly guy named Rob on the phone. Rob asks me for information: dad's social security number, date of birth, etc. I spell his name multiple times. No one has ever heard of the name Klen, so helping anyone to get this right is always a blast. After deflecting Rob's attempts at "Ken," "Glen," and "Clem," I'm within minutes of a scheduled appointment with Klen. Then, Rob asks me for insurance information. Klen has none at the moment.

Rob tells me the doctor won't see patients without insurance. I thank him, hang up, and return to the list of clinics I got from the social worker. After a few more phone calls like the first, I find a free clinic. I get my dad an appointment for 2:15 p.m. Hopefully, the visit to the doctor will put my mind at ease.

My white Toyota rental car was towed from my apartment complex a day ago because my black Mercury Milan was stolen, and the rental doesn't have the requisite sticker. I have to find a ride to the impound lot to retrieve *the rental car*. Ironic that it was towed from the “reserved” carport space I pay extra for to shield my now stolen black car from Tampa's blistering summer sun.

I get to the rental and think I have just enough time to stop at a coffee shop, eat something, get coffee, and start reading for class. I turn first to *Manufacturing Depression* (2010), by Gary Greenberg, coming to rest on the following paragraph:

The arbitrary nature of fortune, the near certainty that unbidden catastrophe will visit each of our lives, the inevitability of mortality, a nature that is more generous with pain than with pleasure, in short, all the stacked-deck calculus of human existence—these are challenges to optimism if not outright invitations to pessimism, and that's before we even consider what a hash we've made of both civilization and nature (p. 34).

*Seriously this Greenberg guy gets it. Could I ever be an optimist?* I stare off into the corner for a while. Wellbutrin certainly doesn't make me an optimist. It's not a miracle drug. Wellbutrin and Xanax are more like Febreze for the brain, drugs that disguise the odor of sadness, and encase the scent of fear in feel-good bubbles.

My attempt to read more is thwarted by three young undergraduate women who decide to sit near me and laugh like hyenas at a deafening volume—a volume I can't seem to drown out,

even though I'm blasting classical music directly into my ear. I try not to be mad at the loud undergrads. Deep down I know they're just like I was, in another time and place.

I decide to leave to get my dad for his doctor's appointment, after getting no more than a few chapters finished at my PhD station. I think back to the last words I read from Greenberg as I pack up my things. Greenberg makes the case that pessimism, or "a fixed tragic view of the human condition," is often a criterion on the depression checklist that doctors use to diagnose patients (p. 33).

The words "depression" and "pessimism" carry with them different connotations. "Pessimism" denotes a way of looking at the world, while "depression" suggests a way of being, or, in academic speak, an "ontology" of internal deficiency, ontology meaning an assumption about the nature of being. Gergen (1997) warns that our application of deficit language to mental states, like the application of the term "depression," to a "fixed, tragic view of the human condition," creates a kind of person (Hacking, 1999), one who is labeled mentally ill, which is quite different from calling someone a pessimist.

Will I, as Gergen puts it, "face a potential lifetime of self-doubt" (p. 151) because I'm labeled depressed? Has the deficit discourse of our culture induced me into experiencing myself as depressed? Could this mean that I have unwittingly learned to blame myself for feeling sad? Hacking (1999) calls this interactive cycle of blame a "feedback loop," because each form of blame informs the other. I walk to the rental car, remembering how the police blamed me when my car was stolen. Absurd. That wasn't my fault, was it?

I get in the rental to drive downtown to my dad's, and call to say I'm on my way. When I reach the towering senior citizen apartment complex, I park in the garage and call him again to

have him come downstairs. He toddles into the garage and walks right past me. I roll down the window and yell to him.

“Dad!”

He turns his head toward the opposite side of the garage, dazed. He’s hardly 15 feet away. Finally, he sees me and gets into the car. He’s short of breath. His large belly takes up most of my peripheral vision. I back out of the garage.

On the way to the clinic, I immediately make a wrong turn. As I try to find my way, he’s talking to me about a woman. “I had a date with a woman. She didn't show up. I went, and she didn't show up. We were supposed to go to a bridge downtown and see everything from above,” he says.

I wonder if this is true. Of course it’s possible, but he’s not exactly the social type. He’ll say, “I don’t mind all the women talking to each other, you know, but I don’t want to listen to them. It’s never interesting.” Comments like these make the interaction he’s described hard to picture, but, maybe? Perhaps he missed her or forgot the time or place they planned to meet. His memory is spotty since the stroke. I nod along and try to reassure him.

“Maybe one of you screwed up the time and place and you missed one another,” I suggest lightly. His face scrunches up; his gaze, soft, rests on some distant nothingness.

Tensing up, I miss my turn. I finally figure out where we’re going and get on the freeway. When I was a kid, our car rides were characterized by a great deal of deep conversation that often provided me with guidance and insight. Now he’s talking to me about his pension, and about being with a woman.

“What if I were to find a woman and go with her? If I died, could I give her my pension?”

“Well,” I reply, planning my response. “You would probably need to marry her for that.” He immediately backs away from the idea, saying, “That might be one thing when you're a young man. I didn't mind your mother, it seemed like the right thing to do.” He goes on, a now familiar string of words and phrases about my mom and about me entering his life unexpectedly.

I tune him out. Not long after he had the stroke, he told me their pregnancy with me was “an accident.” I was provided this new information just after I moved him to Mount Pleasant and began graduate studies and was making plans to secure a future for my father and me, and this news about my birth shook the ground of my past. I had to revise my biography—the part where I believed my existence was a plan. Funny, a love child is someone born from unmarried parents, usually out of passion, implying that children from marriage are not made from love? So what are they made from? Sugar and spice and impossible expectations?

Perhaps what I believed before, my parents' story of trying and trying until the miracle of me happened was their idiosyncratic way of narrating my birth, their way of turning a difficult situation into “a blessing.” One day, I asked my mom what happened over breakfast at a café we went to after church when I visited Clinton Township and she verified what my dad said. “You were a miracle, really” she said. “I'd been told I could never have kids. No, your dad and I didn't plan it, but that doesn't mean you weren't a miracle. To me, you were the ultimate gift.”

What seems like an hour of uncomfortable conversation later, we find “the clinic.” Parking is on the lawn. The place looks like a warehouse or storage facility. When we walk in, I see that it is indeed a warehouse. Cement floors, grey walls, a giant, open garage door, and a large tinted glass window. It looks like there is a silhouette of a person behind the window looking out at us.

My dad looks around. Even I feel dazed as I take in our surroundings. “This doesn't look like a doctor's office,” he says. I feel the fear in his voice and a pang of guilt cuts at my gut. He’s probably already confused, and here I am bringing him to a “clinic” that gives the appearance of a creepy warehouse—a bad trip. The woman behind the glass beckons me in.

“Is this the clinic?” I ask. I see a few chairs and a fax machine nearby, I’m in what looks like a strange secret office. She shakes her head no, and says, in an accent I can’t name but enjoy hearing, “The clinic? It’s across the street.” She sees the blank look on my face and walks us outside. Across the street is a long line of storage units. “It's there,” she says, pointing to one of the garage door type units. I squint in the sun and see a regular white door next to the garage, thank her, and start walking in that direction.

My dad waffles around behind me reluctantly. A big and tall black man with long braids draped over his shoulders emerges from the regular white door, and I ask him, “Is that the clinic?”

He looks at us suspiciously. “Are you looking to get tested?” he asks.

Confused, I take a moment to think, then reply. “No, I'm just here to take my dad to the doctor.”

Now *he* looks confused. “This is an AIDS testing site. We test for AIDS, chlamydia, and gonorrhea.”

I need a few seconds now.

“Oh...” I mutter, trailing off as my brain works to make sense of what’s happening.

“What were you needing to do?” he asks, seeming concerned. “I just need to get him to a doctor. I thought this was a clinic that takes patients without insurance,” I say, gesturing toward



my dad, who is looking off into another direction and teetering a bit from about ten feet away. “He needs meds refilled and his feet are swelling,” I explain.

“We don’t do that here, but come inside and I’ll get you the number of a clinic that takes patients with no insurance,” he assures me, reading off a number as I type it into my phone. I thank him and head outside. Just before I touch the door, he says, “Hey, if you ever need to get tested, come on back.” I nod and walk out, thanking him once more.

I call out to my dad who has now wandered even further from the building. “Let’s go!” I shout so he can hear me. He gets closer. “Well, apparently they only do AIDS and STD tests here, and I don’t think you need that!” I say this in a half-joking manner, although it’s no joking matter, and we get back in the car. As I start the drive back to his apartment, he says, “It’s just nice to be out driving around with you anyway.” I smile warmly.

A few minutes later, we’re back on the highway, and he’s talking about a cruise he wants to go on. Two days ago he handed me a pamphlet and said, “I got this and I thought maybe I could spend some money to go on this cruise ship, just for a month.” I looked at the pamphlet and immediately noticed it was for a free-running bus for elderly folks. Like a pro, I didn’t flinch. Instead of listing all the reasons that this would never work, I told him, in a chirpy tone, “Sure, we can check it out. I’ll look into it.”

As he’s talking and I’m trying to pay attention, I realize I’m about to pass yet another exit that would get me going back in the right direction, as I’ve already gotten on the wrong side of the freeway. As I get over, I almost sideswipe a car that’s going 90. Again my heart starts thumping out of my chest and my eye twitches, but I try to appear calm.

By the time we make it to his apartment, I’m feeling tense and itching to get away, but I get out of the car instead to go upstairs so I can interpret the notice he got about his dog, Sky.

He's always worried about what people think of the dog. Sky's just a little, unassuming, quiet cocker spaniel, but some people don't like him, I guess. I often wonder if my dad uses Sky therapeutically, to talk about himself—as if the dog is a medium through which he can covertly talk about his fears, bad habits, and insecurities. The dog has a persistent cough. “That’s just a part of his personality,” my dad says.

As we walk through the parking garage, I notice that my dad’s back is covered in needles of some kind, from a plant. Lots of them dot the back of his shirt. I start picking them off one at a time and notice a big grass stain on his back, evidence that he must have fallen down earlier with the dog. A familiar knot returns to my stomach.

We walk upstairs, greet Sky, and I give dad the meds he should have taken several hours ago. I go to the bathroom, urgently, and avoid the feces-smearred seat. *I’ll clean it later.* I read the mail when I come out. The notice informs us that service dogs are allowed in the lobby.

“It's not about Sky,” I assure him.

I also find an assistance letter from the local Commission on Aging that my dad must sign and bring back. There is no envelope for return mail, so I have him sign and take it with me. It looks like there are no bills to pay, save one late notice I already took care of yesterday online. “I’d better go and read my work for class,” I tell him. He takes the dog and joins me on the trek through the halls and to the elevator. I notice his shoe is untied.

“Stop for a second,” I say, kneeling down to tie his shoe. While there, I notice the swelling in his ankles. I poke the skin; it’s hard, taut. I pull his sock back and see the deep imprint from its stranglehold on his ankle. His foot looks like a latex glove, blown up and tied off to amuse bored children in doctors’ offices.

Calmly, I say, “Oh yeah, I see the swelling,” and stand up.

“I feel fine,” he says.

We walk together to my car in the parking garage. We hug each other hard, and for a long time.

“I love you, Dad.”

“I love you too, Erin.”

Every time I leave him I'm afraid I'm saying goodbye for the last time. I get in the car and pull away. As I drive by, he raises his arm in the air briefly to salute me, without looking in my direction. I beep the horn lightly and turn out of the garage. As soon as I get to the corner, I start to cry.

I reach into the center console and feel around for a familiar shape, a cylinder. My hand rests upon a misshapen piece of hard plastic. I move my fingers down its side until I reach the smooth, glossy finish I'm searching for. I pull out the orange, transparent bottle. It's the Wellbutrin. My hand ventures back to try again. Success. The Xanax.

### **The Free Clinic**

Five fearful, tearful, Xanax-propelled days go by, like boulders in quicksand. Each phone call to the free clinic weighs a ton. The clinic is overwhelmed with patients in need, but I assume this is true of all free clinics.

I call relentlessly, getting the clinic's voicemail over and over. I build strength in numbers; after 16 phone calls, and even more waits on hold, a receptionist answers. I speak to her carefully, respectfully, as if I have only one chance to get medical care for my dad and this is it. She doesn't tell me her name. I don't ask.

“Walk-in and wait,” the receptionist mandates. “Tell the staff that your dad needs to be seen for an emergency medication refill when y'all get here.”

I'm just glad someone's answered the phone.

An hour later, my dad and I walk into the clinic. I inhale the pungent scent of urine as it infiltrates my nostrils. My breath shrinks back in horror. The smell of hospital trails in just behind urine, a lovely combination of latex and vomit. I revert to an old tick; I twist my hair anxiously, tearing at the ends until they look like little shreds of straw.

My thoughts drift from the panic room to a creative corner of my brain. I combat bad memories of hospital visits with my imagination, and design a Bath & Body Works candle inspired by the scents of the clinic. I'll call it "Free Clinic." Its description will read: "Powerful notes of urine mingle with soft latex, highlighting subtle undertones of vomit."

I swallow hard and breathe from my mouth as I walk up to the front desk. My dad sits down. The woman at the desk is not friendly. I have to tell her twice that his feet are swollen badly and getting worse. She has a grumpy disposition and bad fake eyelashes. I give her my credit card for the \$20 sliding scale fee. She tells me to take a seat and that she will call me back up to the desk once she runs the card, so I sit down next to my dad. He is sitting by the windows, in the back corner. The windows of the clinic are tinted. From outside the place looks closed, and from inside the weather looks gloomy, even though it's a sunny day. I glance around the room. A little boy is curled up in one of the boxy, vinyl chairs, his knees at his chest in an upright fetal position.

"I'm out of food," my dad says.

"But I just got you food," I reply in protest. I did, I got him groceries on Friday, over \$100 worth, gone in a few days. I know he can't remember how much he's eaten. I know it's not his fault. I notice a man looking at me. I'm not sure, but his facial expression seems sympathetic. He looks me right in the eye, and I turn away, afraid I might burst into tears.

“Erwin! Erwin!”

One of the receptionists is calling for somebody. The woman calling for Erwin walks up to the receptionist who took my card. I have a feeling she’s calling for me. *I’m Erwin*. Fake Eyelashes tells the other receptionist it’s my card, pointing at me from the counter. The other receptionist erupts with laughter, her whole body shaking with delight. I join her. Erwin has a good sense of humor.

“Here you go little mama,” she says. She’s much friendlier and way more fun than Fake Eyelashes. I sit back down. The room is full now, and the pharmacy area is really busy. Finally, a young man calls my dad back to be seen, “Klen, Klen S.?” Funny, he gets my dad’s name right. No one ever does. He weighs my dad at 175 pounds.

Recently, I discovered an organic health food store in town called “Rollin’ Oats” and have only been buying him health food since, expensive health food, hoping it will both help him lose weight and magically cure him of the swelling.

We go into the exam room. There are two people ahead of us. I get out the book I’m reading. I feel sorry for my dad in his boredom, but whenever he talks, I only half listen and mumble a reply. I need to read for class. Graduate school is like running a relay race; only I’m stuck in that agonizing moment just before the handoff—reaching so hard that I’m about to drop the baton and trip over my own feet. I need to read while I have the chance, so I open the book to the page I’ve marked.

*They fuck you up your mum and dad.*

*They may not mean to but they do.*

I recognize the famous Philip Larkin poem in Greenberg's sixth chapter immediately. I look up at my dad. He's staring at the ground now. I know he never meant to fuck me up... I sigh and go back to reading.

The doctor comes in. I don't know her name. I make a point to look, and see it stitched onto her white lab coat, Dr. Riggins. "Hi," she says, and walks right over to the counter where his chart is. She opens it and comments on his blood pressure. Good, but not good enough. I tell her about his feet and tell my dad to take his socks off to show them to her. She bends down and takes a closer look, poking and pressing the swelling. After a few minutes, she stands up. "I'm going to ask for a second opinion."

Dr. Riggins walks out and returns a few minutes later with another doctor, who also bends down to examine my dad's feet. She pokes his calves. When she presses them, her finger imprints stay after she removes her hand, like his leg is made of memory foam. She does this three times, with two fingers each time. I stare through her lingering fingerprints. The room spins.

Both doctors walk out and I hear laughter from outside the door. They must be joking around with one another. I shift my focus back to reading.

"The absurdity of my situation—that I have created both the grounds and the opportunity for cure of my depression by endeavoring to write about it—made me laugh, which itself made me feel even better" (Greenberg, 2010, p. 109).

Dr. Riggins comes back in. I snap to attention. My dad stares past her, so she turns to me to speak. "I'm going to prescribe your dad a stronger diuretic and compression socks," she says, confidently.

I'm not so confident. When my dad's feet began to swell, I immediately turned to Web MD for the doom and gloom diagnosis, and found it. Obesity, high blood pressure, heavy breathing, and swelling extremities are symptoms of congestive heart failure, and he has them all. In other words, death is coming.

Isn't that what usually happens when the heart fails? On Web MD, I read that life can be sustained for years with medication that helps the heart continue to pump blood into the body. I hope the doctor prescribes something. I can't continue to live in this state of hyperanxiety (Penn, 2001). I fear my dad will die any minute, and I won't know what to do.

So, I turn to Dr. Riggins, and speak up.

"I hope this isn't annoying, but I did some research on the Internet about his swelling. It seems the fact that he is overweight and has had a stroke puts him at risk, and his breathing is heavy. I'm worried about..." I pause, trying to get the acronym together in my head, "C-H-F. I read that there are medications that can help the swelling and make the heart pump harder."

She listens intently and looks me in the eye as she answers. "Yeah, I noticed the breathing. We need to get him an echocardiogram. When did you say your dad's health insurance starts?"

"December 1<sup>st</sup>."

The doctor and I continue to talk about him as if he isn't here.

She thinks for a minute, then replies. "There are different medications for different heart conditions, and with CHF we need to know what part of the heart needs help." I am losing her now as she starts using words like "systolic." I feel a little better anyway, braver. I made it to the free clinic, and I asked the difficult questions I came to ask.

My dad sits awkwardly on the examination table, staring at the ground.

“Thanksgiving is soon,” I tell him.

He looks up and smiles.

“I’ll make mashed potatoes and green bean casserole and a turkey and we’ll drink baby Cokes,” I remind him.

“Oh boy, Erin, I can’t wait for that,” he says.

There will also be wine. Lots of wine. I figure if I’m doing all the cooking I deserve it. The only thing I worry about sometimes is if it is going to kill me to drink with the Wellbutrin. According to Whittaker (2010), when psychiatric medications are taken for lengthy periods of time, the brain becomes dependent on them, and thus, dependent on the pharmaceutical industry. Dependence on substances drives our economy, but some are more fun than others.

My therapist, Greg, teaches mindfulness instead, a practice of training the mind to be present independently, rather than focused on past regret or future worry. Greg also used to work in brain injury and rehabilitation, so he’s admirably familiar with the biological and chemical structure of the brain.

“I’m just having a hard time coming up with things to say in class,” I complain. It’s our second session. “It’s like, I can listen well and understand exactly what everyone is saying, and understand the reading, but my mind is blank. I asked the psychiatrist if it could be the Wellbutrin, and she said it *enhances* concentration.”

“Yes, it *can* increase concentration,” Greg says matter-of-factly, before continuing. “Wellbutrin enhances convergent thinking in the brain, but it *restricts* divergent thinking, which might be why you’re struggling in your classes.”

“I want to get off the meds,” I say, defiantly.

“We can work on that,” he says. The look in his eyes feels promising.



But we never do. After the ten visits I am allowed at USF, Greg is gone and focusing on his career somewhere in Sarasota, as he said in our last meeting. I'm on my own again. I try to remember all he taught me, but it's hard because I am grieving him like he's dead. More often, I'd like to forget.

## **Thanksgivings**

"I remember when these used to cost ten cents!" my dad says, incredulously, holding his little glass bottle of Coca-Cola Classic up to the light, as if he can see the distant past somewhere in the caramel colored effervescence. I marvel at the thought of a ten-cent Coke.

"It was a big event to go get Cokes, and oh man, they were so good, we'd sit right there in the store and drink 'em up" he says, his eyes twinkling, wistfully. I listen intently, sipping on my little bottle of Coke. Each sip transforms as he speaks. The soda tastes so new and exciting, and it tickles my throat like magic, as if I have never had Coke before.

It's Thanksgiving, and every year my dad and I sit around, sharing stories, eating, and watching football. Thanksgiving is our special holiday, just for us. Every year, my dad cooks the turkey. Cooking the bird is such a thrill for him. He's always trying some new trick he saw on a cooking show.

In November of 2008, our Thanksgiving tradition was dropped on its head. After my dad's stroke, I had to start doing the shopping and cooking the turkey. The amount of literal blood, sweat, and tears that go into this process really makes me appreciate my dad's heroic efforts to cook the perfect bird.

In contrast, I recoil at the task. I find the turkey's innards disturbing, and its icky, pimply, white skin makes me feel sick. Dealing with a raw bird is too real for me. It's painfully obvious

that the thing was not long ago a living, breathing creature, and is now a headless carcass, bloody and cold.

I long for the days when all I had to do was surf the channels while my dad dressed the bird for its autumn funeral, but I've been doing it for five years and should be used to it. I'm not.

But it's still my turn.

Besides, the wine will help me rip its insides out, and my dad will do that big happy grin he does whenever good food is involved, and we will watch the Detroit Lions lose, and we will feel like a normal father and daughter, if only for a little while.

### **Drinking as Method**

I am asleep until consciousness drifts in, a cold chill. It's winter in Florida, meaning it is 60 degrees. The holidays are over and I'm working on living through the coming spring. Squinting, I reach for my phone and see only my faint reflection in the still, black screen. Dead.

*I'm late for the interview with Ariane.*

I'm interviewing her for one of my grad classes: "Intimate Interviewing" with Dr. Carolyn Ellis. We decided to partner up because we are both caregivers for our parents. I sit up in bed to the throb of a base drum; it comes from somewhere deep inside my skull.

*I shouldn't have had the NyQuil. Or the wine.*

I lay down to make it stop, but stress sets in immediately and drives me out from under the covers, my head screaming in protest. I throw on a sweatshirt and jeans, wash my face, brush my teeth, and walk out the door.

I didn't sleep well last night.

I send Ariane a series of frantic text messages:

"I'm on my way."

“Ahggg so sorry.”

“Must've been the NyQuil.”

She replies:

“It's all good—no worries.”

What is *with* me not sleeping last night? I couldn't sleep before the first interview either.

Am I anxious? About *what*?

Maybe it's because I don't know what will happen. Maybe I'm afraid of the trauma we'll stir up when we talk about our parents' chronic illnesses (Penn, 2001). The trauma I know Ariane is experiencing as she cares for her mother, who suffers from Parkinson's, dementia, and depression, is a trauma that I've buried somewhere in the back of my mind, a thing I've murdered and tried to hide.

Maybe I'm in denial. My dad suffers from two thirds of those ailments post-stroke: depression and dementia. Both my dad and Ariane's mom are on depression meds. I am too. Ariane also struggles. Maybe I'm afraid to feel how she feels. When I look at her I see it in her eyes, the very thing I am trying to kill, bury, and hide. Maybe I'm afraid of how we both feel. If we say our feelings aloud, we make them real.

I wonder if she's afraid. But anxiety and excitement are two sides of the same coin. It's fun to be let into the past lives of others; it's time travel. Ariane's past is fascinating: full of glamour and sparkle, with a chic, vintage edge that feels expensive and tastes sophisticated. Her mom was a teacher, an artist, a chef, a designer, she meditated, traveled—a free spirit. But of course there's more to it than that; I don't know the whole story. I never will (Bochner, Ellis, & Tillmann, 1997).

I listen intently as Ariane tells me bits and pieces of her biography. I try to emulate Rosenthal's method of interviewing people who are in crisis, but I'm somewhere in between friendship as method (Tillmann, 2003) and the biographical-narrative interview (Rosenthal, 2003).

It's weird.

Ariane's biography begins in California:

I was born in Carmella California, didn't live there very long, we moved when I was three. I was one of four children. I was the baby. Everybody says I was spoiled. It was kind of bohemian, you know—it was the late fifties/early sixties; my father was a jazz critic during the west coast jazz movement. We would actually have people like, ah gosh, one time Steve McQueen was at our house. We had kind of this bungalowish home. My mom made her own clothes. She was very stylish like Kim Novak, you know, that kind of look. It was a really cool era to be born into.

“Cool. So cool,” I sputter

She goes on, “I grew up as a latchkey kid in the sixties and seventies.”

“Me too, not in the seventies, but 90's latchkey kid, totally.”

“Always running around, taking care of myself, knocking on people's doors, asking people to play with me, even if they were old people. My siblings were grouped together in age and did their thing during the drug days of the seventies. My sister ran off to Woodstock in 1969.”

*I remember watching “Live at Woodstock” on my friend Renee's black cable box in the early 90s. We were way too young to be watching, but that's why we did it. I remember the naked mud wrestling most of all.*

When she finishes her biography, she makes it known:

“That’s kind of a snapshot of my growing up,” she says, smiling warmly at me.

I’m unprepared for this conclusion.

*Shit. I have to come up with a question.*

I refuse to look at my interview schedule. It just feels wrong. I default into what I know. I make conversation as I would in a natural setting, only slightly more awkward.

“Yeah, so…” I sigh to relax. “Wow, alright, let me think about this.”

“I can talk more about that if you want,” she says. “If you want me to go on and on. I’m old.” She laughs.

“Well, so, there are a lot of similarities there that we’ll save for later, when the tables have once again turned and you interview me.”

I go on, awkwardly, “But, so, you were kind of your mother’s person you said…”

“Oh yeah. I knew that at an early age.”

“To what degree has that factored into the negotiation of you becoming her caregiver now?”

“It was assumed. Without even formally saying, ‘Would you do this for me, would you please take care of me, would you be my designated medical POA and financial POA?’ She just informed me: this is what I’ve done.”

“So you were the only viable candidate?”

“Yeah, I am. It’s a terrifying feeling. Particularly when I got cancer a few years ago, because I had just divorced. So I was on my own as it was, my, all my children, five of them, were all spread out in the United States and I was down in Florida. And there she was in Nebraska, living on her own, supposedly doing okay, and I would get on the phone with her and

she seemed fine. She performed very well on the phone, but she had definite symptoms then. Now in retrospect, I kind of go, ‘Ohhhhhh, she’s hiding, she’s hiding this or that,’ and then my sister-in-law, she’s technically my ex-sister in law, but I call her my sister-in-law, and I call my brother my ex-brother. Because I have a good relationship with her. She’s down the road about twenty minutes in Nebraska and she would check on my mom and say, ‘Hey, Kaye’s not eating’ or ‘we had an ice storm and she was without power for three days. I’m so glad I checked on her.’ So when those things started happening, and I was still coming out of cancer treatment, I began to feel incredibly vulnerable. I thought, ‘Well, if I die, who’s going to take care of my mom?’ I didn’t care that I would die!” She laughs hard. “So you see I’ve been taught well!”

“So, tell me more about your relationship with her growing up...I mean I know you say you were pretty independent. Uhm, as a child, but what are some of your fondest memories of her?”

“Oh boy, that’s uh, gonna have to...” Ariane laughs nervously, “Need to think about that...uhm...” She pauses, as if under a spell. “I’m really going to have to think about that! It’s not that I have a lot of bitter memories. I just don’t have a lot of comforting memories because I don’t feel that my mom was a particularly comforting person.” Her voice begins to crack.

“Agh!” She lets out a frustrated cry. “Emotions!”

“Emotions are okay, that’s what we’re doing.”

“Well, I was thinking back to your car rides with your dad, and I was thinking back to the rides that I had with my son, and thinking, ‘Thank God for that because I never had that with my parents.’” She wipes away a few tears.

“And at least I got it with my kid. And so I know what that feels like. To bond, because it’s not about the event, it’s about being together.”

The interview ends and both of us are clearly relieved to be finished with it, for now.

“I can’t have coffee next time.”

“Next time wine, it will slow us down.”

“Exactly. I’m gonna bring it in a little flask, okay? So, that’s definitely a plan—we talked about it and we didn’t do it!”

“Yeah, in retrospect I think it was a good idea.”

Our plan to drink next time is a good plan. It can’t hurt. In our first interview, I left the recorder next to me. I can’t do anything much stupider than that. Sometimes I think I’m denser when I’m anxious and sober. When I played the interview back it was so hard to hear her. I was WAY too close to the microphone. So loud...I had to crank up the volume to hear what she said. Then, my own voice would erupt from the headphones and pierce my eardrums without warning and I’d cringe.

What an idiot, but I guess I learned something, even if it was common sense.

I also learned from my botched attempt to emulate the Rosenthal interview method (2003). Instead of a light start, followed by a deep dive into trauma, and subsequent emergence, we stayed on the surface until that little moment at the end. Maybe this method will work better in the next interview, when we get into deeper trauma associated with caregiving, namely mental illness.

When we get into the wine.

“Okay, go ahead, take a swig.”

“Alright, drinking as method take one,” I laugh, reach for the bottle of wine, and drink from it.

“We really are, I just opened a bottle. Tell me what it is.” Ariane talks into the mic as if we are being featured on NPR.

“This is uhhhhhhhhh Bodega la Flour Polenta Wines, a 2012 Cabernet, lovely, from Mendoza Argentina...” I struggle to pronounce the words on the bottle.

“I’ve become a connoisseur of wine of late,” she says. “For reasons that we are going to talk about—the impetus behind the connoisseur.”

“So we did coffee last time,” I say. “This time, we will take a more moderate approach. We decided that we will not be so constricted and constrained by an ‘institutional framework.’ Instead, we want to engage in a free flow of dialogue of what it is that we’re struggling with. We both are taking similar drugs.”

“Yeah.”

“Not illegal drugs, uhm, you know in an effort to try to cope,” she says.

“HA HA HAH!” My laugh is too loud.

Recently, I’d combed through two quantitative studies of caregiver depression (Ornstien, et al., 2014; Polen & Green, 2001). I learned one thing: it is socially preferred for a caregiver to be “adaptable,” while “wear and tear” is problematic, and associated with mental illness. Ornstein et al. manage to link caregiver mental illness to alcohol use and go as far as to suggest that caregivers fail to seek the services they “need.”

Is that what we are?

Failures?

Ariane takes another drag from the bottle, slinging it toward the sky for a second to get in a mini-chug. Her mom’s health continues to decline.



“She can’t move her legs. She can’t get up. She might be uncomfortable.” Her gaze goes soft and she stares off into the distance. “All these things.” She blinks hard. “I’m not saying all this to say, ‘Oh wow this is really bad,’ because it could be a lot worse, and I know it could be.” Suddenly, her voice raises, “I hate that too! I hate that thinking! Where...”

I chime in, loudly: “Yeah! You’re policing yourself!”

“Yes! Yes! I hate this!”

“You’re accounting, you feel like you have to account for talking about caregiver burden. Like it can’t be, it just can’t be! We can’t have caregiver burden! Noooo! Because that wouldn’t fit the normalcy frame.”

*Ahhh, the life of an academic. Drinking during interviews and saying things like “normalcy frame.”*

I chuckle at the thought but Ariane continues vehemently.

“No! Because we’re vibrant! We’re healthy!”

“Yeah.”

“We’re functioning, right? So, therefore, we should not really have too much to complain about.”

“Right.”

“You know what my biggest beef is with all of this? It’s not even the plethora of things to be done, of which there are...”

“Of course, never ending.”

“It is the fact that I’m not able to grieve. It’s really tough. You know, first the loss of the relationship, then, the actual physical loss that’s impending.”

Back to tears.

“I think that you’re going through what I went through post stroke with my dad...” I pause, collecting myself. “Like, when he first...when it wasn’t him anymore, you know? At first, it was just ‘survival mode, survival mode, survival mode’ like ‘don’t let him die.’ It was like his life was *my* life. It was like I was him. We were the same person. I was surviving for me and him, together. At the same time.”

“Same here,” says Ariane.

Survival mode.

Trauma is often its impetus. Ariane and I survive, and we survive hard. Intimate interviewing (Ellis, Kiesinger, & Tillmann-Healy, 1997; Ellis & Rawicki, 2013; Ellis & Patty, forthcoming) and friendship (Tillmann, 2003) are wonderful methods for trauma talk, but they worked better for *us* when we enhanced them with a little “liquid courage.”

And I’m sure we’re not the only ones doing interviews like this. Academics are big drinkers in general. Like a lot of us kept our red Solo cups as we applied for more degrees, bringing them with us from undergrad, to the master’s degree, to the PhD.

But wait. What would my little orange bottle of Wellbutrin XL say about this? I have been warned. Yet, insolently, I ignore the experts.

Maybe I should be institutionalized.

Maybe, I already am. Constrained by cultural rules that would have us renounce pleasure, that would prefer us pious and productive (Reinarman, 2005).

And we are commanded, by love and blood, to care for an aging parent. In this place, life questions us (Frankl, 1946).

Cultural norms that define academic integrity, mental health, and family have us questioning ourselves as well. According to Gergen, depression, alcoholism, and dependence

constitute language choices he calls “deficit discourse” (1994). According to Reinerman (2005), these “diseases of the brain,” are a means of social control, a double-edged sword: an excuse for both compassion and punishment (2005). Reinerman (2005) presents evidence that suggests drug and alcohol use creates a reaction in the brain that is not unique. All pleasurable activities, from sex to sailing, provide doses of dopamine to the brain. Alcohol, in its similarity, is used to cope with trauma, and, chemically, is no different from exercise or talk therapy.

The gravity of the ivory tower and the necessary function of family make creating a work-life balance difficult (Ellis, 2011; Dillon, 2012). When we come face to face with depression in the lofts of our theoretical studies, it’s too easy to let gravity take over, to want to stop fighting (Jago, 2002).

It’s no wonder we drink.

## CHAPTER V

### Molecules

I am sitting on my dad's couch, the stained carpet dappled with darkness below our feet. From the spills. From the dog. From the dirt.

He's petting Sky, who pants and looks up at him, black shaggy ears cocked. His white speckled paw rests on my dad's vintage beer belly. Five stories below us is the highway on-ramp where men looking for change hold up cardboard signs.

"Do you ever have dreams where you know you're dreaming—like in the dream you notice it's a dream? Well I'm trying to learn how. So, what I'm doing is questioning my waking reality. Like, am I really awake? This could all be a dream, ya know," I say, dipping my nose into my Styrofoam coffee cup, the free stuff from the lobby of his apartment complex.

"Well, I don't know, really. I'm such a mind case," he says. "I can't remember what I do half the time."

"Do you remember your dreams?" I ask.

"Well, yeah. There's one I have."

"You have it a lot?"

"Yeah, and I'm building a house—a nice house you know—you know—uhh—it's got three floors."

"Do you know you're dreaming?"

"Well, yeah. I know I'm dreaming—yeah."

“That’s so cool. Because that’s no less real than this, ya know? Like, I’m sitting here and we’re talking but in what way is it more real than a dream?”

Suddenly, his eyes are more focused, clear, certain. Like the dad who used to sit around and talk philosophy with me over beers. Like the dad who used to know more than me, about everything. Like my old dad, seven years ago. Before the stroke.

“Yeah, well, yeah,” he says. “Like all the things in the room right now. It’s all just molecules.”

He gestures toward the TV and table in front of us. I stare at it.

Just molecules.

I stare at him.

Just molecules.

And I think about how he’s going to die and how I don’t want him to.

## **Perishables**

I am at my dad’s apartment a second time, calling him for the 16<sup>th</sup> time in 24 hours. The parking garage is empty. The lobby is empty. It’s Labor Day, 2016. Celine Dion’s “My Heart Will Go On” oozes from unseen speakers. The whole place is deserted.

I have his groceries in my trunk. When I got home last night, I took them out. Refrigerated the perishables. This morning, the other half of the plastic bags sat eerily at the front door where I left them last night. Nonperishables.

The phone rings over and over, obnoxious in my ear like a screaming child. I give up and go back home. I can’t get upstairs without his permission. Without his key. Without him. I keep calling. Call. Repeat. Call. Repeat. I stop paying attention to the sensation of each act, the calling, the lack of answer. I wonder if this is how addicts feel.

Then, there he is, on the other end.

“Hello?” He says. His voice sounds far away, otherworldly.

“Dad? Dad!”

“Yeah, hi Erin—I—uhh—the phone wasn’t working. I saw you there. On it. I don’t—I don’t know what hap—” I cut him off.

“Yeah, I’ve been calling for two days!” I exclaim, my voice shrill.

We stumble through the conversation, talking at the same time, talking over each other.

“I’ve got groceries,” I say.

“Oh, good,” he says.

“I just got home but I’m comin’ back. Call ya when I get there.”

“Okay,” he says.

“Love you.”

“Love you too, Erin.”

I put the groceries back in my car, loading the trunk for the third time with plastic bags full of food. Bags he’ll use later to clean up dog poop. When I get to the parking lot, I call him.

*Ring. Ring. Ring. Ring. Ring.*

No answer. I call again. Again. For the 26<sup>th</sup> time now. I wander around the lobby. Again. It’s empty.

Then, there he is in dirty blue jeans he wipes his food-hands on, worn slightly crooked. Hair messy, too long, I need to cut it. Baby blue polo shirt with mustard stains. Glasses askew. One eyelid heavier than the other, more bloodshot.

“Oh thank god,” I say, hugging him. “I thought I was losin’ my freakin’ mind.”

*I thought you were dead.*

In just two weeks my friend Jon will die an early death on my 32<sup>nd</sup> birthday. I'll never get to say goodbye.

### **Bad Traffic**

"Boy the traffic around here is kinda nuts," my dad says as we wind our way through downtown Tampa. People honking. Screaming. Slamming their brakes.

"It's—oh gosh—it's enough to drive ya crazy," I say.

We are on the way to the doctor's office so my dad can have his heart looked at and so that doctor can say it's doing fine.

"Is that what happened to the people?" he asks.

"Yes that's what happened to the people," I say.

"Maybe that's what makes it so bad. They actually got driven crazy so it's worse," he says.

I laugh.

"What's the uhh—what's the thing your dad used to say about all the people?" I ask.

"He used to talk about people all the time, my dad, I can't remember," he says, his voice breaking, short of breath.

"In the cars—he'd say—uhh—where're they all going? Is that what it is?" I ask.

"That's right. That's what the preacher said at his funeral," he says.

"Did he?" I ask.

"Yeah it was funny, it made me laugh. He always said that: *Where are all the people going?*"

"I like that it's like an existential question," I say. "I was thinking about that when I was sitting in traffic one day. Like look at us so stupid sitting here in our cars not going anywhere."

“Yeah seems to be it, isn’t it? Everyone’s got a car and they’re out there driving it around and they don’t even know what they’re doing,” he says. “They’re all jabbering and talking and they don’t even know what they’re saying.” His voice is stronger now, clearer.

“Nope, that’s the other thing, not knowing where we’re going or what we’re saying really,” I say.

My dad laughs.

“Yeah, that’s just life. Life in general,” he says.

### **Crow Pose**

I am partying at a cabin perched precariously at the edge of a cliff in the Smokey Mountains near Maggie Valley, North Carolina, partying with friends I made at USF. I drove up with Rita, who has the cabin hook-up, and a lot of friends came and went over the course of the week. I left my dad with enough groceries and meds for each day I’d be gone, and I promised to call him.

Among the last standing tonight are me, William, and Rita. Rita is stunning. Dark features. Shining eyes. White smile. Dimples. Olive skin. Tallish. William has cool blue eyes. Salt and pepper hair. Scruffy beardedness. Between the three of us, we drank three regular sized (1.5L) bottles of red wine and two small (750ml) bottles and have made our way down narrow stairs that lead to a door that opens into a musty, vast, cement-floored basement. Tools. Shop vac. A sliding glass door that leads out to the patio that leads out to the cliff that leads out to the forest that leads out to the meadow that leads out to the creek that leads out to the dam—all of it cupped in the hands of the Smokey Mountains.

We are down here to smoke cigarettes and spliffs. But first, drunk yoga.

Crow pose.



I place my hands in front of me and squeeze my knees into my armpits. I round my back and make space to lean into my arms, lifting my haunches in the air just long enough to teeter and fall forward, all 125 pounds of my body weight crashing down on my planted right hand. To make matters worse, I was wearing a ring on that hand. I'd borrowed it from Lorraine, even though she said it was cursed because she got it from her worst ex-boyfriend.

Then come the tears. The duct-tape-paper-towel-piece-of-wood splint William makes me. The spliff he rolls. The cigarettes. The hospital. The Percoset script. The surgery. The Vicodin script.

Then came the scar. The bender. The bad attitude.

### **Attitude Problem**

I'm walking down the narrow hallway that leads to my dad's apartment with my post-surgery hand wrapped in a splint and lifted above my head. To reduce the swelling. The throbbing. To appease the wires and screws that now hold it together ever since I made the poor decision to impress my crush, William, by doing crow pose wine-drunk on a cement floor.

I'm wearing a black and white triangle patterned wrap dress without buttons or zippers, third day in a row. My dad is wearing a red and blue striped polo shirt, second day in a row.

"I don't wanna to go back," I whine to my dad, "I'm not ready. I'm sick of school. I want to be done." He listens but says nothing as we walk, passing door after door, unit after unit. All the same. The first week back to school and I want to kill myself more than I want to do a PhD or teach classes.

Later, I miss a call from him, but it's too late and he's sleeping so I call the next morning.

"Dad?"

"Yeah, hi Erin."

“Sorry, it was too late when I saw you called—what’s up?”

“Well, I was just thinkin’ after you left and it seems like you’ve got kind of a bad attitude about school. And I think it’s ‘cause you’re drinking too much.”

I stop dead in between the den and living room of my house and look down at the golden-brown hardwood floor, at my baggy maroon sweatpants and bare feet, toe nails long and chipped of red polish.

“Ya know, you’re right, maybe I am,” I say.

The next-next day I go to his apartment to refill his meds. Near the phone is a sheet of cardstock, presorted standard U.S. PAID mail, addressed to “Residential Customer.” In black pen and capital letters the first time and all lower-case the second, it says:

“TALK TO ERIN ABOUT HER ATTITUDE.”

“talk about attitude”

## **Rituals**

Lorraine and I sit at an old library table we pitched in for. We found it at a roadside furniture place, the kind with furniture in parking lots, on curbs. It’s 2014 and we are writing, or at least trying to. I sit in one of four wooden chairs, the only one with only three arms. It’s September. A candle is lit at the center of the table.

Lorraine is my roommate and best friend. She leads the meditation ritual.

“Let your body become heavy,” she says. “Let your forehead become slippery and relax your jaw.” Her voice is soft and dainty and her hair is short and messy. I sit and breathe. My mind is loud and clumsy and my hair is long and frizzy.

We are not here to remember. We are here to return. I try not to try. I close my eyes to rest the lines between my eyes that cut into my forehead. My breath leaves my lips slowly, in a

cloud of green mist. I inhale a cloud of blue. Again and again and again and again. Soon I am under the spell I've cast on myself.

This ritual is what helps Lorraine and I get into a place where we can write. This time my mind wanders to my uncle's story about my dad's old dog, Mike.

I lift my hand and start writing slowly, in big letters, eyes barely open.

### **The Dog Pound**

My dad's face is red. He leans against the kitchen counter. My Uncle JR is visiting; his bi-annual drives from Illinois to Florida to stay with his daughter. On his way home he stops in for a quick lunch with my dad and me, his brother and his caregiver-niece. He never stays long.

JR and my dad couldn't be more different. My uncle is bald and my dad isn't, his gray hair hangs coiled and wild around his ears. My dad is short and fat and prefers philosophy and science fiction to religion. My uncle is tall and thin and a fundamentalist Christian. My dad "dodged" (or narrowly escaped) the Vietnam draft to go to college. My uncle went to Vietnam. My dad spent his life breaking laws. My uncle is a retired cop. My dad is JR's little brother, but he's had a stroke, brain damage, memory loss. JR is in perfect health.

My dad's apartment is one big room. There is no wall between the living room and the kitchen. My dad stands on the kitchen side of the counter. My uncle stands on the other side, in the living room. I rock back and forth in the Ikea rocking chair and watch them, eyes darting around the apartment to admire its cleanliness, my sparkling work. JR bends down to pet Sky, my dad's shaggy black and white cocker spaniel mix.

"Kind of looks like our old dog Mike, the one we had when we were kids." JR looks at me as he stands to dust off his hands on his pants.

"Oh yeah! Kind of," my dad says.

“What did Mike look like?” I ask.

“Well, he had shaggy black ears, like Sky, but he had brown paws and eyebrows, I think he was a cocker-setter mix,” my uncle says.

My dad nods along. For two brothers so different, they’re dressed like twins, wearing the same dark shade of denim, similar blue golf shirts, and tennis shoes, both of them in wire-rimmed glasses.

“Mike was a funny dog,” my dad says.

I sit back and listen, waiting for stories. If I’m quiet and don’t interrupt, maybe they’ll forget I’m here and tell stories all day. Maybe JR won’t leave so soon.

“Remember how he would dig holes in the backyard? So deep he would disappear inside! Man, he’d come out a mess, dirt everywhere, even his tongue’d be all full of dirt!” JR slaps the counter.

My dad laughs, his face redder. His eye seems to droop more than usual when he’s excited. “Yeah and dad would throw him in the crick after that!”

They both laugh until the chuckles recede to ouus and ahhs.

“You remember when Mike got hit by a car?”

My dad looks down at Sky. “Yeah, I guess I do.”

“We were up on the farm, and he would run around, crazy. Well, one day a car was coming down the road. Mike tried to get out of the way and the guy swerved, hit him right on top of his head with the bumper. He was out cold. Dad picked him up out of the street and carried him into the barn, laid him down on a blanket. Remember? We thought maybe that was it for Mike. He didn’t move for two days. Anyway, we were in there with him, in the barn, you know,

worried, and all of the sudden his head popped up, he looked around, stood up and he was fine after that! But you could always feel the cracks in his skull when you touched his head.”

“Yeah, he was a tough dog,” my dad says.

“Did die eventually. Remember when Mike died?”

“No, I don’t think I was there, I was with Robby Miller.”

“Well I found him, oh yeah. I went out in the backyard and he was in one of the holes he dug, but he was nose first in the dirt. I yelled, ‘Dad! Dad! Something’s wrong with Mike!’ So, you know, dad came out and picked him up out of the hole and put him in the backseat of the old Chevrolet. To take him to the vet. I sat in the back with him, and his head was in my lap. And he died right there and you know. I realize it, I look at his face and it’s just, hollow. And I’m crying. Dad pulls over, gets out of the car...he took one look at Mike and said, “Yep, he’s dead,” shut the door and got back in, drove us over to the dog pound. And went in, and I’m still in the backseat, holding Mike, you know, just sobbing. Well he came back out, opened the car door again, grabbed Mike by his neck and walked away. They had this cage in the back for the dead dogs. Well, Dad swung him by his collar and just threw him in like nothin’.”

“Wow, you never told me that story.”

“It’s funny now. At the time it wasn’t. Wasn’t funny then. I probably didn’t want to traumatize you. I mean *I* was traumatized.”

My dad’s face is red. His eye droops along with his tone of voice as he looks down at the stained carpet. “You never told me that.”

## Silence and Sound

I shudder and pull the bedcovers up to my eyes, cowering in my room, hiding behind the wooden doors of our little bungalow. The front door rattles. The house sits in the midst of a lush garden, butterflies swooping; its foundation lay on a bed of shells, gently tucked away on Suwanee Avenue.

It's the weekend. *Goddammit, my roommates are here.* Creak, step, creak, a voice:

“Did you get the cat food out of the car?”

“Yes, Lori.”

*The talking.*

Anton, Lorraine's live-in boyfriend, answers her as I sit up in bed, pushing aside the remnants of the day: crumbled tissues, my headphones, laptop, and an empty coffee cup. I wear the same thing I wore yesterday: an old burgundy Central Michigan University hoodie with a ripped neck and yoga pants. I want to hide, to shrink back to Michigan, to duck back into the folds of my alma mater where I'd felt enveloped in some safe space, a place no one could judge me because we all lived there in the same cold hole.

Not that here in this house there is any real need to dress up my sadness in pearls and pink bows, nor am I expected to be any such way, not a soul twin, not alone. Looking back at CMU is just a way to gain perspective on what I'm thinking about what is right in front of me; that same communal hole, it follows me wherever I go. Turns out it's just hot in Tampa instead of cold. And Lorraine is no stranger to neurosis. Neither is Anton. Even their (combined) cats are crazy (yes there are three). Mouse, the craziest, starts to meow-scream in the next room the moment he hears Lorraine's voice. He sounds like a mouse, if a mouse were given steroids and LSD. He wants tuna.

*So much noise. I have to get out of here, now.*

I emerge from my darkened room with heavy eyes and wild hair.

“Hey, stranger,” Lorraine says.

“Hey,” I say, trudging across the hardwood floor as if it’s three inches of snow, purse in hand, shoes on.

“Where ya goin’?” she asks.

“The grocery and my dad’s,” I say. “See ya later.” I close the white lace cloaked front door behind me. The sun on the red front porch is the first I’ve seen today. I step down cautiously, pulling my dark sunglasses from their case to replace my eyeglasses.

I go to Publix and brave the aisles of irritated moms, stoic stock boys, and genuinely nice cashiers. It’s worth it to get to my dad’s, to bring him his groceries, and I like the cashiers.

When I arrive at dad’s apartment, it’s serene, a calm sort of silence, a quiet waiting without anticipation. His place is a site of simply being, of facing mortality, of relaxing into it and moving with it. With time, routine, and healing, he’s adjusted to the effects of the stroke he had nearly eight years back, adapted to his aging body, writing himself notes when he has something to tell me. His philosophical mind has returned, he’s started to dream about death, about “building a house in the sky,” he says.

He’s the inspiration I need right now. We’re both dying; I’m just younger, behind him in the race against time. If I stand beside him, I can feel the pressure, like something pulls at him and pushes on me, as if to say I have to stay here a while, as if to say I’m waist deep in the quicksand, while he has one foot out.

He meets me in the parking garage, standing near the heavy metal door in his gray Central Michigan sweatshirt. I loop my arm in his and we lope over to the elevator.

“Well hey there,” I say.

“Hi Erin,” he says, looking straight at me, his crystal blue eyes a reflection I see myself in: always a hint of despondence.

Years ago, when I was little and I’d cry about something or another as children often do, my dad wouldn’t let me not ask, “why?” He urged me to give everything a good think. I remember when he wouldn’t take me to the miniature golf course on Gratiot Avenue, the one with the giant pink elephant on the 9<sup>th</sup> hole; all because he said the owners were crooks.

“It’s not fair!” I sputtered, tears soaking my size 6x t-shirt.

“Why are you so upset?” he asked, holding back a grin.

“Because you won’t take me and I’m sad.” I hiccupped and looked up, pouting.

“What’s wrong with being sad?”

“It feels bad to be sad.” I looked down at my tear-stained little legs, dangling over the front seat of his boat of a Buick LaSabre.

“What’s wrong with feeling bad?” he asked. “If we’re never sad, how can we know what happy is?”

*We have to be sad sometimes*, I thought, *it’s good*. Twenty-three years and a Wellbutrin prescription later, I wonder if I took this idea too far as we ride the elevator up to my dad’s fifth floor apartment, a morning melancholy heavy in my gut.

Soon, we sit quietly on his six-by-eight foot patio. It overlooks a giant mound of dirt, excavated by construction workers dressed in neon orange. My dad watches them each day, as if they are little characters in a television series. They’ve been working on it for months, building a brand-new complex just like his.

“I wonder what they’re gonna do with all that dirt?” he asks.



I'm convinced we both think they may soon use it for a burial ground, for him, for me, for us. We don't say so. We stand and stare for a long time, not acknowledging that he will soon die, and not acknowledging that sometimes I want to die. The machines dig and the men below mill about. A little dog bounces around between excavated holes, his owner shouting for him.

"Do you see the little dog?" my dad asks, chuckling.

"Yeah," I say, giggling. The pup skips around in circles, and I'm reminded. *If we don't die, we don't live. We can bury the facts, the sad, but without it, we live an unhappy lie.*

I stay and watch for a while before the itch hits. I don't want to go home, I don't want to go anywhere, but I want to go somewhere.

"I have to go write," I say. "Love you dad."

"Love you too, Erin," he says, and I kiss his cheek. He tastes like cold sweat.

I walk outside his apartment to the 5<sup>th</sup> floor emergency exit and run down the cement stairwell, one flight at a time, the smell of urine slapping as hard and echoing as loud as my pounding feet, and I wonder: *Who is peeing in here?*

I burst through the heavy fire door at the lower level and half jog through the parking garage to my car.

Dunedin, Florida. That's where I'm going, a café maybe, a place I've never been.

I arrive and blow an hour driving around, looking for a coffee shop. They're all closed. The Dunedin Brewery will have to do. I go in, buy a Mundofolbick [I have no idea what this means or how it's pronounced] at 7.2 ABV, and take a seat at a round table in the brewery's "nook."

Conversations buzz. I put my headphones on for something closer, louder.

I glance down at my beer. The foam has swirled itself into a sad face, big eyes, one larger than the other, a twisted, thick mouth, turned down. In my ear, TV on the Radio sing, “everything’s gonna be okay.”

I keep telling myself.

### **Blood Types**

Me and my roommates are sitting around talking about mosquitos because we have nothing else to talk about. All of us sitting together in the den, bullshitting.

“I want to know my blood type. Because I get bit by mosquitos. A lot.” I tell them.

“Why don’t you ask your mom?” Anton says. Lorraine nods, pretending she’s paying attention.

So I ask my mom. In a text message.

“You wouldn’t happen to know my blood type, would you?”

It takes her a few days to reply. With a text message:

“I don’t know, Erin. Why don’t you ask your doctor, you know, the one who prescribes your depression medications?”

### **Fallen and Can’t Get Up**

The day my dad can no longer stand up is a day that I am fiercely in love. My relationship with William thrums in my veins like new blood. This man, this beautiful man with sapphire eyes and naturally pointy, messy salt and pepper hair and sideburns, who has big, warm hands and wears jeans with nice suits and ties, hops out of his Infiniti at a red light and jogs toward me in camel colored leather shoes to kiss me through my open window. William has two

kids, Austin and Lee, who I adore completely; they are main the reasons for his innate nurturance.

I am driving to my dad's apartment to check on him and William is going back to work after we met for lunch. After we sort of ate and before we ended up back in our separate cars, we'd stood in the parking lot of Café Hey and hugged a long time, and we'd kissed with eyes open—we almost never close our eyes when kissing goodbye, probably to make sure we see each other one more time.

My dad's apartment is around the corner from the café and I am going to check on him now. I go inside, take the elevator up to floor five and open the door, and he is sitting next to his chair on the floor, the television off.

“I can't stand up, Erin.”

He looks dazed and my heart races.

“What do you mean? Like you can't stand at all?”

“Well, no,” he says, his tone suggesting absurdity. “I can stand I guess. I just can't walk. My muscles. They're weak.”

He tries to stand, wavering and grasping for the chair beside him. I rush over to help but I can't really do much about 250 pounds.

“Dad you need to go to the hospital,” I say, feverishly Googling “stroke can't stand” and grinding my teeth.

I speed walk the hospital halls to get to my dad's room, 409, but he isn't there. I turn around and find the nearest attending physician and tap her on the shoulder.

“I'm looking for my dad, Klen Scheffels, he used to be in this room but now he's gone.”

“Hang on,” she says. “I'll check the system.”

I wait near the bland, open countertops that pass as desks while she fiddles with a laptop that looks like it's from the dark ages. I wait and wait and wait. I don't look at my phone. I don't speak. I just stare at her intently.

“Oh okay, they moved him, he's on the 7<sup>th</sup> floor now, Room 719.”

“Okay, thanks,” I say, already walking away. I get on the elevator and sweat until it gets to Floor 7, where there is a white gurney outside double doors. It's like an emergency room from the dark side of the world, but there is a small plaque outside that says 700-724. I press the red button and go inside. Someone is screaming. A man. I rush down the open hall, little cubbies segregated by curtains, dotted with medical carts with machinery and nurses, the pairs sticking out like boxy ulcers. Cubby 719 is empty. I spin around and grab the nearest available person, a young man wearing scrubs who looks and speaks like he is in high school, though I know that isn't possible.

“I'm looking for my dad,” I say. “He used to be on the 4<sup>th</sup> floor and they said he was here but he isn't here in 719. Will you see if you can tell me where he is?”

He looks confused but walks to what looks like a little nurse station with its own machinery and side curtains. I see him leaning over, whispering. I am wearing a big t-shirt and Victoria's Secret USA sweatpants and in that moment I feel completely ridiculous. Everyone here is sick or wearing scrubs and carrying clipboards.

When I find my dad, after the nurse tells me the third place they moved him, he is asleep. I stand over him for a while watching his breath, watching the heart monitor, feeling the cool temperature of his feet, his hands. I don't know what's going to happen next. I leave without waking him up.

*I'll go back tomorrow.*

## **Evicted**

My dad's apartment is empty aside from furniture, the fleas, the mess still palpating. The apartment complex left the eviction notice on the counter. They have decided not to renew his lease based on complaints about his dog, his cleanliness/my failure at being a good housekeeper. The dog is staying with my boyfriend and me in our little cottage-shed, because my house with Lorraine on Suwanee Avenue doesn't allow him. Old Sky Bear is what we've come to call him.

The eviction—I expected this. It actually works out for us because my dad is now required to live full time in a rehabilitation facility where they are trying to help him walk again. Thirty feet is the goal. I take the dog through there and the old folks go crazy for him. “He looks like a puppy,” they say. He's nearly 13 but he does look like a puppy with his black and white hair shaved close, his little amble of a walk, his big eyes and ears that seem perpetually cocked.

My dad doesn't like it there much. He has roommates that make his own stench seem like roses and he misses the dog. It's like living in the hospital, only for months, with just a curtain separating you and the miserable person next door, whose moaning and groaning and stink might just kill you before it kills them.

But “the food is fine,” my dad says. “They have a pretty good variety. You know I'm not picky.”

## **Wheelchairs are Fucking Heavy**

I scan the double doors of the Bayshore Rehabilitation Facility before I let them slide open and nervously walk the dog into the elevator just after he pees on a bush outside the glass. I go through the sliding metal doors and the dog and I teeter through the halls on a tether. I pull Sky away from the metal food carts and the trash.

*God knows what's in that.*

“There’s my dog!” my dad says when I find him, patting Sky Bear from his wheelchair. He is sitting in the common room with the big TVs. *Not his usual style. He must really hate his roommate, I think.*

I start into the hall to go back down the elevator, punching in the four-digit code I used to go up again to meet the person I am supposed to be meeting with, the person we are supposed to be paying. She turns out to be way less terrible than she seems (her position didn’t seem promising given the money collection thing). She is incredibly sweet and although it’s a boring paperwork driven meeting, it doesn’t go badly.

But there’s worse here to deal with than that.

“Your dad will be approved for Medicare and Medicaid, but what we need to talk about is what he will do beyond his stay with us. We need to discuss where he will go when he’s cleared from rehab. You have to talk to the social worker about this. She’ll help you find a place for him.”

She hands me a phone number on a post-it note.

“Call her, her name is Lynn. She’s really good.”

“Okay, thank you so much,” I say, leaving with the post-it in my hand and pressing the up button on the elevator after entering the four-digit code I have written down on another post-it.

*Time to be optimistic, stay positive.*

A week later I sit with my dad, a brochure for assisted living facilities covered by Medicare and Medicaid in my lap.

“I want to be able to have the dog,” he says. “I’m not going anywhere without the dog.” Sky stands by his wheelchair’s side, his black snout scouting the floor for crumbs and god knows what else I’d prefer not to think about. There is one assisted living facility about 20 minutes away from my house that looks more like a trailer park—separate little places, a doctor, store, and pharmacist—the place feels more like an apartment. My dad “just wants to be alone,” he says.

As long as it’s with his dog, I guess.

My dad and I go to check the place out, which is not as easy as it seemed to be before we’d set off. I sign him out at the desk and tell the people we will be back in two hours or less. I have looked up the directions for “Rocky Creek Village,” but what I don’t have directions for is the goddamn wheelchair. I have to collapse it to get it in my trunk, and I have no idea what a heavy prison it is until I strain my muscles and cut my wrist with its metallic flanges.

After we arrive and park next to the “Leasing Office,” I wrestle the wheelchair back out, cutting my hands this time. My dad gets in it all right, only looking like he would crash to the ground for a few wavering seconds.

When we walk in, the receptionist is talking to an older black man in a leather jacket who smiles and waves at us. I smile and wave back and my dad and I sit down to wait for our appointment. Before we know it (AKA it’s almost an hour later and we’ve taken to making fun of the surrounding signs about events and the like), we swoop off in a golf cart by the lady giving us a tour of the place. I’ve wedged his wheelchair into the golf cart. I hang off the back, clutching his chair by the wheel and him by the shoulder as we rumble along a barely paved path.

“So can he have a dog here, then?” I ask the lady, who is driving the golf cart. “Dog is a small little guy,” I say. “Very well behaved. He never barks.”

“We can ask, but usually we only allow cats.”

“What if the doctor prescribed the dog, you know, as therapy?”

“We can ask,” she says.

### **The Living Hell Curve**

William and I are driving through Tampa to look at assisted living places that will take my dad. Look for them. Either way it's Sunday and my hopes for his ability to have the dog have already been dashed. We just need a place that doesn't seem...fake.

My dad doesn't know that yet.

“I don't want him somewhere awful,” I say. “I think it will kill me, him. Kill me and him.”

“I know, baby,” William says. “The way I see it these places are real estate in the way that it depreciates or appreciates human beings; if everyone around your dad is worse off than him, he will decline with the curve, but if everyone is a little better off, he will get better too, or at least feel better.”

“That's really smart,” I say, wringing my hands and adjusting my bare legs in the front seat. “The place on Davis Island seems promising, I know exactly where it is, the area is pretty fancy,” I say. “Looks like a hotel.”

It's called Hudson Manor and it looks like one big mansion, which I feel is a good thing until we park on the street and walk up the sidewalk past the dark, dank fountain in the center of the courtyard. It seems like it had once been white, but now it sits still, covered in dark green sludge. Who knows how long it hasn't been running.



An old man sits just outside in his wheelchair. He's smoking, his eyes unfocused, his balding white head barely propped up by some unseen force. He looks up as we walk by and William gestures a wave. The old man blinks. Beyond the double doors is a huge audience in wheelchair seating, all of them staring hungrily at the sliding glass panes and suddenly I am too overwhelmed to focus on the task at hand.

They're all waiting for somebody.

I go up to the desk where a pretty young black woman greets me. She has beautiful long braids and wears fuchsia scrubs. For a second, I forget I'm not alone and begin to panic about saying words to her, but then William speaks while I just stand there like an asshole. My heart is racing and I'm so lightheaded that I feel sort of happily numb, stoned.

"Yeah hey, we are just checking this place out for our dad, can we look around or is there a tour or something?" William asks, politely.

"Yes, absolutely, it's a small place," she says. "Our manager isn't here but I will have her call you Monday. For now you can walk down that hall (she points toward a gleaming wheelchair ramp) and then go left into the library, beyond that is the model room, the door is open." We nod. William is already walking up the ramp to the hallway. "Each room has its own TV," she adds. I scurry to meet his pace and shout, "Thanks." In one left turn we are in the library, a tiny room with shelves and books lining the walls. Some of the shelves are empty.

I turn to William. "How does it smell like pee in the library?" I ask. He walks over to the nearest shelf, examining the L. Ron Hubbard series. I point to the spine of a book that reads "DIANETICS."

"No. Let's go," I say. "It smells too much like pee in here anyway."

"Okay, baby," he says, putting an arm around me as we turn to leave.

## **No Dogs Allowed**

The social worker, Lynn, calls on my morning walk to break the news that my dad was rejected by the cool place with the golf carts and little village doctor and (slight) dog possibility.

“We found him another place, it’s in the Hyde Park area.”

My ears perk up at “Hyde Park” because it’s a fancy part of town.

“Will he have his own private room?”

“Yes,” she says.

“Whew, okay, that’s good news I guess. But no dogs?”

“No dogs, I’m sorry Erin.”

“Okay,” I say, but it’s not.

## **Fleas**

The week that I am supposed to move all my dad’s stuff out of his old apartment arrives before I can say the words “Fuck me!” in the middle of Home Depot where I am in line to rent a steam cleaner I don’t know how to use. Luckily it’s summer now and my final papers are all turned in and such.

My boyfriend volunteered to help with the move but he’s a big shot at his work and in the midst of a major Florida Department of Transportation contract; I just can’t see asking him in the middle of the day, in the middle of the week. Today I am just cleaning anyway and I’ve brought Lorraine along, she’s really good at cleaning, way better than me. She’s half Cuban, half Colombian—a second-generation immigrant who comes from a long line of cleaning ladies—because of this, I hope we can figure out this big old piece of machinery and get all the black spots out.

No one has entered the apartment in some time and someone has turned off the AC. The moment we step on the carpet, our feet and bare legs are coated in tiny black dots. At first I think there's something strange and magnetic happening, like we haphazardly stumbled into another dimension—or maybe just a life-sized version of one of those games where you use a magnet pen to draw hair on people, either way, it's a trip.

But within seconds the stinging, the itching starts and I'm back in real time.

Fleas.

They must be starving since the dog left, but they've been breeding. I am troubled by their misguidance, their sad attempt to feed on the likes of us.

## **El Diablo**

The Hyde Park Assisted Living facility could not be less “Hyde Park” than it is. I park my car alongside the chain-link fence that encloses it, surprised that the parking spots in front of what looks like a Motel 6 are taken up. The dog is in the back seat and I let him out cautiously.

“Come on buddy,” I say. “Come on Sky Bear!”

The dog trots along the lot to the stairwell, and I look at the cement and worry my dad will fall down it. A storm is rushing in. Most residents are inside, except for one guy. He has a half pint of brown liquor and is screaming at the sky.

“El Diablo! EL DIABLO! EL DIABLO!”

He is directly across from my dad's doorway, enclosed in a vestibule that separates spaces, one tiny apartment from the next. I walk into my dad's little home but it's more like a dorm room.

*Hah, we are born, we age, and then we come round again. We prepare for death by imitating what it's like to be young adults, then teens, then infants,”* I think, sweating.

## **NYC, Sad Chili and Louis**

I am standing and waiting for the subway in a crowd and I leave everyone I love and I can't stop thinking about jumping in front of the clattering train coming to get us and take us away. I overheard someone say the word "kiosk" twice walking down the densely inhabited sidewalk and nauseously regretted the hundred-dollar winter boots I'd bought for one slushy day. One day slushy and alone in a New York City diner eating sad-chili and pretending I am with the friends and boyfriend I left in Tampa, all because I wanted to be in New York so I wouldn't feel alone anymore. Tonight they are having a huge party with a chili cook-off and a bounce house or some other fun stuff.

*Everyone probably hates me anyway. They should hate me. I used to be good, I think. I used to be good to make up for being ugly by being pretty on the inside, because that's what I was taught.*

"NYC, December 17, 2016" is scrawled in black pen at the top of my yellow steno pad and I'm drinking vodka and tonic with the huge loaded bowl of chili in front of me and I am tired and bored.

I've never felt bored in New York City before.

It must be because, this time, no one is feeding me acid or cocaine. No one is meeting me or striking up a conversation at a bar in the East Village. And everything seems so far away like the stage at Madison Square Garden that I watched Louis CK tell new suicide jokes on a few nights ago.

"You're not supposed to talk about suicide," he says. "You should be able to talk about it! The whole world is made of people who didn't kill themselves today ... life can get very

difficult, very sad, very upsetting, but you don't have to do it. You really don't have to do it ... because you can kill yourself" (Szekely, 2016).

The next morning I couldn't stop throwing up.

I cried and threw up all day and thought of my dying dad in that awful Assisted Living dorm. My dying dad who threw me out last I was there, who I haven't talked to in two months except for one horrible phone conversation.

I thought of that damn episode of the Louie show I couldn't watch where he throws up at the thought of seeing his father. He vomits on a poker table. He vomits on the hood of a car. I tried to turn away. I guess I still saw. I had to turn it off. I can't remember if the premise was that his father was sick and dying or not.

But last time I talked to my dad it was awful and he hung up on me.

"I want to get out of this place," he said. "I want my money but you have all of it."

Losing patience, I said: "Dad, you have NO money."

"Yes I do, my pension, you stole all of it. I am getting a lawyer. They will come after you."

"Okay, get a lawyer, but you know that requires money. That's how this system works, you know. You have to use all your assets before you can get any assistance from the government. Even these horrible assisted living places are unaffordable."

"You're a liar," he said. "And you ruin everything, just like your mother." His voice was thick with contempt and it rung in my ears.

"Dad I know it's fucked up! I want it to change! What do you think I am doing? My whole dissertation is about this! I've dedicated my life to trying to make what is happening to you not happen," I shouted through tears.

“You’re so emotional. See you’re just like your mother. No one is going to take you seriously when you cry like this.” His voice sounded reddish, burning like fire, a hot buzz erupting in my eardrum.

Then he hung up on me. I couldn’t hear right for hours after that.

### **Practice for Death**

I dream of my dad ever since the stroke that took so much of him ten years ago. He is still alive today, as far as I know, according to the memory of the time I last saw him in his refrigerator box-sized assisted living apartment/room and he told me to leave and not come back again. Soon after he called to berate me further.

So maybe “dream” isn’t the right word to describe my sleep-driven imaginings of him.

The word nightmare is derivative of “mare,” which, in old English, means demon, or goblin, a creature of torment—more appropriate given my circumstances.

Tibetan Buddhists believe that dreams, especially nightmares, are practice for death.

I’ve dreamed the same scene over and over for the past ten years. My dad and I are at some unfamiliar but familiar place, maybe a gas station, maybe an eatery. I can’t tell. We are outside on a picnic table, sitting quietly. My dad is eating from a Styrofoam take-out container. The kind with compartments. There are so many compartments. The food is piled up as high as his eyes.

The nerves rise up in my throat as he wolfs down the food and I wish I didn’t know what happens next but I do.

He vomits.

Half-digested food everywhere. The mess covers the table. It spatters the cement below. The nerves in my neck tighten and choke.

“We have to go to the hospital!” I say. Maybe I don’t say. Maybe nothing comes out.

“I’m fine,” he says. But he chokes on his words, the vomit.

“We have to go! Please!”

I beg him to get in the car and he denies me again and again. In dreams, time can stretch out like the rubber band of a slingshot yanked back by an anxious little boy waiting to put your eye out. When you speak in a dream the words never leave your mouth, they linger, dilate in some panicked place where penned letters stretch across taught elastic and disappear into little lines when the sharp rock is released.

My dad gets into the car. Suddenly we are in a gray space, an institution, sitting at a smaller table, in a cubby in the wall.

Suddenly, he’s gone.

I panic. I walk, run. I’m in a big white room. There are no walls. The hospital staff runs around with tools and medical accessories. I try to stop them. They blur by faceless.

Then I see him, his figure is small in the distance. He’s outside. The wall of the hospital is a picture window. He’s walking through a swamp. Into the forest.

I cross the threshold and call out, “Dad!”

He doesn’t flinch or look back. He moves toward the shadowy trees, his feet plunged into the dark water below as he trudges and lurches forward.

I start into the swamp.

He disappears into the dark canopy. I stagger through the muck. My feet are stuck and stumbling. Each step is impossible, each steps pulls me further from him.

I am screaming. No sound comes out. The squishing and squelching muck takes my voice with it, down below, into the deafening dark.

Then, the leaves rustle and the trees open their arms, gnarled and twisted.

A wheelchair emerges. My dad sits inside it.

All the flesh is gone from his bones.

I wake up with a sick feeling and a racing, enraged heart.

I have to go back to sleep. Start over. Forget.

I've been debilitatingly afraid of vomit since I was a little kid. Not an "ew get it away" type fear, but the kind of fear that would have me calling my mom with my heart in my throat to leave a sleepover if another kid seemed like she might get sick.

"At the spiritual level vomiting symbolises a freeing from bad persons," says a website called "dreamtation" that is only loosely translated to English from what I assume is a mystical language from a land full of wise people who live far, far away and have been colonized by Englishmen.

My earliest memories are soaked in vomit. When I was very little I had a recurring nightmare. I was a toddler, standing in my crib, and the crib filled with a brown liquid, threatening to drown me. I tried hopelessly to climb out, but I was too weak. I stood in the vomit that burned my legs. There were chunks floating in the acidic liquid that looked exactly like orange wedges with thin, white veins of pulp encasing them.

I didn't enjoy eating an orange until I was 26.

### **Not Father's Day**

I am arguing with 8-year-old Austin about running the AC in the parked car while William goes in to Publix to get a chicken and a Coke for my dad. Austin is worried about the environment.



I've finally worked up the courage to take my boyfriend William and his two beautiful, dark haired, precocious little boys to meet my dad. We decided on Father's Day, with the plan to bring him a Publix rotisserie chicken and a Coke and his dog, all of his favorite things.

"We should shut it off, we don't need it," Austin says. "Just open the windows."

"But buddy, I need it, trust me, I'm sweating really bad. I love that you are concerned about the environment, and you're completely right baby bear, but sometimes we have to pick and choose our battles with stuff like this."

"Yeah Austin, she's nervous about seeing her dad, leave her alone," says 12-year-old Lee.

It's Father's Day, 2017, and in this moment, both children seem more grown up than me.

We pull in to the Hyde Park Assisted Living facility, park, and get the boys and the dog out of the car. My heart is thumping hard but I try to appear at ease.

I haven't seen my dad since our last terrible fight, since I last brought Sky for a visit, and he threw me out, later calling to spout more vitriol at me. We haven't spoken since; it's been so many months I've lost count.

*But bygones are bygones, right?*

I walk up the stairs with the dog, young Lee sticking right by my side, holding the grocery bag with the Coke and the rotisserie in it. He's such a sweet, empathetic kid. No one cares more deeply about others than him, or feels what others are feeling more completely.

William and little Austin hang back some, taking their time.

I feel pretty confident my dad will at least be happy to see the dog. "That's my dog," he'll say. "There he is."

Not this time. Not on Father's Day.

When Lee and I walk in my dad is standing at the doorway, his faced twisted with rage.  
“Hey dad,” I say. “Happy Father’s Day!”

“Happy Father’s Day Mr. Scheffels, we brought you a chicken. And look, Sky Bear!”  
Lee says. He holds out the grocery bag to my dad who swats it away and glares at him.

“I don’t want anything from you.”

“Dad!” I say, stunned at his cruelty. How could he be mean to such an adorable little boy? I look at Lee, worried his feelings are hurt, but all I see on his sweet face is empathy.

“Get out of here, go away,” my dad says. “I’m not a father.”

“You sure you don’t want the chicken?” Lee says.

“Yes, I’m sure, now go. Get out of here.”

Lee and I turn and walk out, where William and Austin stand just outside the door.

“Hi Mr. Scheffels,” William says, but my dad ignores him and walks past.

Defeated, we all get in the car and leave.

On the way home I cry in the front seat. I try not to but I can’t keep it in, can’t stop it.  
The kids both try to make me feel better, Austin defending me, Lee defending my dad.

“That was really mean,” Austin says. “You brought him all the stuff he likes and he was a total jerk.”

“Austin, he’s not a jerk,” Lee says. “He can’t help it, his brain is just messed up, right Erin?”

“Yes,” I say. But I can’t help but side with Austin on this one.

## Not a Guilt Trip

I am in the car with my mom trying not to comment on her terribly slow, confused way of driving. She isn't great at navigation, but I am being gentle, suggesting turns and lane changes that make sense as we attempt to get to *First Watch*, an easy to find restaurant near her hotel. She is visiting Tampa to make me change my car registration and insurance. I don't think I need to further expound on the ridiculousness of this, because I'm 34 years old. But I never know how to tell her no. Plus, it's nice to have her do something for me, to hold my hand through the things I have to do but try to avoid, usually to my detriment.

She is skinny as a rail these days, but calmer than she used to be after the battle with throat cancer she won recently, on her own, with no help from me. And boy is she pretty, aging gracefully indeed. My dad always talks about how pretty she is.

"So how's your dad?" The inevitable question I knew she was about to ask.

"I don't know. He's been so mean to me, hard to deal with. I tried to take William and the kids to see him on Father's Day and he threw us all out. Truth be told it's been months since I have seen or talked to him."

"Well, girl, you've gotta do what's best for you. You have to do what is healthiest. Try not to beat yourself up about it. Guilt is a wasted emotion. Sometimes, we have to protect ourselves from relationships that are toxic to us, and feeling bad about it defeats the whole purpose. Just take care of yourself. Enjoy your boyfriend and the kids. And if your dad passes, it's okay, because the truest version of him would want you to be happy, don't you think?"

"Yes, thank you mom. I really needed to hear that."

I really, really did.

## **Christmas Beer**

William and I sit on the twin bed in my dad's tiny assisted living apartment on Christmas Day, 2017. It really is as if he lives in a refrigerator box. The building is an old motel, and the rooms have been divided into two separate cells, each with a bed, closet, and bathroom. This time, I bring him my special homemade macaroni and cheese, Lee's favorite.

"Oh, boy," he says as I hand it to him. And then, "Sky! There he is! C'mere Sky!" He's grinning as the dog ambles over to dutifully stand beside his wheelchair, where my dad pets his head. The wheelchair is positioned in front of his tiny television. He turns the television off.

"Well it's good to see you, Sky," he says, looking down at the dog, eyes glazed.

"Yeah, he's happy to see you too," William says.

That morning, the best Christmas ever took place at William's house, with the children shrieking and grinning and playing and hugging us, boy were they the happiest little bears. After, they went to their mom's to have Christmas there and I decided to clean and reorganize their room to make space for all their new toys and clothes.

"You're stalling," William said.

"Let me drink this champagne first."

"Okay baby, I know you're nervous. Whatever you have to do. Just tell me when you're ready and I'll round up the dog and the leftovers."

He stayed on me with the gentle reminders until I agreed it was time to go. I grabbed a few beers. "Maybe we can have one with my dad, sometimes he'll have a beer." The truth is, they were all for me. Liquid courage may be cowardly; I know sobriety would be true bravery. But sometimes it's okay to let someone or something else be brave for you. Today, William does that for me. Well, William and a bottle of Christmas champagne.

It turned out to be way less scary than I had anticipated, when we got there. William and my dad talked quite a bit; my dad is very impressed with him.

“I wish I’d been an engineer,” my dad said. “But I didn’t have the grades or the discipline. I was never a good student. You’ve got a good one here Erin, now don’t screw it up!” He laughed and I laughed along with him.

“You know the people here, they’re not good people. I’d like to get out of here someday. The people are just dumb. They aren’t interesting. All they do is gossip.”

“Yeah, you’re not so much for the people, are ya dad?”

“I like to be around everybody some of the time, but I don’t want to be around anybody all of the time,” he says, curtly. “I don’t want you here, Erin. I like to be alone. You know that.”

“But you like the dog, right?” I say, looking down at the little black Sky Bear sitting at his wheelchair’s side, my dad still petting his head.

“Well yes I like the dog,” he says. “Sky, you’re a good friend.”

## CHAPTER VI

### A Meditation on Caring

This research is about a *narrative education*—what I have learned about myself, about communication in relationships, and how storytelling moved me to know myself better and care for myself more. I am a different person now, different from the person I was when I started caregiving, different from the person who wrote her thesis at CMU, and different from the person who moved across the country to pursue a PhD, to begin this dissertation. I am hopeful that potential readers might benefit from what I’ve lived through.

I have something to show for the hard work of memory and writing in the end, and the best I can do, as Becker says, “is drop it into the confusion, make an offering of it, so to speak, to the life force” (1973, p. 285). And what am I dropping in besides my own confusion? Learning, yes, growth, sure, wisdom, probably—these are potential offerings to the life force, but are also personal and ongoing in the fluid process of relating to others that I am still learning to navigate today. All this is part of the *narrative education* I have cultivated by way of writing this dissertation. I have attempted to ask and answer questions about what it means to care, what makes caregiving difficult, and how I struggled to get past my own suffering to give direct care to my dad when he needed it.

In the end, my story is about living as a “young” caregiver confronted by a deeply complex, ongoing decision making process in one of my most important relationships: the bond I have with my dad as his one and only child, as his *daughter*. What narrative inquiry allowed me

to show is the challenging and exhaustive nature of taking care of my dad in his 60's while in my 20's, and its subsequent and enduring impact on our relationship. Living through, then writing this story is the only way 1.) I am able to show my love for my dad in juxtaposition with my desire to fulfill what I now understand as a moral calling, and 2.) I am able to illustrate my struggle to come to terms with what it means to live a good life, both academically and personally.

When my story began, I had no idea what I was signing up for by taking on this responsibility. I did not know what it meant, "to take care" of my dad, and how my life outside caregiving would be affected. This is what I meant, in chapter one, when I wrote: "The purpose of this dissertation is to examine narratively and question the paradigm shifts in identity that accompanied my role changes and reversals in this daughter-father caregiving relationship. What accompanied my paradigm shifts was an education in caregiving" (p. 6) and in living.

I attribute much of my ability to reprocess and learn from my experience as a young caregiver to storytelling and other artistic modes of representation. As Freeman writes, "poetry, poetic language, rather than entailing the imposition of meaning, entails disclosure [...] its aim being nothing less than the revelation of truth" (1997, p. 43). Stories in the form of poetry and prose subvert the dialectical tension of disclosure. Storytellers negotiate difficult choices to reveal and conceal information, and create new codes of meaning by telling the stories they need to tell in order to make sense of reality and learn something.

At CMU, I was determined to tell the world that what I'd learned was that the task of caregiving was wildly difficult and darkened by illness, turmoil, and exhaustion. I sought out studies that focused only on the negative elements and outcomes of caregiving relationships; this is what Freeman (1997) refers to as narrative foreclosure. Sometimes, we decide that our stories

are objective unyielding realities, experiences that will repeat themselves as fact and remain unchanged. Back then, I used my research to verify and validate what I was experiencing as “the burden” of my own troubled experience, even as I attempted to make the results “scientifically” verifiable. In retrospect I now see my approach to research as its own story, too, one I had foreclosed on from its beginning. Freeman warns that this is often the story we tell in narrative writing as well. Narrative foreclosure may compromise narrative integrity, projecting onto the future a bleak, predestined existence, devoid of reflection. If we foreclose on our stories, we see no possibilities, no other ways in which one’s life story might unfold. However, other paths, other ways of looking at others and ourselves, and other ways of responding that we are missing—not seeing—may be more fulfilling.

Freeman describes narrative integrity in the context of Tolstoy’s *Death of Ivan Ilych*, a story of a man “living his life without an ending in mind,” (1997, p. 388), who, on his deathbed, is able to reflect upon his past with dreadful hindsight and ask the question, “What is the right thing?” (p. 389). As he lies dying, Ivan struggles to see that his life was inauthentic and devoid of care until the onset of his illness when he comes to recognize a true friend in Gerasim, his caregiver. It is when Gerasim comes to his side to express compassion and empathy in Ivan’s time of need that Ivan begins to question the legacy of his life. Gerasim has already lived a good life, and this is why he can develop a strong bond with Ivan as he dies.

When Ivan realizes that he has not lived a good life—that his relationships, aside from the one he shared with Gerasim—were inauthentic, he feels free to die. Upon this realization, Ivan is able to experience joy in the moment before his death. This is the moral of the story: what helps a person make sense of death and mortality is *morality*, or living right. To Tolstoy, living right means living with an ending in mind. Your life is also your story, a story you refine by



learning as you go so that when your time to die comes it comes with a fine legacy, something to leave behind that you can accept, or better yet, something you can look back on and like.

Freeman notes that this process becomes destructive when we slip into deep regret and powerlessness over what one might consider doing “the wrong thing” in past relationships. But this process can also be transformative if we participate creatively in rewriting the self. This ability to rewrite the self is what Freeman means by *narrative integrity*, “the soundness and depth of one’s *ethical*—and, for some, *religious*—commitments, as evidenced by the shape of one’s life” (p. 388).

It is always and inevitably an act of self-transcendence; it is an act of divesting oneself a certain ‘blind view’ of things; of encountering face to face one’s own otherness; and, ultimately, of moving on to a more fully-realised mode of being human. (p. 389)

For me, this means practicing reflexivity to really look at my role, my actions, and my self-interests in this story. In preparing this chapter I now see that it is through autoethnography that I am able to study myself in my writing. Autoethnography has not only helped me to see me, but to see who it is I want to be and how I want to be perceived, to understand what makes a decent legacy, to understand what it means to be a whole, self-aware, virtuous person in the face of adversity. As MacIntyre writes:

Only in fantasy do we live what story we please. In life, as both Aristotle and Engles noted, we are always under certain constraints. We enter upon a stage that we did not design and we find ourselves part of an action that was not of our making. Each of us being a main character in his own drama plays subordinate parts in the dramas of others, and each drama constrains the others (MacIntyre, 2007, p. 213).

## **A Narrative Education**

When I stumbled into the caregiving role with my dad by my side, I entered a stage I had not designed, and became part of a physical and mental health breakdown that was not of my making. In this, I became the main character of my own drama, one I have composed in this dissertation; I also became a character in my dad's drama, and each of us constrains the other's drama in an important, lifelong relationship between parent and child that was abruptly and permanently altered (though neither of us completely forget the past, the many good days that preceded dad's stroke). It is difficult to understand my own role as a character in my dad's drama when he has hurt and rejected me, accosted and accused me. It takes focus and a keenly cultivated awareness to do so, a practice I am still attempting to become competent in.

From this turning point on, I utilized the chaos of life's episodic nature, which MacIntyre (2007) points to as incoherent, to create narrative unity by writing through the experience of caring for my dad, a task that is not yet finished. According to MacIntyre, we attempt to understand ourselves, at least morally, from the unity of a narrative, from looking back on our story in a coherent way. It is through this process that we come to ask ourselves, "What is the good for me?"

To answer this question is to attempt to understand how to live out narrative unity and bring my story to a sense of completion, even though it is ongoing and thus I cannot lay claim to an ending (only an anticipation of one). Moreover, to ask about my own "good" is to ask about the good of others, to ask how we can contribute to the good in others' lives throughout our own narrative quest to achieve it. The good is what gives the experience meaning, not just to me, the author, but to others who may read it. More importantly, the good is what gives the story a moral. In my story about caring for my dad, I am attempting to become the person I want to be,

whose life I can look back on with a sense of narrative unity, and to have my role in the drama be something I can live with, something with virtuosity.

My story about caring for my dad throughout the past decade is told with “a recollection merging into the ongoing business of living” (Birkerts, 2008, p. 6). Frank calls this a quest narrative (1995), a narrative that is “as much about the possible as it is about the actual” (Bochner & Riggs, 2014, p. 198). I call it a *narrative education* because it has allowed me to create space to make new truths out of the mess of memory and experience. According to Penn (2001):

When we look at our usual narrative mode within a social constructionist, collaborative frame, the first thing we think about is a concept called “coherence” which means simply: your story has to make sense to you, it has to cohere, hold together for you and for others (p. 37).

I am content to have told my story (which begins as a chaos narrative) as a coherent quest narrative that unfolds over time, and live it as a spiritual journey (Frank, 1995; Freeman, 1997). I have discovered that coherent storytelling has therapeutic value (Parry, 1991; Frank, 1995; DeSalvo, 1999; Bochner, 2000; Penn, 2001; Rosenthal, 2003; Charon, 2006; Bochner 2014; Bochner & Riggs, 2014) if done competently and reflexively. According to Peggy Penn, stories have healing power: “When we write...we are no longer being done to: *we are doing . . .*” (2001, p. 50).

According to Parry (1991), stories have inventive power, and have the ability to restructure both our lives and our ever-changing worlds, as this one has for me. Through narrative conversation and reflexivity, I have cultivated the desire and some of the ability to create positive change in my life, demonstrating the existential nature of autoethnography and the ways it has helped me to look back on and move through the experience of caring for my

dad; eventually I suspect it will help me move on from it. As for the positive change I speak of, I now attend weekly therapy sessions to work through harmful patterns of thinking and behavior. I have come to live a life I don't feel so alone in by letting my mentors, friends, and family help me when I need them most. I've been guided by my advisor, Dr. Art Bochner, who is helping me get over the fear of sharing my work with others. I have been loved, encouraged, and supported by three brilliant women who have mentored me as well, Drs. Carolyn Ellis, Lori Roscoe, and Heather Sellers. Overall, at the conclusion of this dissertation, I am restructuring my life purposefully to live it as a healthier, happier human being.

I came to graduate school to learn something about communication and interpersonal relationships, and what I've learned throughout my education is that *communication* is the crux of what constitutes relationship: it involves the fluidity of processing our experiences, while paying attention to the ways in which our best and worst selves influence those experiences in relation to others. Our decisions of how to cope with who we are at any given time, in the midst of our closest relationships, in the midst of crisis, in the midst of mortality, are what make this process so complex, mysterious, and at times, maddening.

Throughout the course of my story, I wrestle with the ways in which I think about myself—my consciousness—as I live through the experience of helping my dad. The thing is, living through the hard times made it possible for some of our more beautiful moments together as father and daughter. You may think a good story isn't complete without an end, without sought and found happiness, without "closure." But closure isn't real; we are always beginning and ending, and there is comfort in accepting this. Human beings do not simply exist in the midst of despair *or* happiness, we are both, but because we are trained in objectivity, in Cartesian

dualism, in right or wrong, it is difficult to cultivate balance, to practice steadiness, and to accept uncertainty.

I have learned, in meditation, in therapy, and through experience that there is comfort in *not* waiting for something good or bad to come along. I have also learned that staying present is hard work. But I am learning to seek relief by staying closer to each moment. There is comfort in *not* running away from responsibilities you've chosen or accepted, and there is comfort in escapism, too. There is a necessary balancing act between the two, and I have learned that it's not good to let either (or both) get the best of you. Just as right *or* wrong demonstrate dualistic (not dialectical) thinking, responsibility and escapism represent a similar dialectic. And two academic degrees later, it seems I have responded to what I am calling responsibility-escapism dialectical tension in a variety of ways (Baxter & Montgomery, 1998), with reframing and discussion occurring primarily in my therapy sessions, as I attempt to cultivate responses that nourish me.

It's a lifelong process.

The bond between my father and I has been strong since I was a little girl; it is visceral and it is flawed. As the various illnesses we experience together wax and wane, the bond weakens and strengthens time and again, but never breaks. In many ways, I often feel as if we share something akin to the same skin, that there is a space somewhere in the universe where the constellations of consciousness that remain separate here on earth overlap in me, in my dad and Sky, our little black dog. In the following sections, I reflect on parts of the narrative that I believe might benefit others in similar situations. After writing this story, after all my years of studying human relationships, after being a caregiver at a young age for a decade of my life, the questions

begged are these: What advice could I give another young caregiver in this situation? What would I tell myself to do?

What would I tell someone else to do, someone in a similar situation?

### **Take What You Want and Leave the Rest**

**Like a pro.** “A few minutes later, we're back on the highway, and my dad is talking about a cruise he wants to go on. Two days ago he handed me a pamphlet and said, "I got this and I thought maybe I could spend some money to go on this cruise ship, just for a month." I looked at the pamphlet and immediately noticed it was for a free-running bus for elderly folks. Like a pro, I didn't flinch. Instead of listing all the reasons that this would never work, I told him, in a chirpy tone, ‘Sure, we can check it out. I'll look into it.’” (p. 85).

As communication scholars, we know deception takes on many forms. We also know that benevolent deception is a road paved with good intentions. The question of ethical deception is an interpersonal problem as well as an ethical dilemma. My dad's belief in the cruise ship is an intrapersonal hopefulness, which I want desperately for him, in the midst of what often seems like a hopeless situation. My reaction is a rehearsed response. I have learned to validate him, to let his reality be as real as mine. If I were to give any caregiver advice about what it means to care for someone you love, I would tell this little story. There is no training on how to love someone, how to care for someone when they need you. It requires you to develop an unconventional set of skills. After a series of knee-jerk reactions that would instead invalidate my dad's reality, I discovered that real caregiving requires responsiveness to and validation of the other.

Like meditation, care is a practice. It is a meditation on love and respect, on validation and support. Validation is critical to successful relationships of any kind, and it has become a

different challenge when my dad becomes angry with me. When he accuses me of stealing from him, I react. I reject that version of reality. I have accounted for this lack of validation by visiting and calling less, which my dad says he wants. I don't believe it is what either of us wants, but we seem, at current, to have reached an impasse. I don't know how to validate his accusations. And my need for his validation goes unmet unless he lights up when I bring him the dog, and that is what I have now to be grateful for now, which is hard to digest as an entitled kid.

It is difficult for me to not need validation from my father, or feel entitled to it. He is someone I have known to look up to my whole life, the good and flawed man I learned love from. I suppose my best chance to alleviate this inevitable neediness is to remind myself that for many years, he was my caregiver. For many years, I was his priority. I was never the sad kid waiting on the porch with a fishing pole for a man who didn't show. I was never the kid who searched for my dad at my performances and didn't find him in the crowd. He was always there. Even when I'm sure he didn't feel like it.

We do what we can with what we have.

I have to remember that in comparison to him, I have a lot.

**Revisiting el diablo.** Today, I would tell myself to go over there to "El Diablo" (the assisted living facility) and see my dad. To stay calm and change the subject when he got started on the money rant. To stay cool and to accept him as he is, to keep it together and *not* let each bad experience, insult, or accusation feed my demons. If anything, I should be making friends with those demons. They are far more useful to me then, because then I can learn from them.

In many of these scenes, these lived moments, I am no longer a pro, no longer someone who can give someone else advice. I am a kid and my dad is yelling at me, telling me I'm a bad person. Of course I could handle it better, but I am flawed. I react. I don't respond. Don't spend

my time practicing, meditating on care. Most of us can't do that, and if anyone reading this is in my position or ever has been, they need to know that occasionally, it is okay to fall apart. It is okay to ask other people who love you for help and support.

I would tell myself to be mindful of my dad's experience, to remember that he is going through something too. Something worse. He is unable to walk, to have his dog, to be a dad like he used to, to give me advice, so he rejects me, though he has always said I was the best thing he ever did.

It's no wonder my dad sent William, the kids, and me away on Father's Day. He likely feels he's been replaced. What he needs to know, what I need to communicate to him before he dies, is that he can never be replaced. He projects his anger onto me because of all he's lost in the past ten years, and throughout those 10, I am the only one who has been here. That presence in this, which is often difficult, is also what makes caregiving sacred (Freeman, 1997).

His anger, which tends toward "you're stealing my money!" seems to me to be about something else. Money is the metaphor he's adopted, but it is *social* capital he misses. It is his identity as a father; not just any father, *my* father, an identity he has always been very proud of. I get blamed because my identity as a caregiver is adjacent to the stroke that took away his agency, his identity as a father, his dog—since he lost everything.

**My dad is my dad, no matter what.** If anyone is in a similar situation, remember that. Although your roles have changed, the person you are caring for still loves you as best they can, even if it is difficult for them to express it. An example of this from my story follows:

"The next-next day I go to his apartment to refill his meds. Near the phone is a sheet of cardstock, presorted standard U.S. PAID mail, addressed to "Residential Customer." In black



pen and capital letters the first time and all lower-case the second, with the letter D intermittently written as an F or B, it says:

‘TALK TO ERIN ABOUT HER ATTITUDE.’

‘talk about attitude’” (p. 109).

Though my dad struggled a lot with his inability to be like he used to, to be independent and in charge, he held on to his role as my dad as long as he could, and would return to it as frequently as possible. When he talked to me about my drinking, about my attitude, tears rolled down my face as I walked around the bungalow I lived in then, listening. Not just listening, but listening as a kid, as his young daughter. I loved feeling like his daughter again. I’ve missed it.

**Waking up a different person.** “I just want to forget everything, wake up a different person. Like my dad did” (pp. 41-42). At this point in the story, I am struggling to get my dad on public assistance and am in survival mode, in the midst of a chaos narrative (Frank, 1995). I have just started my graduate program at CMU and I am bitterly spending my time waiting in line at government agencies and filling out paper work. The rest of the time, when I have time to think, I feel irrevocably sad and alone.

I *did* want to wake up a different person, someone with a happy, easy, youthful life: a 24-year-old young person with stable, healthy parents. At this point, I want to disassociate from myself-as-caregiver, but I cannot. This one identity marker is a major focus of this story, with myself-as-graduate student in second place, and my “true” self, the one who encompasses all these roles and swings back and forth between fulfilling my responsibilities and escaping from everything in any way that is available, that’s the self that is casually mentioned, the self that comes in and out of the story like ether, the drunk, high girl. She is in last place. She is the contradiction to the responsible young caregiver and the responsible young graduate student.

But she's okay. She has to be.

When I was the caregiver sitting in that plastic chair at the Department of Human Services filling out that booklet of questions I didn't know the answers to, I was simply reacting to my life, not responding to it. Then, I continually reacted to potential emergencies, one after the other, and was worried sick all the time. It was and is love that keeps me at my dad's side, even though at times, I wish someone, anyone else could do it for me, because I'm exhausted. The times when I'd bring him groceries or medicine (at this point in the story, back in Michigan) were good; we'd talk and laugh. He'd be grateful and show it, and we always shared a big, standing hug goodbye that we held a long time. Sometimes I'd stand on my toes and kiss him on the cheek, something I hadn't done since I was a little girl. Now I kiss his head when I leave him, as infrequent as our visits have become. Only no more standing hugs. Most times, he won't stand up because he can't. And when I go to see him, he barely looks at me. It is my hope that when he sees me graduate, our relationship will be restored and our visits more frequent; he is so proud that I am getting my PhD. Before, when he was still in his apartment with Sky, he often said, "One day you'll be Dr. Scheffels. Wow!"

My dad's slow deterioration has been, and continues to be, difficult to watch. Each painful little loss he experiences hurts me too. His losses are my losses, and are related to my escapism, my drug and alcohol abuse. And when I escape, I am a different person. Someone unencumbered, not worried or stressed. Someone who says what's on her mind, someone who socializes with and entertains people her own age—that someone. So really, I wanted to wake up as me, without my dad as a responsibility, with my sense of normalcy, stability, and freedom restored. And that's okay—normal even.

Always take breaks when you need them.

**My pretend family.** “Shelly and Ed like to party and I take every chance I get to hangout with them. Sometimes, I’ll pretend they’re my parents. That their daughters Alex and Ashley and son Robert are my siblings. That we all have a great friendship and that nothing about my life now truly exists” (pp. 56-57).

This part of the story emphasizes my plight.

I wanted “normal” parents. Back in Michigan, I felt so alone. I wanted a family to take care of me. I felt as if I’d gotten a raw deal with my dad’s stroke and my mom’s lack of involvement. The feeling reminds me of getting sick as a kid and suffering, and asking no one in particular, “Why me?” Why don’t I get the care I want? The care other kids seem to get from their parents? But, looking back, that question implies that the hardship should have befallen someone else instead. Now, that child-like expression of ego is something I have become critical of; it’s okay to be sad, but it’s not okay to want to pass your sadness on someone else.

Let yourself feel pain when you have the time and space for it. Hiding from pain, or running away from it doesn’t work. Pain is perhaps the greatest source of learning.

**Messages of love.** “I love you!” I rush this in before we hang up, and it comes out forcefully, as if I can somehow save myself from feelings of guilt and infinite loss with these three words” (p. 78). “It easier to be parent than a loving parent, easier to be a child than a loving one,” Jules Henry says in *Messages of Love* (1971, p.195). Henry says that family neurosis is learned and passed down as means of gratification that have to be met by both parent and child. He posits that some families lack compassion for one another and struggle to give one another what they need (1971). Throughout the course of writing this dissertation, I learned it is important to have compassion toward my dad even when it is hard to do so. I learned to try to remain mindful of his limitations when he rages at me, in spite of the guilt, the feelings of loss,

the indignation. In the pathological families Henry studied, it was often that the expected means of satisfaction (that the parent will satisfy the child's needs and not the other way around) were not met. In family structures where children take on the parental role or parents fail to, messages of love become distorted.

But that doesn't mean the love isn't there, that it doesn't exist.

### **Relational Ethics in Narrative Writing**

Though I am the author of my dissertation, this work is also about others, namely my dad. As Ellis says, I do not alone own my story (2009), and this is why I have changed the names of most of the characters, aside from my committee members, my best friend, and my immediate family members. I am aware that my dad and the other people I write about also have stories about the same events I have divulged in this dissertation, stories they are unable (or unwilling) to tell in a public venue such as this one. Andrew (2017) urges me to think of the impact my story might have on the people I write about. My dad says extensive reading is too difficult in his condition, but "to write whatever I want about him." This is complicated, because his consent is also colored by his stroke, as is his ability to read it.

Nonetheless, I have worked hard to demonstrate the nuances and beauty of our relationship in the face of adversity. I have always thought my dad is brilliant, hilarious, loving, and thoughtful, and I always will. As I wrote his character, I wanted to show readers that in spite of the stroke, all of these qualities are still in him; he continues to laugh at my jokes and express himself in words of the wise.

When I was six I interviewed my dad for a first grade assignment. All I remember is sitting with him at the white kitchen table, the paper handout with the double spaces and the dashes sitting in front of me, a pencil in my hand. I can only recall the last question on the

handout. It was “How do you want to be remembered?” He thought about it long and hard before saying, “I want to be remembered as a well-rounded person.” And I remember saying, “You are a well-rounded person, dad.” I believe this dissertation honors him and represents him as the “well-rounded” person he once told me he wanted to be considered, or “remembered as”. In spite of all these ethical considerations, I fear that putting my story out there opens it and my life up for harsh criticism.

It’s a real fear and it needs to be recognized and overcome. That’s because there’s no point in writing if you can’t overcome it. There’s no point in writing if you are going to avoid offending, even hurting people. You have to believe in the story. Great non-fiction writers, great journalists—even not so great ones—believe in the importance of the story. The story is its own justification. And the story is their story. The writer owns it (Gawenda, 2013, p. 11).

In parts of the narrative in Chapters III-V, I have depicted my mom’s character in ways that could hurt or offend her. I’ve decided I’m okay with that. If she wants to read it, she can. Maybe it would help us repair our relationship and forgive one another. Maybe not, but either way this story belongs to me and I believe in it. Yes, I have included others as characters, but I am wary of the fact that my interpretation of events is bound to be different from theirs.

I am also aware that I am working with a flawed memory and that my memories will differ from the memories of others. Crites says stories are “moving forms, at once musical and narrative, which inform people’s sense of the story of which they are a part (2001, p. 31). He calls these “sacred stories” because they are fundamental in creating a sense of self, as imagination and memory merge in each retelling.

I am working with a flawed memory, and imagination is what fills in the blanks but also allows for the story to speak, for mine and my dad’s voices to come through it. I should also

mention that the memories of others helped me write this story as well. My Uncle JR contributed with the story “The Dog Pound” and knows it is included in my dissertation. The day he told it, I said it would be written about and published, and he was happy to have helped. Moreover, as I wrote the narrative, I asked my dad to recall events I wanted to include, events that are his memories, not mine. Examples include: what the preacher said at his dad’s funeral, what his dad said before he died, and what his dad said about the people driving around in their cars.

“Where are they all going?” he’d say.

### **The Writing Process**

Needless to say, writing an autoethnographic dissertation is a daunting task. Little did I know just how daunting it would be until I began writing bits and pieces of my life in narrative form. This alone was emotionally taxing, but a source of pride and productivity as well.

For a long time I wrote in a journal about caring for my dad, and returning to the emotion I felt when I wrote those entries, then turning them into memories, only to write those memories into vivid scenes was painful indeed. Needless to say, I wouldn’t often be in the mood to write. Sometimes Lorraine (my best friend and writing partner) and I would perform rituals to inspire ourselves. It started with a meditation technique we learned from Dr. Heather Sellers, who taught us to quiet the mind and drop into memory, letting it come to us rather than reaching for it desperately. We practiced this at the table in our house on Suwanee Avenue, our purple “Spirit of Writing” candle lit, at the table in our apartment on Central Avenue, candle also lit. Other times we would sit with our journals at Oak Lawn cemetery and free write (no candle needed when surrounded by the dead). Other times we visited a picnic table at Lowry Park every day, and yes, the candle was lit there too (as long as it wasn’t too windy).

After much writing and revising, what I found myself with was a collection of scenes that I wrote at different times, memories I wanted to turn into a story, but they seemed to follow no sequence; they did not hang together. In creative nonfiction, Dr. Heather Sellers taught me to fashion scenes that readers can easily imagine, among countless other strategies that have made my story what it is today. One of the skills she taught me was that a story line should be tight, with each scene positioned like a bead on a string. I finally figured out that I was making the task of arranging my story more complicated than it is. To organize the story, I simply needed a timeline. So I went through everything I had written and put it in chronological order, just as it happened. Then, my dissertation was finally a story with a beginning, middle, and end, as my advisor Dr. Bochner had urged me to do from the start. Back then I was more of a novice and stubbornly, I wrote in a pastiche, disconnected way and for some time, dug my heels in.

And I was sad, sometimes struggling to get out of bed.

My account would be remiss if I failed to mention that my bouts of depression stunted my writing at times. Fits and starts and drinking away my sorrows were all part of the process. At times I wanted to quit, give up and move on with my life. But with the support of my friends and family, the little shoves from Lorraine when I need her most, the look of pride on my dad's face when he calls me a future doctor, I made it to the end.

That is why this dissertation is dedicated to him.

## CHAPTER VII

### **Family, Interrupted**

Families are systems wherein communication patterns outlive our predecessors. These patterns are inherited and are the truest and most haunting of ghosts that possess us at times, for better or worse. My family structure and its communication patterns exist in me, or are interjected, as Laing (1969) puts it. I think of it as a prism of possessions that often require exorcisms.

What I mean by this is that my mother's violent, raging alcoholic father passed down a loud, scary banshee of a ghost, while my father's family's rage and violence existed in silence, the kind of ghost that sits by your side at night, making you cold and afraid, the worst part being you are aware of him, you know he's there and you know why.

My dad always says that his dad promised him he would tell him when he died if there was anything on the other side. After the stroke that ended his life, his dad never did come back or send any sort of correspondence in regard to what happens after death, my dad says. But I think he's wrong, missing something, unaware that his dad lives on in him, and that this is his only way of telling him something important about life and death.

His dad's drinking, smoking, stoicism, and indifference toward my wonderful and beautiful grandmother lives on, along with his cutting wit and knack for observing the world closely and describing it in interesting ways. His dad lives on in my dad's drinking and stoicism,



gambling and indifference toward women and the world. He lives on in the version of my dad's masculinity that had a stroke, devalues women, the version that hurts me the most. His dad lives on in the version of my dad that I admire the most, too; the well-rounded guy and all-knowing badass with a sense of humor and sharp intellect I've been lucky enough to come to possess, the man who has always been my hero, my idol who has also come to possess me.

My mother's father and mother live on in a communication pattern between us that we have been working on improving in vain on and off throughout my adult life. The trauma of her father's violence was accompanied by her role as her mother's confidant, which may be related to the distance between us; it is her instinctive way of protecting me from her trauma. Paradoxically, the distance between us likely instills her family sickness in me more than a close relationship would. She is afraid of her worst self, but so am I; my role in this has been damaging, too, and has reproduced degenerative spirals in our communication that continue to haunt us, to maintain the distance between us.

When I talk to my mom, she typically focuses on her current accomplishments, her current joy, and avoids the topic of my life for long periods of time; she can talk forever without letting me get a word in, and usually, I let her; it's just easier than struggling to say something I want to say. It is as if she shows no interest in me unless she's upset—then, in a rage fueled by fear, she either cries or attacks (sometimes both).

Over the course of writing this dissertation I've come to understand that the distance she maintains between us is a learned defense mechanism that I have been taught to rely on as well. Though we have gotten better at connecting over time, the pain of her childhood lives on in her neurological pathways; it cuts deep, and my indifference and vacillation between silence and

rage hasn't been helpful. But we seem to get better with time, and I am confident we will continue to do so.

In summary, the relationship between my mom and dad was built on family communication patterns of yelling and saying terrible things or keeping your mouth shut when you're feeling less than normal or good; this is why they are no longer married. That, and my dad's drinking—the way he learned to keep his mouth shut is incidentally the same way she learned to yell. The night he opened that beer and she snapped and started yelling, igniting a screaming match that ended in physical violence was the first and last time, severing their marriage on impact.

To my mom, my dad's drinking was a source of violence. She associates the trauma of living with her dad and her lost childhood with alcohol. When I still lived at home, she would describe the way her dad used to decorate the family Christmas tree to me every year; needless to say, he was hammered drunk. It would start out as a joke, both of us laughing about the part where he'd throw tinsel all over the house, but as she got to the part where her dad punched her little brother in the face, her laughter would turn to tears and she would quickly walk away from me. Because of her fear of alcoholism and the depths of her parental love, she was aggressive in her policing of me as a teenager, always worried I was drinking. She'd predict I would become an alcoholic like her dad, like my dad; "It's genetic!" she'd say.

And in all that emotional turmoil, in all our bad behavior and questionable decisions are our family's enduring messages of love (Henry, 1971). It may be true that I have inherited what was historically classified as "melancholia," or "alcoholism." Perhaps I just grew up in circumstances that were difficult and sad, like my parents did. But, in *The Loss of Sadness* (Horowitz and Wakefield, 2012), the authors question how we distinguish normal sadness from

pathological sadness. What they find is that we don't, especially in contemporary America. Real depression, they say, has a life of its own that imposes itself on those of us who suffer from it. Depression is something that takes over, possesses you. I have certainly been possessed by it at times, but I have also suffered from normal sadness related to my dad's stroke, his deterioration, and my anticipation of his eventual death. In their book, Horowitz and Wakefield discuss a case wherein a woman's daughter is diagnosed with a life threatening illness, yet, because of the depth of her sorrow about the impending loss of her child, she would meet the criteria for a depression diagnosis.

What is scary about the implications of Horowitz and Wakefield's (2012) claims is the idea that nobody should be sad; it is a tacit cultural norm to boast about happiness and achievement and conceal sadness and grief, that it is unattractive, distresses others, and is unpleasant in general to deal with. Huxley's *Brave New World* (1932) comes to mind, a population that functions robotically with staunch, somatic obedience.

Sadness is stigmatized—we consistently say everything is fine when it isn't, report to others that we're doing well when we're not, and say we've had a good day when we didn't. If we are privileged enough, we share our sadness with our therapists. As R. D. Laing says, for the “mentally ill,” the therapist's office is,

a relatively safe place to tell someone what they really think. They are prepared to play at being a patient and even to keep up the charade by *paying* the analyst, providing he does not ‘cure’ them...not an unreasonable contract (1969, p. 43).

### **Community, Interrupted**

Foster and Bochner (2008) point to the interaction between the cultural constructs that structure reality and personal experience when they write “...narrative research embraces the

details of lived experience, the reflexive relationship between personal interaction and cultural contexts, and the dialogic and dialectical complexity of relationships and communities” (2008, p. 92). Our stories, propelled by language, are analytic glue—they hold us together, connect us to another, and merge the self and society. Through a process of writing my caregiving story as inquiry (Richardson, 2000), I weave in literature to probe for reflexivity, supplement my understandings of self and other, and understand the emerging function of my story within a larger cultural framework. I live and write to navigate my experiential and formal education as caregiver, to subvert dominant discourse and develop as a character in my story, as a whole person merging different and often conflicting selves to make meaning of a life worth living.

When I tell people I take care of my father, I often receive praise, and commonly hear the comment that, “Not a lot of people would do what you are doing.” Others are often startled that this responsibility has fallen to me before being intercepted by someone else in my family. The reason it fell to me is because no one else would do it. I chose to care for my dad while others did not, because I was the first person called, as far as I know. It never occurred to me to say “no.” Because I am his daughter, and it typically does fall upon children to care for their parents when they age—just not quite as soon, and usually when children are grown with established careers, partners, and homes. But no matter your age, caregiving is a choice to make sacrifices for people we love; or perhaps it is not a choice, but a service we are called to as family, neighbors, and friends. So I find it hard to believe that a lot of people wouldn’t do what I’m doing, what I did. The caregiving statistics suggest that a lot of people *do* (43.5 million in America alone).

The literature reviewed on youth caregivers suggests that data on this subject are primarily quantitative and offer few comments or insights on gender, race, and culture; nor does

the plethora of research on older caregivers published in gerontology, psychology, and communication journals (Kane & Kane, 1982; Smith, 1985; Brody & Schoonover, 1986; Hofland, 1988; Pilisuk & Parks, 1988; Pearlin et al., 1990; Wood, 1994; Davenport, 1999; Blankemeyer & Pinkard, 2000; Musil et al., 2003; Wehtje Winslow, 2003; Baus, et al., 2005; Malhotra, 2006; Dysart-Gale, 2007; Frank, 2008; Yedidia, 2008; Burgio et al., 2009; Robinson & Tian, 2009; Roscoe et al., 2009; Centers for Disease Control and Prevention, 2010; Butler, 2013; Institute of Medicine, 2014; Family Caregiver Alliance, 2015). In other words, while useful, it does little to provide a big picture of the experience and demands of caregiving..

Perhaps my privilege of becoming a graduate student, of being surrounded by a supportive community, of being a young white woman in the academy, will not do much to add to the color of current caregiving research. But hopefully, it adds to the content. As a narrative writer, I am only able to offer my own social position, though I have kept it mind that it will not necessarily reflect the experiences of others with less privilege. It seems that those with less privilege than White Americans do not see caregiving as a burden (Roth, et al., 2015). I wonder if this is because many Black and Hispanic Americans deal with much worse each day and have stronger, more tightly knit communities of care.

Julia Wood once wrote,

Being able and willing to care for others is essential for building strong interpersonal relationships and for creating a social fabric that allows us all to live with a modicum of comfort, security, and grace. We want to believe someone will be there for us if we cannot fully care for ourselves; we need to be there for others when they require help, nurturance, or support; most of all, we need to understand that all life is necessarily, intimately interrelated and, thus, our individual and communal lives are intertwined. How

we regard people who need help and how we respond to them contribute to the overall cultural attitude that influences how others treat us when we, in our turn, need help (1994, p. 3).

In her book, *Who Cares?* Julia Wood warns us about the impending crisis of care that threatens the Western world. I am indeed, 24 years since she wrote the book and 10 years since I began taking care of my dad, a product of this crisis, as is my family. Our cultural attitudes about how we regard people who need help have become more disparaging for the helpless over time, erasing them from our communities and invalidating the people who care for them. And cultural bigotry erases entire communities that have healthier perspectives regarding family, community, and care.

The politics of individualism are personal, and the consequences are often dire.

It is not that the crisis of care is a result of something we will not do, the true crisis is that it is something most of us *will* do, and for many it will be costly because most of us are unprepared. That said, the argument between me and my late friend Jon that happened in Tony's Bar in Mount Pleasant in 2010 tells me something quite different now, looking back. Though Jon and I disagreed on just about everything about politics and policy, we wanted many of the same things for other human beings. What Jon was attached to was a staunch romanticism about the American Dream, and he often failed to see its connection to the bleak truth of the American situation. Jon's casual idea that taking care of your family, "your own," as he put it, is a highly revered American value, yet this idea is also evidence of an American attitude that segregates and isolates us from those who do not share our DNA. Like Jon said, "You are okay. You're sitting here, aren't you? So your dad had a stroke. You're handling it. In America, beer in hand. I'd say you're doing fine, goddammit." This is easy to say when it's not you or one of "your

own." But that attitude doesn't address the true structure of our families, of our communities, or our society. Because of this, at the end of our time here on earth not all of us will be able to say that we have lived a good life. Writing this dissertation has changed my mind about what I have lived through, what I have to say, and where I might go from here as a writer. It has taught me the true meaning of a good life and moved me to pursue it.

In comparison to many other cultures, we suffer from a lack of family and community support in this country and this prevents many of us from knowing a good life; this is often the cold truth of the American situation and it diverges from the warm and fuzzy story of the American family and the American Dream; these values and attitudes are reproduced in language and reinforced by our social structure, and are in direct opposition to the truth, which is that many Americans struggle to survive with little to no help from others. Take care of my dad, alone? I don't have the kind of family that is capable of that. It's just me trying to be an adult and my mom somewhere else trying to take care of herself. And, that night at Tony's, it seemed impossible for Jon to understand that. But I was wrong. He did understand, only in a different way.

Jon would sometimes hangout behind Tony's, sit near the Isabella River for hours smoking cigarettes and helping the folks who lived in the trailer park on the other side of the river hunt turtles, so they could eat and feed their kids; he did this with no search for praise or respect; to him, it just made sense. That night at Tony's I wrote about in my story detailing the political conversation about caregiving between us, was written before he died. Now Jon is gone and I see that memory as a clear example of the debilitating loss of effective dialogue in American politics. A lack of dialogue, of acknowledging the other's social position, makes caring for the other an extra step that many are not willing to take.

Now when I think of Jon, I'm reminded that there is a born turtle hunter in most of us, ready and waiting to do whatever it takes to help someone make a soup. Living a good life means recognizing the good in others and yourself. It means caring for others, and facing life with a final chapter in mind.

Then, in the end, everything *will* be fine.

### **Epilogue: Sky Bear and the Heart that was too big**

I arrive at the emergency room for dogs with Sky panting in the back seat of my new Subaru, courtesy of William and our third anniversary. A glowing sign that says Veterinary Services beams down as I pull into a parking spot. I bring Sky inside and they weigh him and put us in a little room. A guy in scrubs sticks a thermometer up his butt, and I look at Sky sympathetically. He's unpleasantly surprised, turning his head toward the man to see what's going on back there.

"He's not breathing right. This morning he was wheezing," I tell the guy with the thermometer.

An hour of waiting goes by before the veterinarian comes to listen to his lungs and his heart.

"I hear a heart murmur, it could be a few different things, but we won't know until we X-Ray him," she says.

Another hour of waiting. Finally, they take a reluctant Sky Bear out of the little room and into the back room and send me into the lobby.



Another hour of waiting. I sit on the floor with my phone plugged into the wall, texting William. “This sucks, I should be writing my dissertation,” I tell him. “I know, baby,” he says. “Thank you for taking care of this.” Then the tiny exam room door opens.

“For Sky?”

“Yep right here,” I say, unplugging the phone and scrambling to my feet.

The veterinarian sits down to face me. I can tell that whatever she’s going to tell me is not good.

“It’s what I thought it was. He’s got grade four congestive heart failure,” she says. “Heart disease is common in cocker spaniels his age. He will be fine as long as we can keep him comfortable and keep the fluid out of his lungs. His right ventricle is enlarged, and it’s not pumping blood evenly into the lungs. He needs some medications; two are diuretics. Sky will need one pill every 24 hours of one diuretic, and one and a half pills every 12 hours of the other. The other pill is a heart medication that’s also prescribed for people, you can get it at any pharmacy with this prescription.” She hands me a piece of paper. He will need three quarters of a pill every 12 hours with that one, too. He will need to pee a lot, too, so you may want to put pee rugs down.”

“How long will he need to be on these meds?”

“Well, until his heart fails” she says.

“Okay,” I say, petting Sky’s little black head.

*So until he’s dead.*

## REFERENCES

- Alexander, B. K., Moreira, C., & kumar, h. s. (2012) Resisting (resistance) stories: A tri-  
autoethnographic exploration of father narratives across shades of difference [abstract].  
*Qualitative Inquiry, 18*(2), 121-133.
- Anderson, W. T. (1995). *The truth about truth: De-confusing and reconstructing the Postmodern  
World*. Warner Books.
- Andrew, S. (2017). *Searching for an autoethnographic ethic*. New York: Routledge.
- Bahrampour, T. (2015). Self-absorbed millennials? Not the ones who are caregivers for their  
elders. *The Washington Post*.
- Bateson, G. (1980). *Men are grass: Metaphor and the world of mental process*. Massachusetts:  
Lindisfarne.
- Bateson, M. C. (1991). *Our own metaphor: A personal account of a conference on the effects of  
conscious purpose on human adaptation*. Washington, DC: Smithsonian Institution Press.
- Bateson, M. C. (2005). The double bind: Pathology and creativity. *Cybernetics And Human  
Knowing, 12*(2), 11-21.
- Bateson, G. (2000). *Steps to an ecology of mind*. Chandler, New York: Ballantine Books.
- Baus, R., Dysart-Gale, D., & Haven, P. (2005). Caregiving and social support: A twenty-first  
century challenge for college students. *Communication Quarterly, 53*, 125-142.
- Montgomery, B. M., & Baxter L. A. (1998). *Dialectical approaches to studying personal  
relationships*. Mahwah, NJ: Lawrence Erlbaum Associates.

- Beck, A.T., Ward, C.H., Mendelson, M., Mock, J., Erbaugh, J. (1961). An inventory for measuring depression. *Archives of General Psychiatry* 4: 561-571.
- Becker, E. (1973). *The Denial of Death*. New York: Simon & Schuster.
- Berger, P. & Kellner, H. (1964). Marriage and the construction of reality: An Exercise in the microsociology of knowledge. *International Council for Philosophy and Human Sciences* (12)46, 1-24.
- Berry, K. (2012). Reconciling the relational echoes of addiction: Holding on. *Qualitative Inquiry*, 18(2), 134-143.
- Birkerts, S. (2008). *The art of time in memoir: Then, again*. University of Michigan: Graywolf Press.
- Bochner, A. (2017). Heart of the matter: A mini-manifesto for autoethnography. *International Review of Qualitative Research*, 10(1), 67-80
- Bochner, A. (2014). *Coming to narrative: A personal history of paradigm change in the human sciences*. Left Coast Press.
- Bochner, A. & Riggs, N. (2014). Practicing Narrative Inquiry. In P. Leavy (Ed.) *The Oxford Handbook of Qualitative Research*, pp.195-222.
- Bochner, A. P. (2012). Bird on the wire: Freeing the father within me. *Qualitative Inquiry*, 18(2), 168-173.
- Bochner, A. (2007). Notes toward an ethics of memory in autoethnography. In *Ethical Futures in Qualitative Research: Decolonizing the Politics of Knowledge*. N. Denzin and M. Giardina (Eds). Walnut Creek: Left Coast Press, pp. 197-208.
- Bochner, A. P. (2002). Love survives. *Journal of Qualitative Inquiry* 8(2), 161-69.
- Bochner, A. P. (2001). Narrative's virtues. *Qualitative Inquiry*, 7, 131-157.

- Bochner, A. P. (2000). Criteria against ourselves. *Journal of Qualitative Inquiry* 6(2), 266-272.
- Bochner, A. P., Ellis, C., & Tillman-Healy, L. (1998). Mucking around looking for truth. In B. M. Montgomery, & L. A. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 41-62). Mahwah, NJ: Lawrence Erlbaum Associates.
- Bochner, A. (1997). Narrative and the divided self. *Qualitative Inquiry*, 3, 418-438.
- Bochner, A., & Ellis, C., (1992). Personal Narrative as a social approach to interpersonal communication. *Communication Theory*, 2(2),165-172.
- Bochner, A. P. (1984). The functions of communication in interpersonal bonding. In C. Arnold & J. Bowers (Eds.), *Handbook of rhetorical and communication theory* (pp. 544-621). Boston: Allyn & Bacon.
- Bornstein, K. (2010). *Gender Outlaws*. Seal Press: New York.
- Brody, E. M., & Schoonover, C. B. (1986). Patterns of parent-care when adult daughters work and when they do not. *Gerontologist*, 26, 372-381.
- Burgio, L.D., Collins, I. B., Schmid, B., Wharton, T., McCallum, D., & DeCoster, J. (2009). Translating the REACH caregiver intervention for use by area agency on aging personnel. *Gerontologist*, 49, 103-106.
- Butler, K. (2013). *Knocking on heaven's door: The path to a better way of death*. New York: Scribner.
- Centers for Disease Control and Prevention. (2016). Caregiving: A public health priority. Retrieved from <http://www.cdc.gov/aging/caregiving>.
- Clough, P. T. (1997). A Reading of Carolyn Ellis' Final Negotiations. *The Sociological Quarterly*, 38(1), 95-110.

- Crites, S. (2001). The narrative quality of experience. In L.P. Hinchman & S.K. Hinchman (Eds.), *Memory, identity, community: The idea of narrative in the human sciences* (pp. 26-50). Albany, NY: Sage.
- Davenport, G. M. (1999). *Working with toxic older adults: a guide to coping with difficult elders*. Springer: NY.
- Dellman-Jenkins, M., Blankemeyer, K., & Pinkard, O. (2004). Young adult children and grandchildren in primary caregiver roles to older relatives and their service needs. *Family Relations, 49*, 177-186.
- DeSalvo, L. (1999). *Writing as a way of healing: How telling our stories transforms our lives*. San Francisco: Harper.
- Dillon, P. J. (2012). UnBalanced: An autoethnography of fatherhood in academe. *Journal of Family Communication, 12*, 284-299.
- Dunleavy, K., Wanzer, M., Krezmien, E., & Ruppel, K. (2011). Daughters' Perceptions of Communication with Their Fathers: The Role of Skill Similarity and Co-Orientation in Relationship Satisfaction. *Communication Studies, 62*(5), 581-596.
- Dysart-Gale, D. (2007). Respite: Cultural values in North American and Caribbean caregiving. *Canadian Journal of Communication, 32*(3), 401-415.
- Ellis, C. (1995). *Final Negotiations: A Story of Love, Loss, and Chronic Illness*. Philadelphia: Temple University Press.
- Ellis, C. (1996). Maternal connections. In Ellis, C., & Bochner, A. P. (Eds.). *Composing Ethnography: Alternative Forms of Qualitative Writing* (pp. 240-43). Lanham: Altamira Press.

- Ellis, C., Kiesinger, C. E., & Tillmann-Healy, L. M. (1997). Interactive interviewing: Talking about emotional experience. In R. Hertz (Ed.), *Reflexivity and voice* (pp. 119-149). Thousand Oaks, CA: Sage.
- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: Left Coast Press
- Ellis, C. & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity. In Norman K. Denzin & Yvonna S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp.733-768). Thousand Oaks, CA: Sage.
- Ellis, C. (2001). With mother/with child: A true story. *Qualitative Inquiry*, 7(5), 598-616.
- Ellis, C. (2009). *Revision: Autoethnographic reflections on life and work*. Walnut Creek, CA: Left Coast Press.
- Ellis, C. & Rawicki, J. (2013). Collaborative Witnessing of Survival during the Holocaust: An Exemplar of Relational Autoethnography. *Qualitative Inquiry*, 19(5) 366-380.
- Ellis, C. & Patti, C. (2014). With heart: Compassionate interviewing and storytelling with holocaust survivors. *Storytelling, Self, Society* (10)1, 8.
- Family Caregiver Alliance (2015). Selected caregiver statistics. Retrieved from <https://caregiver.org/selected-caregiver-statistics>
- Family Caregiver Alliance (2015). Millennial Caregiver Profile. Retrieved from [http://www.caregiving.org/wp-content/uploads/2015/05/Caregiving-in-the-US-2015\\_-Millennial\\_CG-Profile-FINAL.pdf](http://www.caregiving.org/wp-content/uploads/2015/05/Caregiving-in-the-US-2015_-Millennial_CG-Profile-FINAL.pdf)
- Frank, A. W. (1995). *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.

- Frank, J. B. (2008). Evidence for grief as the major barrier faced by Alzheimer Caregivers: A Qualitative Analysis. *American Journal of Alzheimer's disease and Other Dementias*, 22(6), 516-27.
- Frankl, V. (2006). *Man's Search for Meaning*. Boston, Beacon Press.
- Freeman, M. (1997). Death, narrative integrity, and the radical challenge of self-understanding; A reading of Tolstoy's Death of Ivan Ilych. *Aging and Society*, 17, 373–398.
- Freeman, M. (2010). *Hindsight: The promise and peril of looking backward*. New York: Oxford University Press.
- Foster, E., & Bochner, A. (2007). Communication as social construction. In *Handbook of Constructionist Research*, J. Holstein & J. Gubrium (Eds.), Guildford Press, pp. 85-106.
- Gale, K. (2012). Knowing me, knowing you: Becoming father, becoming son in the fluid play of memory, affect, and intuition. *Qualitative Inquiry*, 18(2), 149-152.
- Geertz, C. (1973). *The interpretation of cultures*, [Basic Books](#): New York.
- Gergen, K. J. (1997). *The cultural consequences of deficit discourse*. Harvard University Press.
- Gergen, K. J. (1994). *Realities and relationships: Soundings in social constructionism*. Cambridge: Harvard University Press.
- Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity*. Touchstone: reissue edition.
- Goodall, H. L. (2012). The fatherland museum. *Qualitative Inquiry*, 18(2), 203-209.
- Goodall, H.L. (2000). Voice, reflexivity, and character: The construction of identities in texts. In *Writing the new ethnography* (pp. 131-151). Cumnor Hill, Oxford, England: Altamira Press.

- Greenberg, G. (2012). *Manufacturing depression: The secret history of a modern disease*. Simon & Schuster.
- Guberman, N., Lavoie, J., Blein, L, Olazabal, I. (2012). Baby boom Caregivers: Care in the Age of Individualization. *The Gerontologist* 52(2), 210-218.
- Hacking, I. (1999). *The social construction of what?* Harvard University Press.
- Hacking, I. (1998). An indeterminacy in the past. In *Rewriting the soul: Multiple personality and the sciences of memory*. Princeton University Press.
- Hayes, C., de Arroyabe, E., & Calvete, E. (n.d.). Positive Aspects of Caregiving in Spanish Caregivers of Individuals With Acquired Brain Injury. *Rehabilitation Psychology*, 59(2), 193-202.
- Henry, J. (1971). *Pathways to madness*. New York: Random House.
- Hinck, S. S., & Scheffels, E. L. (2015). Transforming argumentative dialogue in prison service-learning projects. *Argumentation and Advocacy*. 51(3), 135-213.
- Hofland, B. F. (1988). Autonomy in long-term care: Background issues and a programmatic response. *Gerontologist*, 28, 3-9.
- Horowitz, A. V. & Wakefield J. C. (2012). *The loss of sadness: How psychiatry transformed normal sorrow into depressive disorder*. Oxford University Press: Reprint edition.
- Huxley, A. (1932). *Brave New World*. New York: Harper Brothers.
- Institute of Medicine (2014). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Committee on Approaching Death: Addressing Key End of Life Issues. Available from the National Academies Press at [http://www.nap.edu/catalog.php?record\\_id=18748.PDF](http://www.nap.edu/catalog.php?record_id=18748.PDF)



- Jago, B. J. (2002). Chronicling an academic depression. *Journal of Contemporary Ethnography*, 31(6), 729-757.
- Jago, B. J. (2012). A primary act of imagination: An autoethnography of father-absence. *Qualitative Inquiry*, 18(2), 398-426.
- Kane, R. A., & Kane, R. L. (1982). *Long-term care: Principles, programs and policies*. New York: Springer.
- Kirby, A.P. (1991). *Narrative and the Self*. Bloomington: Indiana University Press.
- Kolb, D. (1984). *Experiential Learning: Experience as the source of learning and development*. Englewood Cliffs, NJ: Prentice-Hall.
- Kuhn, T. S. (1970). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Laing, R.D. (1961). *The Self and Others*. London: Tavistock Publications
- Lindolf, T. R. & Taylor, B. C. (2017). *Qualitative communication research methods*. Sage Publications.
- MacIntyre, A. (2007). *After virtue: A study in moral theory*. University of Notre Dame Press.
- Musil, C. M., Morris, D. L., Warner, C. B., & Saeid, H. (2003). Issues in caregivers' stress and providers' support. *Research on Aging*, 25, 505-526.
- Ornstein, K., Guagler, J. E., Zahodne, L., & Stern, Y. (2014). The heterogeneous course of depressive symptoms for the dementia caregiver. *International Journal of Aging and Human Development*, 78(2), 133-148.
- Parry, A. (1991). A universe of stories. *Family Process*, 30, 37-54.
- Patti, C. J. (2012). Split shadows: Myths of a lost father and son. *Qualitative Inquiry*, 18(2), 153-161.

- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.
- Pelias, R. J. (2012). Archiving father and son. *Qualitative Inquiry, 18*(2), 144-148.
- Penn, P. (2001). Chronic illness: Trauma, language, and writing: Breaking the silence. *Family Process, 40*, 33–52.
- Pilisuk, M., & Parks, S. (1988). Caregiving: Where families need help. *Social Work, 33*, 436-440.
- Polen, M. R. & Green, C. A. (2001). Caregiving, alcohol use, and mental health symptoms among HMO members. *Journal of Community Health, 26*(4), 285-301.
- Poulos, C. N. (2012). Stumbling into relating: Writing a relationship with my father. *Qualitative Inquiry, 18*(2), 197-202.
- Punyanunt-Carter, N. (2005). Father and Daughter Motives and Satisfaction. *Communication Research Reports, 22*(4), 293-301.
- Punyanunt-Carter, N. (2008). Using Attachment Theory to Study Satisfaction in Father-Daughter Relationships. *Human Communication, 10*(2), 103-120.
- Reinarman, C. (2005). Addiction as accomplishment: The discursive construction of disease. *Addiction Research and Theory, 13*(4), 307-320.
- Richardson, L. (2000). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *Handbook of Qualitative Research*, (pp. 923-948). Thousand Oaks, CA: Sage.
- Robinson, J. D., & Tian, Y. (2009). Cancer patients and the provision of informational social support. *Health Communication, 24*(5), 381-390.
- Ronai, Carol R. (1995). Multiple reflections of child sex abuse. *Journal of Contemporary Ethnography, 23*(4), 395-426.

- Ronai, Carol R. (1996). My mother is mentally retarded. In Carolyn Ellis & Arthur P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp.109-131). Walnut Creek, CA: AltaMira.
- Rosenhan, D. L. (1973). On being sane in insane places. *Science*, 179(4070), 250-258.
- Roscoe, L. A., Corsentino, E., Watkins, S., McCall, M., & Sanchez-Ramos, J. (2009). Well being of family caregivers of persons with late-stage Huntington's disease: Lessons in stress and coping. *Health Communication*, 24, 239-248.
- Rosenthal, G., (2003). On the Conditions of Curative Storytelling in the Context of Research and Counseling. *Qualitative Inquiry*, 9(6), 915-933.
- Roth, D. L., Dilworth-Anderson, P., Jin, H., Gross, A. L., & Gitlin, L. N. (2015). Positive Aspects of Family Caregiving for Dementia: Differential Item Functioning by Race. *Journals Of Gerontology: Series B: Psychological Sciences And Social Sciences*, 70(6), 813-819.
- Scheffels, E. L. (2010). *Caring for the caregiver: Online support and the navigation of dialectical tension*. Unpublished thesis, Department of Communication, Central Michigan University.
- Scheffels, E. L. (2015). Taking care of dad in America: Healthcare, madness, and other drugs. *Journal of Medicine and the Person*.
- Smith, E. M. J. (1985). Ethnic minorities: Life stress, social support, and mental health issues. *The Counseling Psychologist*, 13, 537-579.
- Sparkes, A. C. (2012). Fathers and Sons: In Bits and Pieces. *Qualitative Inquiry*, 18(2), 174 - 185
- Sun, F. (2014). Caregiving stress and coping: A thematic analysis of Chinese family caregivers of persons with dementia. *Dementia*, 13(6), 803-818.

- Szasz, T. S. (1960). The myth of mental illness. *American Psychologist*, 15, 113-118.
- Szekely, L. (2017). *Louis CK: 2017*. USA: Netflix.
- Tillmann, L. M. (2003). Friendship as method. *Qualitative Inquiry*, 9(5), 729-749.
- Tolliver, D. E. (2001). African American female caregivers of family members living with HIV/AIDS. *Families in Society*. 82(2), 145-156.
- Wehtje-Winslow, B. (2003). Family caregivers' experiences with community services: A qualitative analysis. *Public Health Nursing*, 20, 341-348.
- Whittaker, R. (2010). *Anatomy of an epidemic: Magic bullets, psychiatric drugs, and the astonishing rise of mental illness in America*. Crown.
- Wood, J. T. (2014). *Gendered lives: Communication, gender, and culture*. Boston: Wadsworth.
- Wood, J. T. (1994). *Who cares?* Southern Illinois University Press.
- Wyatt, J. (2005). A Gentle Going? An Autoethnographic Short Story. *Qualitative Inquiry*, 11(5), 724-732.
- Yedidia, M. J., (2008). How do family caregivers describe their needs for professional help? *American Journal of Nursing*, 108, 35-37.
- Zarit, S. (2006). Assessment of Family Caregivers: A Research Perspective. Retrieved from <http://caregiveraction.org/resources/caregiver-statistics>