

# Sorrow: A Therapist's Reflection on the Inevitable and the Unknowable

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*People who live with a painful gap between who they have been and who they are now, of who they dreamt themselves to be and who they still long to be, are living with chronic sorrow. Chronic sorrow is a normal, nonpathological state of pervasive, continuing, periodic, and resurgent sadness related to the ongoing losses associated with illness and disability, in this case not loss of an other, but loss of self (Roos, 2002). Focusing on the lives of four women, one of whom committed suicide, I explore the macroprocesses that invade the experience of even so personal an experience as self-loss. The role of the therapist is made transparent through anecdotes and by discussing implications for clinical practice.*

*Keywords: Chronic Illness; Pain; Chronic Sorrow; Self-loss; Suicide*

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In 1989, a few months after I had completed treatment for cancer, a year of intensive chemotherapy, multiple surgeries, and 35 days of radiation, a colleague stopped me in the cramped kitchen space of our Institute and posed a pointed question. “What,” she asked, “has been the biggest loss for you about having cancer?” Without a moment’s hesitation, and shocking both of us, I replied, “I no longer have the energy to be a good person.”

This article is an extended meditation on the meanings for people like me—people who have lived for long periods of time with disability or illness—of living with a painful gap between who they have been and who they are now, of how they want to be and how they can be, of who they dreamt themselves to be and who they still long to be. We are people who live with chronic sorrow, a normal, nonpathological state of pervasive, continuing, periodic, and resurgent sadness related to the ongoing losses associated with illness and disability, in this case not loss of an other but loss of self (Roos, 2002).

I am interested in tracing how something that would seem so particularly personal, like an experience of self-loss, can also be connected to issues supra-ordinate to an individual. I will illustrate this observation with examples from the lives of four women, all of whom have coped with illness and all of whom have experienced painful self loss and chronic sorrow.

The four women are Tania, a vibrant entrepreneur with a passion for theater, in her early sixties, who is the daughter of a father who was a child survivor of the Armenian

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genocide. An unpredictable neurological disease that has twice created episodes of incapacitating muscle weakness has shaken her to the core. Thrown into a life crisis, the drama of the historical past lives inside her daily world, creating confusion about “next steps,” with all the irony of that clichéd phrase. Neither she nor her family knows whether she is or is not sick, does or does not have a condition. Tania is tumbling within herself; she feels lost.

I am just beginning a therapeutic relationship with Tania. Her uncertainty about whether or not she must face a radically altered life showed up in her choosing to work with me. Initially, she called to refer a friend and when I told her I would be away for 7 weeks in the winter, she let me know that her friend would need continuity of care; I was not a good match. A week later she called to make an appointment for herself. During our fifth session she confessed: “I wanted someone I couldn’t lean on. And who wouldn’t lean on me. You are strong and resourceful and you will leave.”

Connie, in her fifties, was born with a congenital heart variation. Connie began working with me in 2004 after deciding she had had it with able-bodied therapists. Having read a few of my articles and chapters, she came into the therapy convinced that between my own medical problems and being the parent of a child with significant medical problems she could trust me. We have worked steadily since then, often having phone meetings because she is too sick to drive to the office.

Elizabeth,<sup>1</sup> in her forties, is a theater artist, writer, and director, who has recently staged a solo show about her 2-year pharmaceutically induced psychosis, from which she has completely recovered (Kenny, 2011). Her harrowing experience has created a devotion to expose the systemic fault lines in the health care system that turned her request for treatment of a gynecological problem into a 2-year living nightmare. She is shadowed by a residue of sadness from having known a mind so radically different from her own and this shadow is a leitmotif running through her profoundly rich and meaningful life.

I met with Elizabeth a few times when she was in college and so, when she became psychotic at age 33, her mother turned to me. I was the first professional in a slew she had seen in the 2 years she got progressively crazier and progressively more medicated to suggest that she might be toxic on the very medications being prescribed for her. I remained a consultant during her ordeal and now, a decade later, she and I have what Anderson (2005) calls a conversational partnership.

Last, I will talk about Suellen, age 36, a sparkling, multi-talented woman who committed suicide in the summer of 2011. A dancer, Suellen was enrolled in law school at the time she was diagnosed in 1997 with Chronic Fatigue Syndrome. The pain and exhaustion of her illness progressively isolated her and required serial reinventions of herself. The new identities—narrative therapist, CFS advocate, farmer—never extinguished longings for each prior one. She experienced what Christopher Hitchens so eloquently described as, “every passing day represents more and more relentlessly subtracted from less and less” (Hitchens, 2012). In the end, those who loved her found themselves in terrible binds as the very care she needed no longer restored her to herself but made her feel less like herself. There was an insidious paradox: to keep Suellen alive diminished the very experience of self that was precisely what she needed to draw on to exist.

Like Connie, Suellen sought me out also after “knowing” me for several years through my writing. Suellen lived in a state with few therapy resources and having trained as a narrative therapist herself, she wanted to work with someone who was an expert on both

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<sup>1</sup>Elizabth Kenny is this artist’s real name. Her play is called *Sick* and she has performed it all over the United States. The names of the other women are not their own and identifying data have been changed for Tania, Connie, and Suellen but not Elizabeth.

illness and narrative therapy. I declined the request to be her therapist, but I offered to consult with her periodically about relationship issues if she could find a psychopharmacologist and a therapist locally who would become part of her care team. In 2009, she did. However, as it turned out, neither adequately assisted her in making key medical and psychopharmacological decisions. At the end, when she took her life, neither knew she had reached her limit of loss. Nor did I.

These are four of the bravest women I have ever known. It takes immense courage to live a life that is fundamentally not the life you know you could have lived had your body/mind remained intact. Tania, who has been grappling with this possibility for a year, is shaken just by glimpsing it. Connie has had to advocate for herself since she could talk. Believing she could do more than others did, she has fought tooth and nail for her rights and her dignity. Elizabeth, who lived it for 2 years, hopes audiences will get an inkling of it. Suellen lived it for fourteen years, experiencing a progressive whittling away of her sphere of doing in an eclipsing circle of pain.

As anyone would be, I am haunted by Suellen's suicide. Words are important to me and early in my grief I tried to attach one word, like a talisman, to my feelings: sorrow. I looked up how you say the word sorrow in many languages to hear if the sound of sorrow was onomatopoeic in other languages; it is in some and not others. Searching PubMed for citations with the word sorrow in the title I discovered a vein of articles on a subject I had never come across: Chronic sorrow. Chronic sorrow turned out to be the very term, construct, area I had been working in—living my life in—for decades, with no awareness of it.

Thrilled, appalled, reflective, I wondered if I had told Suellen she suffered from chronic sorrow might that have validated her experience even more than my avid support of her had? Could it have bolstered her for some period of time until her situation changed, as it would have, as all do, or would it have been just another stopgap? As I was applying it to myself with such resonance and relief, was I fooling myself to imagine that Suellen too would have been buoyed by a concept, in the end, two words?

Chronic sorrow is a term that originated with Simon Olshansky in 1962 to account for the experience of parents living with children with significant developmental impairments. Understanding the lifelong challenges faced by these parents and the unending grief they experienced as their hopes for their children could never be realized, Olshansky proposed the concept of chronic sorrow as a normal response to living with ongoing losses. While initially there was interest in the concept, it went virtually out of the literature in the 1980s until, in the 1990s, there was a resurgence of interest within the nursing profession. Under the direction of The Nursing Consortium for Research on Chronic Sorrow, several studies were undertaken, among them research that shifted the focus from other-loss to self-loss. The concept has now been validated for persons with a number of chronic diseases and impairments, including ALS, Parkinson's disease, multiple sclerosis, AIDS, and chronic mental illness (Roos, 2002, 2009).

In a 2007 article published in the *Journal of Clinical Nursing*, Ahlstrom interviewed 30 individuals living with serious diseases, on average, for 18 years, all of whom had required personal assistance for at least the past 3 months. Most had previously been diagnosed with and already met the criteria for chronic sorrow. Inquiring about losses, she found that her interviewees listed, in order of frequency not severity: loss of bodily functions, loss of relationships, loss of autonomous life, loss of roles, loss of activities, loss of identity, loss of life imagined, and loss of uplifting emotions (Ahlstrom, 2007).

These perceived losses make it challenging to do what Neimeyer has called the work of building and revising a self-narrative, which he defines as “an overarching cognitive-affective-behavioral structure that organizes the ‘micro-narratives’ of everyday life into a ‘macro-narrative’ that consolidates our self-understanding, establishes our characteristic range of emotions and goals, and guides our performance on the social stage” (Neimeyer,

2004, pp. 53–54). In a study suggesting that chronic sorrow is often preceded by a traumatic event and subsequent realization that a chronic illness or disability is a person's new reality, Roos and Neimeyer (2007) write about three kinds of disruption to the self-narrative that can then follow.

They identify *narrative disorganization* when the self-narrative is shattered by a “seismic” event, as illness can be, and there is no longer coherence and meaning in one's life circumstances. This is usually precipitated by an acute event. Narrative dissociation, a second form of narrative disruption, results in a thinning of the self-narrative. At times the loss is not named or put into words even to the self. As a consequence, the self-narrative lacks both voice and audience. The third form of narrative disruption is almost the inverse of the second. In the case of *narrative dominance*, one narrative takes over and in effect “colonizes” the self-narrative, “crowding out” all other versions (Roos & Neimeyer, 2007, pp. 91–92). All four women have struggled with these kinds of disruptions to the self-narrative.

As we will see, it is unclear whether the therapist's job is to assist in the development of a coherent self-narrative that takes into account the current circumstances, to validate the incoherence of any self-narrative, and to help increase tolerance for the fractured and fragmented self-narrative or something else, what the Buddhists might call assistance with lessening the zeal to experience a self, and therefore a self-narrative at all.

I turn now to an exploration of chronic sorrow and self-loss presenting versions of the four women's stories that make figural these concepts and not the contexts of their lives. In a second article, interpersonal relationships will be central, both familial and therapeutic dynamics. In the second essay, I will also review literature on the impact of chronic illness on couples, of which, to anticipate, articles by Boss and Couden (2002), Charmaz (1983), Landau and Hissett (2008), Penn (2001), Coffey (2004), Rolland (1994), and Skerrett (2003) provide foundational ideas.

## FOUR WOMEN'S STORIES

### “Nobody Wants to Hear Your Sadness”

Tania is 60 years old, a vibrant, creative entrepreneur who has always juggled marriage, family, extended family, community, work, and projects as easily as if she had four hands. Decisive, intuitive, multi-talented, she accomplishes her goals. She dusted herself off from her few failures and moved on.

She sought me out because she feels “lost.” Widely networked, she told me in our first session that during her first episode of incapacitation she wanted to burn her rolodex. It was intolerable to her to think that others would imagine her less than perfectly functional. This comment cued me in to a central feature of Tania's current experience: she is hiding from others and herself. She has thinned the self-narrative to such an extent that she cannot locate herself within it. She suffers from narrative dissociation. In part the narrative dissociation comes from her difficulty in tolerating the idea that she may have physical limits and in part the dissociation comes from features of her condition itself, the “politics” of her illness (Weingarten, 1999).

Illness characteristics influence the kinds of responses we can make. Illnesses that are common, time-limited, and well understood, for example, call forth different reactions than illnesses that are rare, of indefinite duration, and poorly understood. Tania's “lost” feeling is partially attributable to the unpredictable nature of her condition: illness episodes may or may not recur; episodes may produce lasting or no negative effects. It is extremely challenging to “adapt” to such uncertainty.

Based on descriptions of Gergen (1994), I applied the types of story arcs to illness narratives (Weingarten, 1999). Plots can be converted to a linear form in terms of their

evaluative shifts over time. In the Stability Narrative, the individual's trajectory remains unchanged with regard to outcome: the illness is no better, but it is also no worse. By contrast, in the Progressive Narrative, there is movement toward incremental improvement. Every day one feels a little bit better. The third story arc is that of the regressive narrative and it is the most feared form of illness narrative. In this narrative there is a downward or backward slide.

These narratives are not value neutral. The regressive narrative often produces isolation, both because the person who tells it feels the potential of stigmatization and marginalization, as well as in the telling, the person is likely to experience both. A culture that prefers a progressive-illness narrative, tolerates a high-stability narrative, and recoils from a regressive narrative reveals a great deal about itself, including the embedded assumption that effort always yields positive outcomes. Illness defies this Western expression of individualism, but not without leaving pain in its wake.

Tania's life story has been a progressive narrative: marriage, career, family, friendship have all evolved in rich and satisfying ways. However, the onset of her illness has confused her. She has no idea which illness narrative she is living or whether, for that matter, she is living any.

For a woman who was "selected" to thrive and protect others, the uncertainty is mind bending. Carrying the past as she does contributes to her disequilibrium now. While anyone would find her circumstances disconcerting, for Tania, who has experienced life being in a "shooting gallery where my job is to keep everyone safe," the possibility that she may now need to focus on herself places her in a terrible bind. Her mission has always been to protect others.

This mission was established early. Despite having older siblings, she was "selected" by her father to heal a genocide legacy (Balakian, 1997; Danieli, 1998). The attention and the lessons were burdened with an historical imperative to thrive as the best way to defy the horror of the forced marches, murders, pillaging, and rapes. The degree to which she remains connected to the historical legacy and its demands was brought home to me in our first session. She spent 75 of our 90 minutes telling me the history of her grandparents and parents including sharing the pithy explicit lesson her father had taught: "Think differently. If everyone is on the caravan, get off." It was not until the last 15 minutes that I learned what had brought her to see me. She said, "I have brushed against disability. My (adult) children need me to be well. I can't imagine otherwise. I feel irreplaceable."

In her day to day life, Tania is unsure what to pay attention to now. Her bodily sensations may or may not be signals that have import. Told to rest, she is afraid of immersing herself in a new venture. Bored and at loose ends, she is unclear where meaning resides.

I see my job as helping her release herself from the intense effort of making sense and making meaning of her predicament and helping her feel comfortable just looking clearly at what is happening now. We are working on lessening the narrative dissociation. Tania feels and disowns her sorrow. This too is part of her legacy. Her mother was very clear with her: nobody is interested in sad stories. Her self-loss is already intense and yet because it is also split off she experiences significant confusion. Masking the confusion and concealing her fears, she remains so "locked in" that this central experience is largely not seen and not shared with others. She is quite alone in the present and even though she knows her husband wants to feel closer to her, it is to her dead survivor father that she feels connected now.

### **"I Hate Able-Bodied People"**

My work with Connie, a married woman in her late forties, is in a different place than that with Tania. No tentativeness, we are known to each other in rich and complex ways. Long ago we abandoned the project of making sense, and often meaning making feels like

a luxury that her medical crises make irrelevant. When the spaces in between crises stretch to months not weeks, meaning making does happen.

When I first met Connie she was suffering with a lifetime of accreted armor that she had built up adaptively to deal with a well world that had demeaned and rejected her. Small for her age, limited in her physical activity, she was shunted into a classroom for “handicapped” children<sup>2</sup> by second grade, where she was not seen for who she was. A super smart child, she was placed in a classroom for children with severe intellectual impairments. There was no learning in her classroom and the children were forbidden to go “upstairs,” our own 1970s version of upstairs/downstairs, where “normal” children were to be spared looking at “defective” children.

By fifth grade, on her own and without parental encouragement, Connie had become an activist, fighting for her right to be placed in a regular classroom. However, the cost to her was great. She internalized the prevailing discourse about people with disabilities and she developed an exterior battle-ready rage that camouflaged her helplessness, fear, shame, and despair. She would alternate between an inflated angry self and a deflated, self-loathing self. Her self-narrative was colonized by the prevailing discourse of disability at an early age and while she herself had been an early disability-rights activist, the self-narrative had already been disrupted. Our work has been to create a middle range between the inflation and the deflation and to soften the two ends, the rage and the despair.

Many people have written about the experience of disability and the cultural context that makes living with a disability so much harder than it already is. Goffman (1963) famously wrote about stigma and the experience of “spoiled identity.” Grealy (1994), who lived with a disfigured face following years of treatment for a Ewing’s Sarcoma until she committed suicide at age 39, focuses on the problem of identity formation when, as a person with a visible disability, one must disentangle your own from others’ perceptions of who you are.

One frame that has significant negative implications for people with disabilities is the American obsession with productivity. This obsession currently creates misery for the millions of Americans who are unemployed and it creates misery for those citizens with disabilities whose necessary productive work must include caring for themselves.

In a 2007 survey conducted by Disaboom, a leading web-based resource for people with disabilities, they found that 52% of Americans would rather be dead than live with a severe disability (Disaboom Survey, 2007).

This represents an internalization of the revulsion people attach to those with impairments. In Europe, before the second World War actually began, the gas chambers were used to kill weak and disabled, or as Adolph Hitler characterized them, “superfluous beings.” Over 200,000 disabled adults and children were murdered and yet, as Susan Roos astutely observes, there are no public memorials to them (Roos, 2010, pp. 174–175).

Connie understands this revulsion all too well. She loathes herself for having what she calls a “pea-sized life,” or so it feels to her because compared with what she might have, she is constantly having to retreat, cut back, relinquish, let go of experiences she would otherwise wish to enjoy. Although an industrious and determined person with a wife who is devoted to her, she is besieged with medical ailments and crises that limit her activities and constrain her partner too.

I have never shared with Connie this image I have of what my life is like. I call it the *boatman’s plight* and I know it would resonate: life is about waking up each morning with

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<sup>2</sup>Like many others, I had read that the word handicapped derived from the practice of begging, “cap in hand.” This is apparently untrue. The OED definition places the word in the context of sport, as it is still used today in golf and horseracing. The handicap is a benefit given to the disadvantaged. In sport it has the meaning of overcoming a disadvantage, and this meaning is still offensive to many people with disabilities (Oxford English Dictionary, 2012).

a full boat and finding that the day consists of jettisoning overboard all but the most essential items so that one can stay afloat in the rough seas one sails. Each day's losses recapitulate at the micro level the macro level dilemma: how to care for a self that longs to be other than it is? How to care for a self that cannot be what it might be, were illness not a factor? How to integrate chronic sorrow into a consciousness already burdened with choices one would never want to make?

These are Connie's dilemmas. How does she take care of herself and not have a pe-sized life, an empty boat? How does she nurture her intellectual gifts by partaking in what her community has to offer without exacting too high a price to herself? How does she live with the prediction that she will die prematurely? How does she live alongside chronic sorrow so that it is only one color in a full palette of experience? These are questions we ponder together, not because either of us knows the answers but because we trust each other to grapple with integrity and love.

### **"The Couch Has Too Many Meanings"**

Elizabeth's situation would seem different from Tania and Connie's and yet her life too is permeated with chronic sorrow, its intermittency being predictable at this point in time. Ten years ago, Elizabeth, with her drug-induced psychosis, experienced radical self-loss and this still haunts her. Recently, during a bout of flu, needing to rest, wanting to lay down on her couch, she felt a tug, as if doing so would suck her back into the vortex of incapacitation that she experienced during her psychosis. "The couch has too much meaning," she reported with a bit of self mockery. She is keenly aware that even the innocuous couch may trigger unwelcome and potentially unmooring memories.

Elizabeth and I have stayed in touch since her ordeal. A year after she had recovered, I suggested that she present at a combined Med-Psych Grand Rounds at Cambridge Health Alliance. We assembled her PCP, neurologist, attending in-patient psychiatrist and mental health worker, her mother—who had been her primary caregiver—her acupuncturist, and myself to participate. Her out-patient psychiatrist, who had reluctantly agreed to taper her medications, backed out of the Rounds at the last moment.

The Rounds was a tour de force; I believe it was one of the seeds that led Elizabeth years later to create a performance piece out of her experience. *Sick* had a triumphant extended run in Seattle in 2011 and Elizabeth is performing it all over the country. Harrowing and hilarious, the play would be a nail biter if the actress/writer were not also the patient/protagonist.

*Sick* and a sequel in the works fundamentally exposes issues in health care/sick care. Elizabeth's honesty, willingness to see things as they are, and acute bull detector make her an astute and curious collector of anecdote and an observer of pattern. However, her internal life is marked by more than objective analysis. She is still emotionally affected by what happened to her. She lived inside a chemically poisoned mind for 2 years and behaved according to impulses that were enacted by her, but were not directed from a mind with which she was familiar. Her self-narrative was profoundly disrupted.

Living back into her familiar self has not been seamless. She is haunted at times by nightmares and in a conversation with me she shared the content of one. She is back in the hospital watching the other patients being treated in a dehumanizing manner. One young woman is on specials because she cuts. Elizabeth witnesses this cycle: she stops just long enough to have her privileges restored and then cuts again.

A nightmare is an expression of lasting trauma; there are many approaches to helping people with them. During our conversation my tack was to point out the way the nightmare was not only a fragment connecting Elizabeth's dream life to her disturbing past but

also a connection to her activist present. As ill and disoriented as she had been at the time, she still noticed the plight of others and was deeply shaken and angered by what she saw. Just as her play is fundamentally about injustice, so too her nightmare focused her attention on that theme.

When people live with self-loss, whether acutely, like Tania, or chronically, like Connie, or in an episode in their life, like Elizabeth, the experience is profound. For all of us, continuity of self is predominantly a magic act; it is an act of *invisible weaving* that we all do moment to moment, repairing small tears that happen continuously—ways we act and feel inconsistently with the primary experience of who we believe we are—and repairing larger ones as best as we can. Certain life experiences, like our responses to illness and disability, war, abuse, are just too large, the rends too great, for invisible weaving to suffice. In these situations, we become aware of the gaps, the holes, the fissures, the places no weaving will close. Something else is required to restore our sense of wholeness and we usually must live a long time before we understand what that may be. The awareness that the invisible weaving will never be adequate is painful. In the mean time we live with chronic sorrow.

### “Chronic Illness Should Not Be a Death Sentence”<sup>3</sup>

Suellen lived for 14 years with chronic fatigue syndrome (CFS). During that time she was indefatigable in trying to come to terms with self loss, with chronic sorrow, with *the weaver’s dilemma*, and with *the boatman’s plight*. As inventive and creative as a person can be, she tried all kinds of ways to address the gap between who she had been and who she was now, who she had always thought she would be and who her body permitted her to be. She understood that invisible weaving of a sense of continuity of self was no longer possible and she was committed to constructing a life adapted to current reality. She was prepared to throw overboard her plans for each day. However, in the end, the losses entailed in living her actual life were unbearable for her. It was almost because she loved life so passionately—her friends, her animals, her art projects, movement itself—that the falling away of her ability to be deeply engaged with each was just too much suffering for her to bear.

Jonathan Frantzen has written an elliptical homage to his dear friend David Foster Wallace, who hanged himself at home in 2008. He writes, “He was a lifelong prisoner on the island of himself.... How easy and natural love is if you are well! And how gruesomely difficult—what a philosophically daunting contraption of self-interest and self-delusion love appears to be—if you are not!... he felt undeserving. And this feeling was intertwined, ultimately to the point of indistinguishability, with the thought of suicide” (Frantzen, 2011, pp. 80–94).

I can think of few passages so unlike a description of Suellen as this one is. Wallace was depressed. He looked at life with a thick sheet of plate glass between him and it. He could not feel or touch what was there for him. Suellen tingled with delight with everything and everyone in front of her; the problem was that there were fewer people and fewer experiences before her. Friends peeled off; they could not bear their helplessness in the face of her physical and emotional pain. Her devoted parents and caretakers were not enough to keep this spirited, intellectually and relationally gifted, sexually vibrant woman alive.

In 2009, she had spent months living wretchedly with symptoms from an experimental drug that promised to improve the cognitive functioning of people who suffered from viral induced CNS dysfunction. She had gotten so sick from the medications that she had had to withdraw from the treatment. However, she believed scientists were on their way to

<sup>3</sup>Personal communication from Suellen’s mother, January, 2012



finding a cure. Her doctor had told her that a team of researchers in Nevada had found a link between CFS and a retrovirus related to the murine leukemia virus. This prospect filled Suellen with hope and sustained her through cycles of significant pain and limitation. Along with millions of others, she was crushed to find out that the research had fallen under suspicion. She was dead when *Science* retracted the 2009 article that showed an association between CFS and XMRV (Tuller, 2011). But as she plunged into hopelessness about her worsening condition, so too did the people around her. With no prospect of cure in sight, stalwart friends backed away, unable to bear their own insufficiency. "There weren't enough fingers to fill the holes in the dike and none of us had enough fingers to give anyway," one friend remarked.

How Suellen would have hated that image. It would have enraged her, made her feel that no one understood her. She was the last person to deplete others: she was the giver, the comforter, the sparkling one who could always make others laugh. She drew people to her; she was the honey. CFS changed all that.

When I began talking with her in 2009, the phrase in my writing that was most important to her was "turning private pain into public purpose" (Weingarten, 2003). She was starting to come to grips with the possibility that she would not marry and would not have children. Any man who wanted to be with her wanted to feel strong in relation to a dependent woman. She could never fit that bill. Her relationship skills ran circles around the men who were attracted to a bedridden woman. In 2009, she had not given up, but she wanted to develop a second path. Activism was her choice; I seemed a perfect coach.

She was brilliant. She designed a web site; sold art works for the benefit of CFS research. She raised specialty small animals in her back yard with the assistance of others during the days and weeks she was too sick to leave her bedroom. She joined Facebook communities and became a leader there. Painful, distracting dynamics eventually made that space unhealthy for her and in her final days, she felt truly alone. The relationship path, the activism path, the cure path all seemed irreparably blocked.

At the time of her death, I had not spoken to her in 9 months. In December 2010, I had had an adverse reaction to an antibiotic I had been prescribed and I woke up blind. Each eye was filled with a dense scotoma leaving me one small spot of vision in my right eye that quickly became color blind as well. I called Suellen to tell her that I was reducing my work to focus on vision rehabilitation. She was devastated for me and while I assume she was also miserable for herself, she said not one word. She was a grown-up.

It is really hard to be a grown-up when you are as sick as Suellen was. In August, the night before I was to leave on a 2-week vacation, I received an email from Suellen. In it she told me that she was scared because she was having suicidal dreams. She and I had agreed on a contract before I accepted her request to have conversations with her. She had promised to let me know if her thinking/feeling about suicide ever switched to intentions or plans. We had had several crises around this contract, but my side of the contract was clear to her. I would not continue to talk to her if she did not keep me fully informed.

The timing of the email was strange; we were in a hiatus of sorts, but it is true I had not specifically spoken to her about the contract in our December conversation. I myself was puzzled as to whether I was in the contract with *her*. Her father was cc'd on the email, for which I was grateful. In an hour I was going to be off email for at least 4 days and away for 2 weeks. I was exhausted with my preparations and confused about what to do. I decided not to pack my computer, but to get up earlier so that I could write a considered response in the morning.

I wrote, "We have a bit of a challenge before us. First, however, I am very sorry that you are having dreams with suicidal content; that must be very scary. I am glad that you cc'd your father on this email. That makes me think that your self-care is functioning."

I enumerated the challenges: my vacation, my not having easy access to email or phone; and my not being her therapist, that is, I was someone to have a conversation with, not someone to help her manage issues of urgent care. I went on: “I recognize that dreams are not the same as waking thoughts. Still, they represent a pressing, urgent matter. It is good that the dreams are frightening you because this speaks to their violating what you hold dear: your life.”

“My preference would be to schedule a time to talk to you when I return home and for you to mobilize your supports and the people with whom you are working.... I recognize that you are only asking for a conversation. If the content were not suicidal imagery, I would have no difficulty writing back, ‘Let’s schedule for the week I return.’ But it is dicier than that. Right?... I won’t be able to be on email for another few days but I will expect a reply... and maybe a solution.”

When I next checked my email, there had been an immediate reply and one from her father as well. Her father wrote about plans to take her to his home for a break and she wrote as follows:

Hi: I have called to schedule an appt. with C. my therapist here. I have also informed my support team of my fears and situation. Could we schedule for when you return?

Thank you,

Two days later a friend of hers called to tell me Suellen had killed herself.

Suellen died of chronic sorrow. She died of exhaustion from battling the losses with which CFS piled her high. She died because she was her own care manager and she could never put together a medical or psychiatric team that worked for her. She died because she had no romantic relationship and only a few friends left. She died because she was exhausted. She died because too many paths were obstructed. She died because she could no longer bear how different her life was from what she had imagined it would be. She died loving life and hating her suffering.

I suspect, but can never know, that had I spoken with her that morning, she would not have killed herself 3 days later. In that belief, I join a large group of people around Suellen and the larger group of survivors of suicide who review and consider what might have happened had they only done x and not y.

## IMPLICATIONS FOR A THERAPIST

### Joining: Compassionate Witnessing and Accompaniment

Had I only told her about chronic sorrow and self-loss. These are the inevitable thoughts of a therapist whose client—or in my case, consultee—commits suicide. They are worthy thoughts: we should care, we should be haunted, we should second guess ourselves. This is part and parcel of what it means to be a compassionate witness.

I agreed to be a compassionate witness to the experience of all four women whom I have discussed in this article. Compassionate witnessing entails empathic awareness of suffering followed by actions in the interests of the other person, not in the interest of relieving one’s own distress as a witness to another’s pain (Weingarten, 2003).

Suffering from the impossibility of truly knowing the other’s suffering is an occupational hazard of compassionate witnessing (Hatley, 2000). Having our own issues stimulated by our patients’ suffering is too. Both are different from empathy. While our own distress provides useful information to us, unlike expressing empathy, our distress is rarely useful to our patients. Connie puts this idea more succinctly: “It’s not my job to gratify able-bodied people!” It is our responsibility to manage our feelings and reactions; to do otherwise is to burden our patients unfairly. If we do communicate our distress, even nonverbally, our

patients will likely sense our need and feel an obligation toward us that is unhelpful. Or, they may break off therapy, unable or unwilling to teach us what we should already know.

People who live with chronic sorrow also live with chronic disappointment; their experience of loss is so easily overlooked, whether from denial or obliviousness. People learn to tolerate a measure of this, but where it is not expected but occurs—like from therapists or health care professionals—the resulting anger can be explosive. As therapists, it behooves us to understand the force and source of the outrage and not distance ourselves from it by labeling it as pathological.

Suellen sought therapeutic help, but failed to find someone who understood her and whose opinions she trusted enough to guide her. She interviewed many therapists, but did not settle on any because in one way or another they cast doubt on her experience. As is the case with many poorly understood diseases and individuals with lifelong sensitive body/minds, she presented with unusual symptoms and sensations, and providers were often skeptical. That critical juncture where a reliable informant meets the edges of someone's knowledge is a delicate one, and all too often providers fail to open their expertise lens to become curious precisely where they feel ignorant. Several therapists Suellen met with implied that she was drug seeking, which was ironic because she could barely tolerate pain medications. On occasion she would explode in their offices to learn later that her medical records contained diagnoses as varied as borderline personality disorder, bipolar disorder, and schizophrenia.

People who live with chronic sorrow need accompaniment (Weingarten, 2004). By accompaniment I mean that we place ourselves alongside a person as she makes and remakes her relationship to a body/mind that is unreliable. It means we support a person while she figures out what caring for her body/mind means now. It means being a container, a mirror, a sounding board, a researcher, an educator, an advocate, a rest stop, a sidekick, and a comic. It means being strong and vulnerable. It means taking good care of ourselves, especially knowing our limits, so that we can remain alongside of those whose care is complex and challenging.

All of these women had significant relationships with spouses and/or family members, not to mention multiple health care professionals. The dynamics of living with and/or being the primary caregiver for a person suffering from self-loss and chronic sorrow are exceptionally complex and are the subject of my second essay. For instance, what does accompaniment mean when you live with someone you knew as a well person and then she becomes sick?

The therapist working with a chronically ill person is always working in a complex system that includes many others, like moons circling a planet. There are frequent moments when decisions have to be made as to whether or not—and if so, how—to include others. In the second article, I look at these decisions from the perspective of chronic sorrow and self-loss.

## Pragmatics

If accompaniment is a stance, it is also an attitude. I remind my patients that whatever is happening is happening only now. We are *always* talking about now, for that is all that we can be aware of. Psychologically, the past and the future actually exist only in the present moment.

This creates a useful container around the work. Tania cannot change the genocide history of her family. However, she can change what she carries with her every day. I believe that she will need to find ways of honoring her special role while doing less for her extended community, siblings, husband, and adult children. Elizabeth's commitment to

portray her 2 years of psychiatric trauma must be charged with motivation each day or she will exhaust herself in a project that lacks meaning now.

Those living with chronic sorrow, as I have discussed, experience disruptions of the self-narrative. Pain, confusion, uncertainty all contribute to the disruption. They produce a kind of secondary suffering. While authors must have a coherent narrative to write fiction that works, to suffer, particularly to suffer physical pain, is to be precisely unable to tell a story about it. Pain is the quintessentially untellable, unshareable experience at the moment it is happening (Scarry, 1987). Enveloped by pain, the sufferer experiences incoherence. Trying to wrestle that experience into coherence may not be that helpful. Even if one can find words that fit, a frame that gives an account, the fundamental quality of incoherence remains. What is so remarkable about Elizabeth's play *Sick* is that 10 years after the events she dramatizes in her play, she has captured moments of her pain then. But the play does not exist in that time period; it exists in Elizabeth's mind now and that is where her audience joins her, in the astonishment, gallows humor, confusion, rage, gratitude, love that exists in the present moment where, even now, there remain gaps in the story that make perfect coherence impossible.

Chronic sorrow is different from a trauma response, although many people with chronic sorrow also suffer trauma. With a trauma response, the past invades the present, distorting it. Peace *is* in the direction of coherence—being able to tell what happened, moving from seeing in one's mind's eye, black and white jumbled images to full color continuous video—such that one can cognitively and emotionally integrate how different the current reality is from the terrifying past.

By contrast, peace for the person who lives with chronic sorrow is in the direction of tolerating incoherence. Therapists can validate the experience of incoherence, assist understanding of how this relates to narrative disruption, and work to diminish the disruption that incoherence poses to the self-narrative.

Of the three forms of narrative disruption, narrative disorganization is the one that is probably inevitable. (Just regularly dealing with the health care and insurance systems accounts for some proportion of this.) Narrative dissociation and dominance are not inevitable and they present reliable problems that can be anticipated and addressed.

Changing narrative dissociation necessitates facing what is happening. The dissociation represents failure to accept the present circumstances: protecting the self and others from looking clearly at what is unfolding now, warding off the changes that must be made, and keeping oneself from toppling into bottomless grief.

Shifts in narrative dissociation happen in the context of caring relationships, in and out of therapy. As I have written at length elsewhere, voice is dependent on audience (Weingarten, 1994). If a person does not believe that those around her can bear to hear what she has to say or if she cannot bear to be the cause of the pain she knows her listeners will feel, distortion of reality will creep in and dissociation will be likely. As therapists we know how to work with this, gently and relentlessly, pacing ourselves to minimize resistance (Penn [2001] provides a beautiful example of this). But work with it we must. Ultimately narrative dissociation is destructive for the person and her network.

Shifts in narrative dominance also happen in the context of caring relationship, but the work is different. In this context, the work is identifying the myriad of ways that insidious and explicit "messages" have gotten folded into the person's self-narrative such that it is as if colonized by mean and denigrating voices.

The dominant discourse of disability takes its inspiration from Western ideas of productivity, individualism, and independence. Within this discourse, dependence is loathsome, even repellant. People who are disabled are made to feel shame for what is no one's fault. Even those who are keenly aware of it can decode it and have a sophisticated Foucauldian

analysis of “discourse”—understanding that its power resides in defining what is and is not considered acceptable—can still be made miserable by it.

Suellen, as a narratively trained therapist, was an expert at recognizing the negative effects of the discourse of disability on her life. Still, it plagued her, both when she recognized its impact on herself and on those around her. She and I often discussed this. Her activism in the CFS community was a way she used her perspective to help others locate the negative effects of the discourse of disability on their lives. And still, this was not enough to protect her from its harmful power.

Recently, I have identified another component of the discourse of disability that did not enter my conversations with Suellen and I wish it had. Embedded in the discourse is an understanding of “care” that itself poses problems. As Beasley and Bacchi (2007) point out, most models of care assume asymmetry “between ‘strong’ and ‘weak’, ‘carers’ and ‘cared for’, ‘altruistic’ and ‘needy’” (p. 293). As Bateson (1972) might say, these models fracture the ecology of care, for, at any point in our lives, any of us is likely to be a caregiver and a care receiver. Positions of altruism and vulnerability exist only as moments in time; they are temporary, not stable. We all live with ratios of dependence, interdependence, and independence (Tronto, 1996).

However, we obscure this. Those in healthy body/minds act as if those in unhealthy body/minds live in a foreign territory that is utterly different. Suellen felt diminished by this and out of alignment with her core sense of who she was in the world. She was a giver; being on the receiving end of care year after year created a skewed ratio.

I have come to see that my own unreliable body and the evident care that I have had to receive has made me a good fit as a therapist for those who loathe feeling dependent. I exemplify the limits of that view. For while with patients I am a giver, they know that like them I must be a receiver of care as well. My very being represents a softening of the dichotomy. I make them feel less inferior.

This also gives me some leeway to give advice without exacerbating the subordinate/superior positioning dilemma. If Connie asks me what to do and I oblige, she has no way of knowing—unless I tell her—whether I know this from my patient or therapist role. I am an “expert” in both.

Most therapists would not have my history. But most therapists will have had some extreme experience of dependence, if only with a bad case of the flu. One can remember the ache, the pain, the exhaustion. The fear that one will never be well again. The brain fog and lassitude. These memories are allies.

## Unknowables

Two decades ago, in a conversation about patient suicide, a respected, older colleague of mine, Harold Goolishian, told me that in his experience no one ever killed himself who felt he was in a relationship. Over the years I have had to unpack what I am sure Harry meant because people *have* killed themselves who were in relationships. Just not the ones they wanted, the way they wanted them to be. Suellen had many important relationships. Her parents, friends, and live-in caretakers all loved her. She was beloved, but she was nobody’s beloved. She lacked the one relationship she desired.

Had I not become blind, had I stayed her consultant, had she told me she was making plans to kill herself, had I been her therapist, had I lived in the same state so that I could have driven over to see her, what would I have done? Everyone around her has told me she would never return to a hospital again. She could not have been committed. Would I have told her I would accompany her unto death? Leaving aside for the moment the legal ramifications, could I have entered into a richly described conversation about the path to

suicide? Having thought about this daily, I know that I was a partisan. I do not believe Suellen had nothing more to live for, even knowing her desires as I do.

In a letter she composed before she died, she wrote:

*Chronic Fatigue Syndrome attacks your dignity, through the words of doctors, professionals, who call you lazy, or crazy... or worse.*

*It destroys careers, dreams, erodes the spirit.*

*It cuts the threads that hold relationships together. I think this is what was too much for me. As I watched the serial destruction of so many relationships that had been precious to me, a crack began to crawl across my heart. Through that crack leaked my love for life, my drive for life, my fight for life, and in its place grew an exhaustion deeper than bone.*

Would I have told her to hold on? Yes. Could I have convinced her to do so? Unknowable. Had I been her therapist, had she been able to convince me it was cruel to ask her to live on, would I have told her I could no longer care for her? No. Would I have accompanied her unto death? Yes. It would have been my very sad privilege to do so.<sup>4</sup> It grieves me that Suellen died alone. But, of course, she died because she felt she *lived* alone.

In such a dire circumstance, what might I have had to offer? Two ideas, both influenced by my own investigations into Buddhism as a means to mitigate my own suffering.

First, for people who live with self-loss, the self is not a reliable construct. Nor a reliable companion. It diminishes, it disappoints, it lets us down. However, awareness of self, awareness of the doings of the self, exists on another plane entirely. One can come home to awareness and return to a quality that, if changed, is only more refined. Buddhists call this state equanimity.

Olendzki (2006) describes it thus:

Although such equanimity is often regarded as a “distancing” of oneself from experience, those who practice it regularly will soon discover that a far greater intimacy develops, calling for a good deal of courage, as the intervening concept of self is moved aside and experience is encountered more directly. When self-hood and identity are constructed in any given moment of experience, one is not capable of engaging the full force of consciousness with the sensory or cognitive field. And when awareness is fully engaged with an object as it is, there is nothing left over with which a sense of self can be created. Put another way, when the senses are filled to their capacity by consciousness, one loses oneself. While this sounds threatening in principle, most people actually cherish the rare moments of heightened awareness that often accompany such a “loss of self” (p. 258).

After days of silent meditation on retreat, I have reached a state I would call tranquility. There I could observe my pain and not want it to change. It lasted for moments.<sup>5</sup> But memory of that state is with me still and it supports me to know it is possible and available. I am starting to encourage patients toward awareness of self as providing a more lasting comfort than constructing a coherent self. Time will tell.

Second idea. My search for comfort in anticipation of greater losses has led me to an unexpected conclusion. There is no solution to sorrow. An image comes to mind. When I was a child, older friends would playfully put their hands on my head as I

<sup>4</sup>See Maytal & Stern, 2006, for a cogent discussion of factors to consider in evaluating suicidality in the context of serious medical illness.

<sup>5</sup>I am uncomfortable with the construct of healing as applied to psychological/spiritual matters. I do not believe that healing happens the way, for example, healing of a wound occurs. Rather, I believe that we can experience moments of healing that last for different durations and are integrated into our sense of self to different degrees. I am in favor of reaching for moments of healing while at the same time I discourage people from the notion that they can strive for healing.

was coming up from a dive in the town swimming pool. I vividly remember the feeling of flailing against their hands, trying to push myself up out of the water by forcefully kicking away their hands. Of course, it was impossible. We may think we embrace sorrow and we may think we escape sorrow, but in the end, there is no way to solve sorrow; we can only swim in it.

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