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NON-FICTION | SPRING 2016

## A Life Less Terrifying: The Revisionary Lens of Illness

By Ann Wallace

Did you know that Frederick Douglass wrote his autobiography three times? First and most famously in 1845, seven years after he had escaped slavery; again in 1855; and finally in 1881, years after slavery have ended. He lived but one life, so why three books, three versions? Although each is written later than the one before, he repeatedly covers the formative years of his life. Surely, those early memories did not change.

Or did they?

Perhaps they did, if we think about revision in the broadest sense of the word, as an act of re-visioning, of looking again and of seeing reality differently, whether by choice, by strategy, or by necessity. The act of living and of moving forward requires a constant recursive motion of looking back and re-visioning. Those interested in placing their lives or views into a broader context regularly re-examine their lives from new angles. Frederick Douglass's early life hadn't miraculously changed by 1855 or 1881, but his understanding of it had—and, more importantly, the message he wanted to tell through it was constantly evolving along with the historical moment. And so, he returned again and again to his early moments, editing, excising, adding, recasting his narrative as his perspective and rhetorical purpose changed.

Those who engage in such acts of looking back, anew, tend to gain fuller understanding and navigate changes of course more adeptly. I know this kind of re-visioning work well, as my own life has been rife with moments in which new embodied experiences layer upon and break down what was once seemed to be immutable reality.

*I feel cold, a deep cold that penetrates to my core. I need a blanket but I cannot think how I will get one. In the dark stillness, I am certain that I may never be warm again. It takes time, too long, to realize that I might be able to speak. I think of it, but it is impossible. My mouth is parched, my lips dry, my jaw firm, unmoving. My attention shifts from the cold to the pain. My lower abdomen, my pelvis, straight through to my spine, is engulfed in a pain unlike any other. I cannot articulate it, but it is real, not throbbing but still, settled in, permanent. Time passes and I struggle to understand the pain. I am asked to move from the stretcher, onto a bed. I puzzle through the notion of this for a long time. I don't know how long, but it is too long because the voice threatens to move me herself. I move, a centimeter, an inch, at a time. It is the best I can do. I have no idea why she says I can do it. My heart races, not from the pain, but from the panic that the rest of my life is held here, in this moment. Nobody had told me about the pain, and now I am facing a life so terrifying that I cannot open my mouth to speak or my eyes to face this future.*

My memory, of waking up from surgery to remove a large malignant tumor from one of my ovaries, when I was 22 years old, is my first and still most potent experience of pain.

Twenty-five years later, I still cannot find words, metaphors to describe the sensation. I honestly believed, before I had even opened my eyes that the pain would never, ever go away. When I was in it, it was all I could feel, all I could imagine. I could not imagine life without the pain—and *that* was terrifying.

The pain, of course, would soon abate. But nobody could have told me that then, and I was in awe when it did. I needed the time to pass, for that truth to become true before it could even exist as a possibility. In the moment when a conviction is formed, especially when it is confirmed by physical sensation, momentarily no other possibility exists. When we first experience that feeling of falling in love, we cannot imagine ever falling out of love. Alternately, when we are frightened, we cannot imagine the source of fear disappearing. But our vantage point does change, and along with it, so does our understanding.

I have had surgeries since that one—two of them in my abdomen—, but nothing has sparked the recovery-room terror I experienced when I was twenty-two years old. I now know that bodies have the miraculous ability to heal from the physical trauma of surgery. I did not know that, fully, then.

My understanding of pain and of terror has evolved, and keeps evolving, in ways that enable me to view my own experience and those around me in ever-changing ways. I know that many people live in a state metaphorically akin to my post-surgical pain, unable to think beyond the crisis, the panic, of the moment. The challenge is to move past the paralysis into reflection and re-vision.

As a teacher, I feel I have been successful if I can inspire two things in my students: to step outside of their limited perspective and view the world, including themselves, through a new lens, and to extend empathy toward each other and those around them. Last semester, in my first writing assignment in my composition classes, I asked my students to write of a time when they were denied some kind of essential or fundamental human need—love, compassion, respect, dignity, shelter, the possibilities are many. In our in-class scaffolding work to build this narrative, using a strategy of memoir teachers, I prompted the students to reflect on what they did not know at the time, but have since learned. This work of reflection is important, because it allows the students to consider the difference between their past selves and their present selves. It is an act of re-visioning, taking them out of the metaphorical hospital bed and into the reflection that time and knowledge allow.

But that is not the only re-visioning that this assignment inspires. I invite any students who are up to the challenge to share their narratives with the class. Student after student read aloud and we were moved, sometimes to tears, by the ways in which classmates, peers, parents, strangers, even their own bodies, had betrayed or hurt these writers. We identified with the stories, even as we ourselves had never experienced the specific pains and losses. We looked in through what poet Marilyn Hacker calls “known neighbors’ unknown rooms” and we were able to recognize something of ourselves in each one (91). In one of my classes, students became angry at unnamed bullies, cousins who turned their backs, parents who didn’t understand, among other antagonists, quickly becoming protective of classmates they, in many instances, hardly knew.

Time and time again, the point of these stories was that “I don’t let anyone treat me like that anymore,” “I’ve learned to not to let these things bother me,” and “I’m stronger than that; I’m a survivor.” These reflections, however, were not automatic. The specific memories stayed with each writer for a reason, as moments of transformation, moments after which each

writer determined that she must change the course of her life's narrative. Whatever course she had been on was no longer working, and she was at a loss. For some the decision was immediate, while for others the transformation came through the act of writing, but each writer found a way out through re-visioning.

The writers have decided these things now, but in the vulnerable moments, the narratives could have gone either way, the endings unknown and unknowable.

To live up to the word re-vision, we need to stop when we want to walk away: turn around, walk back, look again from new angles, even enlisting our friends to ask what they see. Sometimes this kind of re-vision is easy, but often it is work, for it entails a willingness to let go of what we first thought was true.

But consider this: how many times have you thought that something was a lost cause? How many times have you given up and known that there was no way anything was going to change? That you would not change someone's opinion, or you would not be able to achieve the goal you wanted, or even that your mind was set and nobody was going to change it? How many times have you been wrong? That breakup was *not* the end of your life. You *were* able to reconcile with your best friend after a serious falling out. The pain of your surgery *did* subside. You revised your opinion on these matters because your perspective changed. Often, time passed and gave you a larger context from which to view the situation.

In illness, the work is of adjusting to a new normal, of adjusting when the worst moments—the recovery room pain—reveal themselves to be temporary, but the fact of the illness itself remains. The arc of one's life is disrupted, redirected, and one's life, both past and present, must be re-visioned. Marilyn Hacker experiences such a disruption in her sense of identity when she, who had watched and recorded as her friends had died of AIDS and cancer in the 80s, was diagnosed with breast cancer:

It's become a form of gallows humor  
to reread the elegies I wrote  
at that pine table. With their undertone  
of cancer as death's leitmotif, the rumor  
of random and pandemic deaths. I thought  
I was a witness, a survivor, caught  
in a maelstrom and brought forth, who knew more  
of pain than some, but learned it loving others.  
I need to find another metaphor (81)

We spend our whole lives shaping and finetuning our stories, creating identities, images of ourselves. Diagnosed with cancer, Hacker needs to find a new metaphor, as the old one is no longer adequate.

My story is different; cancer is the story that set my adulthood into being, the identity I was given at a pivotal moment. My identity was still being shaped and it easily took the shape of a good patient, one who responds well—on every level of what that means—to treatment. I viewed life through the lens of a cancer survivor. I felt exceptional, that my story was unique, that it made me strong. I showed up in my doctor's office banged up from a roller-blading fall or telling stories about backpacking debacles. The nurses laughed, enjoying the fact that I was young, bold, fearless, unlike their other patients.

I hadn't been able to step away to look from another angle. The unimaginable post-op pain had lasted only hours, but the cancer survivor identity I adopted stayed firmly in place for years throughout my twenties, perhaps until I had children and had to decide for the first time, what kind of patient I would be. That question quickly became moot, replaced with Hacker's dilemma of how we adjust our identity when our proximity, perspective, and diagnoses change.

Seven years ago, I was in such a place when, newly diagnosed with multiple sclerosis, I struggled to locate my shifting identity, my sense of direction lost:

*MS, this is the piece that makes me feel I have gotten a raw deal with this body of mine. Hit twice—hard—before age forty. My body—which seemed so strong in the face of not only cancer, but also miscarriages, appendicitis, broken bones, the list goes on—has proved that it is not ultimately resilient. The fact that a degenerative disease like MS could take hold within me, rooted within my brain no less—well, I do not yet know what to do with that. It does not fit into my image of who I am, or where I am headed. And the task ahead is not so simple. Because there is no getting better with MS—unlike cancer, it is incurable.*

*All of the effects of MS are bearable right now, today. But where they lead, and whether or how much or when they will abate—those are the questions that leave my story without that arc, culminating in a tidy ending, that I so desperately crave.*

*MS is forcing me to reframe my sense of who I am. Cancer is the story that set my adult life into motion, fitting easily, smoothly within my conception of who I am. Now, MS—it changes the story in ways I do not yet fully appreciate. It is a story of slipping away, of losing control. And while I am sure I will eventually incorporate it into the broad rhythms, the larger meaning, of my life, right now I do not know what to make of it. Because it is a story without the possibility of resolution, of completion, and that is not one I could have ever imagined for myself.*

Today I can feel sadness and compassion for the person I was in 2009 when I wrote this piece, as I remember how terrifying that long moment of unknowing was. But I waited, and as I waited I wrote, as I often do when I feel such despair, and I found a new identity. The fact of my MS has not changed; my symptoms are neither predictable nor stable, but I have consciously decided not to live in fear.

As I know from my students, in the vulnerable moments when we become unhinged from our expectations, our narratives can lead us in any direction, the endings unknown and unknowable. There is no possibility of getting back on course, when the old course is no longer available. Disease, loss, pain, betrayal—these events shake us to our core but what I have learned as I have had to re-consider and re-vise my identity time and again, is that they are not exceptional; terrible things happen to people all the time. We usually cannot control the fact of them, but how we respond to unexpected upheavals, how we make sense, how we revise our sense of meaning and start a new narrative is always entirely up to us.

## Works Cited

Hacker, Marilyn. *Winter Numbers*. New York: Norton, 1994.

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