

Witness: On Telling

By Josephine Ensign

When trauma, illness, or injury occurs, a common human response is to want to tell the story of it, and to reach out for the stories of others who have had similar experiences, yet found ways to recover, or at least to make peace with what happened. Trauma is an experience that threatens our physical and emotional wellbeing, causes fear and a sense of helplessness. Trauma changes how we understand our world and ourselves. We seek ways to create a coherent narrative out of trauma, illness, or injury—the ‘tick’—this happened, which causes the expectation of the ‘tock’—then that happened. Plotting presupposes and requires an end, just as the plot of our lives requires death. Narrative in some form—spoken, written, or visual—organizes human ways of knowing and of remembering the past.

Sociologist Arthur Frank, in his book *The Wounded Storyteller*, presents a typology of illness stories. Frank contends that there is a universal urge for ill or injured people to tell their stories, to change the passivity of being a victim of fate into the activity of what the ill or injured person did in response to the trauma. He points out that the sharing of these illness stories can be of healing benefit to both the teller and the listener. Being seriously injured or ill threatens us; it becomes a form of trauma. These types of events force us to confront our own mortality, to redraw our personal maps, to rethink our destinations. Stories we tell ourselves and others are ways of redrawing these maps and of recalibrating our destinations.

Serious illness or injury—what Frank calls ‘deep illness’—disrupts our memory. It makes us, at least temporarily, become disoriented and lose our way. Painful bodily, psychic, and spiritual memories are so threatening that they can distort past, present, and future. The making and telling of our stories help us reconstitute self and memory. But this making and telling of stories always presupposes an audience—even if we are our own audience: story happens within a social context, and story takes on social functions.

According to Frank, one of the most common illness narratives is the restitution story: I was healthy, then I became ill or injured, but now I’m healthy again. These are the illness stories that are most strongly sanctioned by our society and institutions. They are the illness story plot lines conveyed in get-well cards. We all want the healthy, functioning, predictable, and seemingly safe body back again. At the community level, this is the illness story told by the post Hurricane Katrina New Orleans Mardi Gras celebration and the Boston Strong Campaign after the marathon bombings.

The restitution storyline is the type used in those somewhat saccharine personal testimonial fund-raising efforts of various helping agencies, including hospitals. They are easily digestible sound bites of stories. “Suzie O had a life-threatening automobile accident that left her temporarily paralyzed, but with the excellent medical care of our hospital, she is walking

again.” But, as Frank points out, restitution stories aren’t an individual’s own illness story because they are prescribed and proscribed, part of the larger metanarrative of societal expectations.

What would it mean if I were to tell you the story with the following plot summary?

I had a reasonably happy childhood, but as a young adult I spiraled into things I shouldn't have, including into abusive relationships and into homelessness. Then, with help from friends and family and institutions, I got on my feet again, and now I am fine. I am a homeowner. I have raised two well-adjusted children. I am a tenured professor. For the past twenty years I have been in a healthy long-term relationship. I could be the poster child for the National Alliance to End Homelessness.

What would this version of my story mean for people who have not been able to ‘overcome’ or ‘get well’ from homelessness and poverty and abusive relationships? Doesn’t this version of my story convey the message: if I can do it, so can they; therefore, what’s wrong with them? But for many years, this is the illness narrative I tried to tell myself, and that I told other people. The narrative felt safe—the easy way out; it also rang false in the telling. I always wanted to blurt out at the end but really, that’s not what happened. I didn’t actually say that because I wasn’t sure what came next. I wasn’t sure how to tell a different version of my story.

The second type of illness narrative according to Frank is the familiar quest narrative. We often have a rigid, scripted notion of what a good, straight, linear, satisfying, and effective story arc should be. It is usually the hero slaying demons and dragons of some sort, and emerging at the end triumphant and transformed, and even stronger and more handsome. The feminist version of the quest narrative has the young woman descending into the land of the Underworld, wearing a lot of jewelry (and perhaps fancy shoes) as armor and for buying her way out of difficult circumstances, and then emerging again into the light and land of the living much wiser and more beautiful—although with much less jewelry and perhaps also barefoot and pregnant. These are the New Age Joseph Campbell sort of ‘you are the hero or heroine of your own story.’

In his book, Frank implies that the quest narrative is the privileged way to go; it is the higher order illness narrative. Our society seems to agree with him with its myriad personal storytelling projects, memoirs, novels, confessional-type television talk shows, tabloid articles, movie scripts, and narrative therapies. We want soft-focus Hallmark moments that make us feel all warm and cozy inside.

So here is the quest illness narrative version of my story—with a feminist slant:

My father was a Presbyterian minister. I had a reasonably happy childhood until age 14, when I had a string of serious illnesses including red measles, followed by panic attacks and a deep depression, followed by anorexia. My parents admonished me to use the illnesses as a dark night of the soul, as a message to get right with God. I tried that. After college, I married a soon-to-be Presbyterian minister, hoping that by ‘finding religion’ I could cure myself. But I fell back into a depression after the birth of my first child. Depression was my Underworld. I had an affair with a much older—and, as it turned out, abusive—man, and lost my job, home, and family—more or less in that order.

My turning point came through swimming. Despite living in my car for a time, I had access to a YMCA gym where I showered and swam miles each day. Determined to face one of my deepest fears, I trained for and competed in the Chesapeake Bay Bridge Race: 4.4 miles of cold, dark, fast moving water between Annapolis, Maryland and the Eastern Shore of Virginia. I had twelve percent body fat. For the Bay Bridge race, I wore a one-piece racing suit with a neoprene vest partial wetsuit. I wore no jewelry since I was convinced it would attract sharks.

Halfway through the race, my hands and feet went numb. When I turned my head to the side for a breath, through foggy goggles, I saw the looming pillars of the bridge and the black race number written on my left bicep. I hallucinated that the bridge was a war ship, and that the black number on my arm was a Nazi concentration camp number—a concentration camp from which I was escaping. I realized I had hypothermia so I kicked harder in order to get to warmer water. I finished the race. This experience gave me the strength to kick like hell, get myself out of the suffocating South, out of the abusive relationship, out of homelessness. I emerged from this ‘deep illness’ stronger, transformed—a wounded healer. I experienced a redemptive rebirth through the trials of homelessness and its attendant ills. I emerged transformed and resilient. I could write a best-selling memoir and have a Hallmark movie made of my life.

This is the version of my story I held onto—like a safety kayak—for many years. Although it is unlikely to become a best-selling memoir, I wrote a book manuscript using this version of my story. Decades after I had survived these chapters of my life, I had this story published and made public. But I did this only after my career was well established, my children were grown, my parents were either dead or essentially mute from illness and old age. Because it was a dangerous story; it was a disruptive story. This story could derail my career, and complicate, if not end, my personal relationships. The more I lived with this story, the more I realized that it wasn’t true—not that the events didn’t happen, but that I did not experience them in the simple Aristotelian plotline way that I was retelling them. This version is too sanitized, too streamlined; it doesn’t dip into the murky depths of emotions, of power dynamics, of what I was experiencing internally at the time, or of how I remember it now.

The least desirable illness narratives according to Frank, are what he terms chaos stories. Frank states that chaos stories are difficult to listen to or to read, as they have no coherent story structure, timeline, the tick and tock of plot. He contends that chaos stories convey distress and are themselves distressing. They aren’t really narratives at all. Instead, they are collages, fractured shards of memories, feelings, sensations, and images.

There are times when people have experiences that don’t fit neatly into a storyline, a narrative of what happened. Especially within the contexts of trauma, suffering, and oppression, our ability to arrange these bits together into a coherent narrative is overwhelmed. There are human experiences beyond the reach of narrative, yet these experiences can be formulated, conveyed, and communicated through metaphor, poetry, art, photography, and gesture. Perhaps it is like Virginia Woolf’s existential moments of being, moments of knowing, behind the cotton wool of everyday life, moments she conveyed through her ‘breaking the sequence’ style of writing.

Donnel Stern, a psychoanalyst and researcher on witnessing, trauma, and dissociation—the

defensive splitting of self—contends that there are important non-narrative ways to organize experiences, as well as times it is best to leave them unorganized. He calls these the unthought known: experiences that are in some sense known, but are not yet (or perhaps ever) available to reflective thought or verbalization. They are a type of implicit knowing—there but not there. Metaphor, poetry, art, photography, and gesture speak directly to our implicit knowing.

Listen carefully. Here is the chaos illness narrative version of my story, told through the fractured bits and fragments of my life, as recorded in my journals and poems:

I have often asked myself the reason for the sadness, in a world where tears are just a lullaby.

Thump.

*The door closes
with soul-deafening
sentencing sound.*

Nowhere to hide.

I worry if I'm sane, if I'll kill myself.

Maybe it's just useful to be somewhat depressed, who knows?

There are advantages to being sick. It gives permission to stay in bed all day and read yet another book. A day of quiet and solitude.

There is something constant, stilling, and small about rain. The warm gentle sound envelops and shields from the intense brilliance.

If I could have said "no"

I would

have said, "This place is hell

I don't want to stay here anymore."

I would have said, "I hate you

for killing my dreams

for shredding my soul

for never touching me kindly

for turning your back."

The gossamer moonlight danced its way around the gnarled branches of the great oak trees outside, fluttered in through the open window, and settled on the form of the naked girl. She sat on her bed gazing with fixed eyes at her ghost image in the mirror. The mirror was three-sided, perched on a bureau on the far side of the room. The right side reflected the tree forms and moonlight outside. The larger middle section framed the image of the girl.

The left side was black, turned towards the bedroom door.

When words were poems

our body's understanding

was written in flesh

There I lay on the cot on the cold concrete floor of the storage shed, unable to sleep for the thought of how bare I felt. Stripped of most everything that gave me identity—work, husband, child, home, possessions. Lying bare and naked facing the night and the unknown.

Now each word is a poem,

draw knowledge softer,

suckle life from all splinters,

embrace shadows beyond words.

What do you hear within this chaos narrative? What is included and what is left out? Are you able to hear the silences, the dark places? Is it too distressing? Pause a moment to consider what would enable you to listen and to hear.

This illness narrative feels the closest to conveying the truth of my experience. It is the version that I continue to have difficulty reading through without gasping for breath. It is the version that is written on and in my body. It is the version that no longer makes me depressed; instead, it makes me angry. It occurs to me that the combination of anger, frustration, and pure rage was what propelled me out of that situation, is what gave me the strength to get out, get away, at least sufficiently to be able to regain my breath, my bearings, my sense of direction. And to get away sufficiently to be able to tell my story.

Is there a moral imperative to witness, to tell our stories? Telling personal illness narratives is not an equal opportunity affair. There are important, nuanced differential power issues within witnessing. Some people, some communities, take bigger risks than others when sharing their stories of trauma, of deep illness. I can afford to tell my story now—especially my truest, most chaotic illness story—because in doing so, I no longer risk losing my job, my relationships—or at least not the ones worth keeping. I am now firm enough in my personal identity that I don't risk having the story define me. I know that I am much more than my collection of traumas and scars.

But in rescripting my illness narrative, I am haunted by an even older, deeper story. When I was a child and was at home sick in bed with tonsillitis or the flu, my mother would take care of me. She consulted her American Red Cross Home Nursing manual. She checked my temperature, brought me juice, ice water, and chicken noodle soup. And at some point during my illness, when I was over the worst of it but still stuck in bed, she would take two boxes off the top shelf of the hallway closet and bring them in to my bedroom, sit on the edge of my bed, and open the boxes. The larger box contained a porcelain doll that had been hers and her mothers. She said it was now my doll but I was only allowed to play with it when I was sick because it was so old and fragile. So I called it my sick doll. She had no other name. The doll had glass blue eyes that opened and closed, and long wavy blonde hair—real hair, my mother told me, a fact I found bizarre. But I was more interested in the contents of the second box.

Before she opened this box, my mother grew quiet, gazed out of my bedroom window while absent-mindedly caressing my forearm. Then she'd open the box, pull out a leather pouch full of old, musty-smelling letters, a sepia-colored photograph, and a Nazi armband with tiny, even stitches all around the black swastika. She told me the photo was of Jack Murray, her fiancé, an artist who was killed in the Normandy invasion. She let me hold the photograph and the armband, but not the letters. Jack was tall and handsome, with a wide grin. At those times I wondered who I would have been if Jack had been my father. Would I even exist?

Of the many mysteries of my childhood and of my parents, this one stands out as among the strangest. My three older siblings insist my mother never did this with them when they were sick, and that they only knew of the Nazi armband from when she mentioned it offhandedly

while they studied WWII in high school. So why me and why when I was sick? I never asked my mother, as I suspected she wouldn't be able to tell me. When she died in 2008, I inherited the doll, the letters, the photograph, her aquamarine engagement ring from Jack, and the Nazi armband.

Tracing these stories, I realize how intergenerational trauma occurs, how insidious it is, how it seeps into the pores during fevers and open sores. I now see the connection between this deeper illness story and my hallucinated personal narrative. The nonsensical storyline of escaping a Nazi concentration camp that flashed through my head when I had hypothermia. The story that helped me survive the open-water swim. Stories, story fragments, moldering letters, metaphors—they come to us unbidden, and they either pull us through or under.

In *The Wounded Storyteller* Arthur Frank states, “To tell one’s life is to assume responsibility for that life,” and by witnessing to our own stories, we are able to mourn not only for ourselves, but for others. Witness is a relationship. It draws us in as participants. If we listen, if we see, we are witnesses; we are implicated and affected even if we avert our eyes, close our ears, turn our backs.

But in order to do this, we need to expand the possibilities of forms of witnessing, of telling our stories. We also need to find ways to increase our capacity to listen to—and to hear—different types of illness stories, including the more distressing chaos stories.

Feminist literary scholars like Susan Lanser and Helene Cixous point out that fractured stories, lyric stories, chaos stories, are a more common form used by women and marginalized people. Not surprisingly, these forms are themselves marginalized.

*Now each word is a poem,
draw knowledge softer,
suckle life from all splinters,
embrace shadows beyond words.*

This was part of a poem I wrote on the back of a ferry crossing fare receipt in the fall of 2014 soon after my father had died. At the time, I was simultaneously on a writing retreat on Whidby Island and teaching community health with a health humanities flare to nursing students in Seattle. During times of intense emotional turmoil, I am tossed out of narrative. I wrote poems while crossing the Puget Sound, back and forth to work and to retreat.

It requires more effort on the part of readers, of listeners, of healthcare providers to allow people the space and time it takes to tell their illness stories in whichever form they want, including in the more realistic chaos or fractured narrative form. It requires more effort to be able to listen to, to hear, these stories. It requires being able to stay within the cold, gray waters of uncertainty, the waters from which spring life.

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