Voice Giving (Way)

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Abstract

This feminist, embodied narrative explores the shame, blame, and desire that accompany a professor's diagnosis of disabled body and speech and the paradoxical importance and near impossibility of reclaiming her voice. The writer resists the traditional story arc and avoids the rhetorical patterns of triumph, horror, conversion, and nostalgia found in many disability narratives. Aiming for what Couser (2008) calls a "rhetoric of emancipation," she challenges stereotypical attitudes toward women with chronic fatigue immune dysfunction syndrome (CFIDS) by offering "testimonio," a politicized narrative of growth and transformation that connects with and advocates for, in this case, CFIDS sufferers and sexual abuse survivors. She describes how writing her experience of disabling illness for publication has enabled her to testify in court on behalf of others who suffer in silence and has led to a more peaceful way of being, rather than always doing—a necessary shift for those who navigate daily the conflict between participating fully and resting enough to avoid serious relapse.

"In illness … we cease to be soldiers in the army of the upright; we become deserters. They march to battle. We float with the sticks on the stream…"

Virginia Woolf, On Being Ill, p. 12

"The struggle of the sick and disabled to earn a living is one you will rarely see depicted, even in all the memoirs by the ill and formerly ill."

Susan Griffin, What Her Body Thought, p. 18

I do not remember signing up for long-term disability insurance when I went to work as a temporary instructor of college English in 1993. My experience with disability was limited to lying in bed for weeks with mononucleosis and hobbling around on crutches as a teenager with torn ligaments; listening to illness narratives as a medical journalist in my twenties; conversing with my deaf aunt and cousin in (my) halting sign language; and watching as my wordless cousin with autism dismantled Granny's radio, cooed at each component, and reassembled the pieces. I had lost a friend to AIDS and a father to Alzheimer's, but I did not feel vulnerable—at least
When I checked the disability insurance box at age 33, I was still a somnambulant soldier in Woolf's "army of the upright," marching unaware to the mythical tune of forward only. I was still in denial about the long-term health consequences of being sexually abused at the hands of authority figures and the crushing silence that ensued, my own and that of the church and state systems that allowed such abuse to continue unchecked.

I could not know in 1993 that one year later, my brother would break his neck driving drunk and spend three months in the intensive care unit looking for his paralyzed legs. Or that my partner's bright grandson would be diagnosed with schizencephaly pachygyria and never walk or talk. Or that a decade later, her brother would be diagnosed with Huntington's disease and eventually come to live with us. These possibilities were not apparent when I casually agreed to have a few dollars deducted from my monthly paycheck in the unlikely event of incapacitation.

For the next 14 years of academic life, I rarely called in sick. I had a few stubborn infections, chronic shoulder pain, and a protruding disc in my neck, nothing life-threatening. The one constant since adolescence had been work; my parents and their parents labored, and so would I. I raced through two degree programs while writing for daily newspapers in Alabama and Connecticut, finishing the bachelor's at age 20 and the master's at 23. I repeated the pattern with the doctorate while teaching fulltime, minus one semester off to draft my interdisciplinary dissertation on the transformative potential in grief writing.

Typing the phrase "grief writing" derails me. I stare at the computer screen. Adjust the white brace that holds my trunk upright. Uncross my legs. Breathe. Swallow. Start again.

The story I am trying to tell resists the disembodied scholar's tone and the traditional arc of event, rising action, climax, falling action, denouement. It resists the structure of testimonies heard at tent revivals and 12-step speaker meetings: what life was like before, what happened, and what it's like today. And it resists the rhetorical modes of stereotypical disability tales of triumph, horror, conversion, nostalgia, or redemption. My story, like the body whose disease it signifies, resists containment, prefers seepage. Who wants to read such a saga when "the subject of illness can be tedious" to hear? (Griffin, 1999, p. 14). In What Her Body Thought, Pulitzer Prize finalist Susan Griffin notes that "telling a story of illness, one pulls a thread through a narrow opening flanked on one side by shame and the other by trivia" (14). Feeling shamed or trivialized has kept me and countless trauma survivors quiet for years. Until my body crashed in 2007 and demanded of me, via throat-closings, cognitive roadblocks, and crippling pain: Who are you protecting, and at what cost? Who are you hurting with your silence? Whose interests might be served by your coming to voice?

The paradoxical life-giving importance and near impossibility of telling the disabled, disenfranchised body's story is precisely the problem I explore in this essay: how to access and articulate what my body knows but fears and struggles to speak; how to speak it so that readers and I find better ways of being with loss and losing; how to locate the story in a larger political and cultural context that includes diverse voices and resonates with rather than alienates variously-able readers; and finally, how to compose a disability narrative that resists the rhetorical structures that reinforce conventional, discriminatory attitudes and systems. Ultimately, I aim to produce what Couser (2008) calls testimonio, "a rhetoric of emancipation" that contests stereotypical attitudes toward women with disabilities by writing an assertive, self-possessed story that challenges medical, academic, church, and state authority and speaks of specific others who occupy similar political, embodied predicaments (p. 195). The testimonio avoids the "common rhetorical patterns" seen in most autobiographical disability narratives, identified by Couser as "triumph, horror, spiritual compensation, and nostalgia" (p. 192). Instead, it draws on "dialogue, poetry, and metaphors from an eyewitness perspective" to correct the
on “dialogue, poetry, and metaphors from an eyewitness perspective” to correct the dominant discourse (“Who is the Subaltern and What is Testimonio?” p. 2), which in my case explores what it means to be a lesbian academic living with an incurable, chronic viral infection connected to sexual trauma and grief. I expose the shame and desire that accompanied my crash and resulted in my “inability to function in almost all areas” after living a “highly functioning” life, as my therapist notes in her letter to the disability insurance officer.

Unlike the traditional, Western testimony that emphasizes individualism and universal truths and invites readers to put themselves in the role of the heroic narrator, I offer my story as a specific and local account of multiple forms of oppression—an account that may be representative of others but does not claim universality. I offer a modified testimonio, a literary genre defined by Yudice (1985) as “an authentic narrative, told by a witness who is moved to narrate by the urgency of a situation” such as war, revolution, or oppression (as cited in Brabeck, 2001, p. 4-5). I know from reading students’ and other writers’ narratives and listening to survivors’ stories that sexual exploitation and oppression of people with disabilities continues. My urgency to testify, both in court and in academic conferences and publications, stems from decades of knowing and doing little to stop violence against girls and women.

In the spirit of testimonio, I serve here as a witness who offers “her own experience as a representative of a collective memory and identity. Truth is summoned in the cause of denouncing a present situation of exploitation and oppression” (italics in original) (Yudice as cited in Brabeck, 2001, p. 5). This narrative denounces both the exploitation of my partially shared past growing up female in a working-class, predominantly Southern Baptist culture and the ongoing exploitation of other young women in circumstances similar to mine. However, my testimonio does not reflect the cultural memory of indigenous people or of one united group. It emerges from my “collective identity, both inherited from [my] past and renegotiated in [my] present” (Brabeck, 2003, p. 255). My urgency to bear witness against oppression emerges from the multiple groups to which I belong: children molested by clergy in the 1970s; clients exploited sexually by psychologists in the 1980s; lesbian academics with intermittent cognitive impairment and chronic illness today; sisters of men with quadriplegia; and women with disabling disease that is often misdiagnosed and misunderstood.

I attempt to compose testimonio because, like the 1992 Nobel Peace Prize winner Rigoberta Menchu, my experiences of assault and illness are not just my own and are not the result of individual “monsters” acting alone. Menchu’s book, I … Rigoberta Menchu, chronicles what happens to a Maya woman—and her people—during Guatemala’s Civil War, where “the overwhelming response to state-sponsored repression was silence” (Lykes et al., 1993, as cited in Brabeck, 2003, p. 254). Brabeck notes that while their silence saved many Mayas’ lives, “it also exacerbated people’s feelings of isolation [and] engendered mistrust of individuals, families, the community and the state” (p. 254). While ours is not “equal to” the collective damages of the Mayas’ civil war, their mistrust resembles that of children or adolescents in America who remain locked into silent fear after sexual assault at the hands of clergy or state-licensed professionals, or female academics with CFIDS who lack the energy or language skills to advocate for better working conditions. Rather than being rare, perverse events committed by so-called “evil” authoritarian perpetrators, I argue that the sexual violence that harmed me and many other girls/women resulted from misogynistic, patriarchal systems that quietly cultivate inhumane, unequal conditions at church, at school, at home, and in the privacy of health care settings. We will not reduce the violence that permeates our culture if we remain silent and complicit. Some forms of silence are toxic to body, spirit, and mind, and the action of testimonio, both in writing and in public speech, connects us to and advocates for others working toward healthier lives.

The telling is complicated when writers—Susan Griffin and I and others with
chronic fatigue immune dysfunction syndrome, CFIDS—feel tugged in “two contradictory directions, toward concealment and revelation” (p. 25). We want both to reveal the “nightmarish quality” of CFIDS and also to pass as a healthy person, partly because people with CFIDS are accused of making it up. When my dentist of two decades asked what was wrong with me, and I told him the diagnosis, he smiled and said, “Oh, yeah, the yuppie flu.” I shook my head no but was too stunned and weary to respond. Like other disabled folks who have spent too much time as a patient, I had “been socialized in the medical culture to be compliant, and that has often undermined our ability to challenge authority or to function autonomously” (Linton, 1998, p. 29). I went home, searched online, and printed out the official definition of CFIDS, which the U.S. Centers for Disease Control has called chronic fatigue syndrome since 1988; I wrote the man a note and took it to my next appointment. Once there, my courage wilted. The subject did not come up.

Remnants of my dentist’s dismissal linger and layer into a stack of similar insensitivities. One friend who had seen me struggling to walk asked casually on the phone how I was doing, and when I said a bit better, she said, “Oh, have you been sick?” Defensively, I replied that I was on medical leave, not vacation. Two others said they were sorry I was ill but they “saw it coming” and had warned me to slow down, take better care of myself. Why, they wondered, hadn’t I listened?

Griffin (1999) describes the painful effects of being told you are not really ill when you are. The disjuncture between private experience and public image is so severe, you can easily become obsessed with establishing the truth… You will be followed into your privacy by phantoms of rejection and even ridicule for what your body continues to know. The sound of these phantoms may be inaudible, but it will be distracting enough to erase your own voice, to quell any attempt to articulate even for yourself what it is you experience. And this is a serious loss because it is this voice, the intelligent and observing companion to feeling, that dignifies even the worst misery. (pp. 95-96)

The erasure of my voice began in childhood in the south, when the new music minister at our Baptist church offered me voice lessons. He was 30 when I was 13. He cultivated my trust, flattering and grooming me for the times he would lock the choir room door and reach for my breasts under the guise of teaching me to breathe properly. His fondling finally led to kissing and attempted rape, but we didn’t call it that—didn’t call it anything—in Alabama in the 1970s. As U.S. Senator Scott Brown of Massachusetts told a television journalist recently, victims of childhood sexual abuse carry the secret for decades in shame and fear of the perpetrator, convinced that no one will believe us (CBS-TV, 60 Minutes, February 20, 2011). In my working class family and community, who would have believed us back then? My throat, chest, and pelvis remember and rebel. But reclaiming an assaulted voice and body requires time, energy, and empowerment that many survivors lack, until, as the poet Marge Piercy (2001) says in “Right to Life,” “the bill comes due, with interest” (p. 387).

Of Beginnings and Endings

Living with a chronic, incurable, and sometimes invisible disability such as CFIDS, complicated by the sporadic speaking and swallowing problems of vocal cord dysfunction (VCD), how do I mark the beginnings? My disease abides, abates, and returns to inflame joint and muscle, tighten throat and ear, disrupt balance, digestion, and sleep when what I need most to restore my malfunctioning immune, endocrine, and nervous systems is equanimity, nourishment, and rest. Taylor and Eisele (2003) cite research by Friedberg and Jason (1998) that identifies CFIDS as “one of the most debilitating of all chronic health conditions, affecting virtually every major system in the body including neurological, immunological, hormonal, gastrointestinal, musculoskeletal, and respiratory systems” (p. 11).
gastrointestinal and musculoskeletal systems” (p. 11). Its exact cause remains unclear, though recent evidence suggests a viral or retroviral component (Grady, “Virus is Found”).

Did my dis-ease begin with an adolescent body being violated by the married music minister or with his edict to safeguard the secret? With a 21-year-old being exploited by the married, much older clinical psychologist whose job was to help clients sort through their soiled psyches? Did my neck harbor memories of whiplash from multiple car wrecks and latch onto moments spent retching after binge drinking? Did the roots take hold during the stubborn case of mononucleosis from tenth grade, returning now as the reactivated Epstein-Barr virus whose antibodies appear in my blood in high numbers (2,300 vs. the normal range of 0-99)? Did it start with the unexpected death of my first “out” lesbian student, Ally, who was in two of my classes in spring 2005? Did my systems begin to break down when Ally’s body flew off the back of a three-wheeled motorcycle at the moment she would have been in class writing—had I not permitted her to turn in her portfolio early? Did my disease escalate with the death of our artist friend, Kitty, whom we cared for during the holiday break and through her final breath in early January 2006? Or was it later that year, with the deaths of our three dogs from unrelated causes, followed by my partner’s older brother dying and younger brother with mid-stage Huntington’s moving into our suddenly silent house in the woods?

Or were my already overloaded adrenal, immune, and nervous systems blown, as my doctors suggest, by the violent death of my friend and colleague, the poet David Starnes? He was heading home from Savannah that sunny day in May 2007 when a woman driving a BMW hit his car head-on, apparently intoxicated, grief-stricken, and disoriented. Witnesses reported that David, like Ally, died instantly. Could David's crash have precipitated my body's crash, my inability to chop carrots, write checks, wash hair, make sense, make peace? Could his wreck have triggered the onslaught of cellular, un-integrated memories that led to panic attacks and post-traumatic stress disorder and rendered me unable to drive or tolerate noise for nine months?

**Bearing Witness on the Witness Stand**

I need to return rhetorically to the scene of the crash(es). Until recently, I was unable to write this story, perhaps because I am still living it; studies estimate that fewer than 10% of people with CFIDS “report substantial improvement over time” (Taylor and Eisele, 2003, p. 11). We live with the specter of relapse. Every day we navigate conflicting desires to participate fully or to avoid overdoing it, choices which can have devastating consequences for the work and social life of someone with CFIDS.

I was relieved when my writer's voice returned in June 2010. Attorneys for the family of David Starnes had asked for victim impact statements to be written and read aloud at the sentencing hearing for the woman who pleaded guilty to first degree vehicular homicide in David’s death. My subject, occasion, audience, and purpose were clearly defined, and I wanted to speak. The following is a relevant excerpt from my statement:

In August 2007, three months after David died, I was scheduled to report on the status of the Starnes Memorial Scholarship fund at our department's fall faculty meeting. When I stood up to speak, no words would come out. I was not tearful, and I had notes in front of me; I simply could not say anything. The department chair called my name a second time and asked if I had a report to give. I stood there and stared at my notes, waiting for my voice. Eventually, a friend picked up my notes and read them aloud. I sat down, stunned. I'm an academic. We speak. I couldn't. Earlier that day, I had left a technology workshop halfway through when I was unable to process or follow what was being
A few days later, driving eastbound on I-16 toward Savannah, I passed a mangled car and emergency response vehicles within a mile of the place where David was killed in the westbound lane. Seeing the wrecked car triggered memories of David's crash and of my own car accidents in my 20s. I cried for the next 20 miles. I made it to my appointment on time but was unable to drive myself home, so two friends drove from Statesboro to bring me back.

Later that week, I was trying to teach an upper division writing theory class and had to stop. I was lost. I stared at my students and wondered what to do. I stood up to write on the board and could not figure out what to write or where to put the chalk. I dismissed class early and told them something was wrong but I didn't know what. Within a week, I was hospitalized and diagnosed with vocal cord dysfunction (VCD) and chronic Epstein-Barr virus (EBV), conditions the doctors said were often triggered by a traumatic event. For the first time in 47 years, I was unable to function, completely disabled. I was unable to drive for nine months. I used up all my sick leave and was on long-term disability [until January 2009]. The virus and PTSD combined left me with cognitive impairment related to brain fog, debilitating fatigue, migraines, muscle and joint pain, insomnia, and chronic sore throat and hoarseness. I could not take care of myself and spent tens of thousands of dollars seeking treatment of every sort in hopes of getting well. (Milner, p. 1-2)

Disability and (Feminist) Discourse in Academe

With limited physical and cognitive energy, and fueled by the need to earn a living and remain afloat, we try to hide our disease. We keep secret what CFIDS sufferer Patricia Foster (2007) refers to as "those terrible days of non-being" (p. 111). As a college writing teacher and "like most people afflicted by shame," Foster constructs a "reassuring persona" who feels she "must be healthy. Energetic… responsible and relentlessly alert. Better to be an imposter than to be herded with the whiners, the fakers and the hypochondriacs. Better to be hyper-vigilant than to be unmasked" (p. 111). References to shame and desire appear repeatedly in stories of CFIDS and other disabling conditions. Those of us with chronic illness learn to fear rejection from those who consider themselves "fit," because as Griffin (1999) says, "expressions of frailty, pain, despair are not always welcome" (p. 25). In fear of wearing out our few caring friends, we hold our tongues and isolate ourselves. Isolation is exacerbated by "the social and cultural intolerance of illness, which leads to a construction of the ill person as ‘other’" (Stanley, 2007, p. 23) and "the construction of illness as failure or weakness" (p. 25). When I returned to work after 16 months of medical and disability leave, an employee who had been friendly in the past was suddenly hostile toward what she must have perceived as an unacceptably dull version of my once competent self. When I misinterpreted a policy change, she yelled and shook her finger in my face in front of student
workers—including one who was in my class at the time—and I walked away humiliated, choking back tears. Griffin (1999) is right that “in the arena of discourse, you can almost feel the distance between yourself and [healthy] others grow” (p. 25). Brain fog and shame only broaden the gap.

The distance between the unwell and the well-spoken drifts ever wider in academia, where language is "the material resource" (Kirsch, 1993, p. xvii) and where discourse serves as arena, game, and tool. This reality poses a major challenge for professors who lose, even temporarily, the ability to communicate clearly. Linda Brodkey reminds us in Academic Writing (1987) that university educators "exchange words rather than money or goods or services, because language is the coin of the realm" (p. 38, as cited in Kirsch, p. xvii). The situation is worse for women, especially lesbians and others perceived as somehow abnormal, who already lack authority in academe: "Women's perspectives have been suppressed, silenced, marginalized, written out of what counts as authoritative knowledge. Difference is erased in a desire to universalize. Men become the standard against which women are judged" (Flynn as cited in Kirsch, 1993, p. 9). In her qualitative study of academic women writers, Kirsch identifies three reasons why our authority is challenged:

1. We tend to occupy marginal positions, in and out of the university;
2. We generally are not perceived as authorities, and
3. We engage in research and writing “that challenges traditional disciplinary perspectives” (p. 63).

In other words, some of us refuse to be contained, intellectually or otherwise, in boxes designed to protect the injurious status quo.

My scholarship in the areas of grief writing and healing, queer studies, and now disability studies definitely pushes the boundaries of traditional English in a Bible-belt, southern university. As a feminist, I insist on using embodied narrative and publishing in venues friendly to such strategies rather than assuming a pseudo-authoritative masculine voice. With Nancy Mairs (1994): "I sought and still seek to avoid the reassuring rigidity and muscularity I'd learned to love in the academy. To abandon the narrative structure inculcated there … To refuse its critical questions (What does this mean? Why does it matter?)" (p. 117). Such shifts are required in writing disability from and of the body to other bodies, whether disabled or temporarily able. The genre of testimonio lends itself to feminist narrative because both are founded on the same basic tenets: "insistence on the value of subjective [experience as the basis for] knowledge, the reappropriation of voice which challenges imposed definitions of reality and morality, the political project aimed at confronting injustices, and most importantly, collaboration and solidarity" (Brabeck, 2001, p. 4). While I do not claim to speak for others, I weave into the fabric of my story the voices of other lesbians, academics, CFIDS sufferers, and sexual abuse survivors. Rather than claiming a definitive, authorial voice, I blend my story with others and propose the narrative "as an allegory for many … a collective self engaged in a common struggle" (Brabeck, 2001, p. 5). In women's testimonios in particular, "experiences are constantly mediated through gender, the body is given prominence, and political acts are understood within the maternal concepts of the primacy of life and connectedness of self and others" (Marin, p. 53, as cited in Brabeck, p. 5). In making my embodied story multiple and mingling my tentative voice with the voices of vocal survivors, I work toward connectedness and against the isolation common among sexual abuse survivors and academics with CFIDS or other chronic illness. We write against easy erasure by those who insist that we and our students' and children's traumatic histories do not exist. We read and re-tell the histories of Foster, Griffin, Woolf, and Mairs in hopes of creating safer, healthier communities in the present.

When words lodge in the throat as they do with vocal cord dysfunction or emerge garbled as they do from a brain addled by CFIDS or other chronic illness, we write in the same raw voice. In the end, we decide to submit this testimonio to the In Media Res collective for publication, in hopes of creating a safer, healthier community for all.
garbled as they do from a brain addled by CFIDS, the desire to disappear intensifies. Fortunately, bowing out or staying stuck are not our only options. Writing—at home in bed between naps as CFIDS sufferer Laura Hillenbrand composed *Sea Biscuit* and more recently, *Unbroken*—can shorten the distance between the intelligent and the unintelligible, reducing fear and isolation on all sides as it brings disease into the light and locates it in a broader social context. Writing enables us to create a new voice when the old one falters, though drawing word pictures of a disease as diffuse and misunderstood as CFIDS can be frustrating. As Mairs acknowledges in *Voice Lessons* (1994), "Catastrophe tends to be composed not of a monolithic event but of a welter of little incidents, many of which bear no apparent relationship to one another" unless we look long and close. "Language, in ordering these [incidents] into recognizable patterns, counteracts disorientation and disintegration. This process of making sense of a flood of random data also produces the impression—generally quite groundless—of control, which may save one's sanity even though it can't save one's own or anyone else's life" (p. 126). For someone whose body and mind malfunction unexpectedly, saving sanity and gaining a sense of control is crucial.

For me as for Kathlyn Conway in *Ordinary Illness* (1997), "writing is like a magnet that draws together all the stray parts of myself" (as cited in Stanley, 2007, p. 28). Since my CFIDS diagnosis, some of my "parts" are gone and forgotten; some remain broken and some repaired or reparable with medication. In the spirit of embodied, feminist writing, I forge ahead. I write because, like Mairs, "I think that my 'story,' though intensely personal, is not at all singular. Beneath its idiosyncrasies lie vast strata of commonality, communality" (119). Weary of the feelings of isolation and ineptness common among academics with cognitive and energetic deficits, I reach for the "strata of communality" to which writing for real readers provides access.

Creating and publishing illness narratives is particularly important for women. Historically, many of us have had our "bodily experiences defined, categorized, and encapsulated through narratives structured by the patriarchal medical system" (Dasgupta & Hurst, 2007, p. 4). Reading and listening to women's stories of illness experience sheds light on their relationships with themselves, their medical providers, families, and communities (p. 5). I have long felt, like Griffin (1999), "a powerful need to be known and understood as I really am. Being misunderstood, either in negative or positive ways, is more than painful for me" (p. 33). Only through knowing and understanding—being known and understood—may we dismantle the shame that binds us. I now recognize, with Foster (2007), that "I can't pretend that fatigue is an illusion, that illness doesn't take its toll." To pretend that I don't have this disease is to guarantee relapse. I now understand that "illness can diminish and disenfranchise and that hiding illness can get you there quicker" (p. 112). Is it coincidence that Foster and I grew up in Alabama in the 1960s and '70s and are both childless writers and teachers with CFIDS? Again, feminist research and testimonio see and speak through the particular lenses of gender, race, class, and location, not claiming universality but noticing commonalities as they emerge. While I have never spoken with Foster, I know from reading her work that our paths parallel, our struggles intersect.

**The Costs of Seeking a (Nonexistent) Cure**

Even with decent health insurance and long-term disability, my medical bills have accumulated quickly, for as Griffin (1999) recalls about her worst bout with CFIDS, "the medical inventory is so long it verges on the comical" (p. 37). My desperate search for a remedy resembles that of others in the first blush of chronic fatigue, most of whom "do not embrace the notion of taking pride in their disability, but instead struggle with their illness, seek a cure, and hope to return to their pre-CFS way of life" (Taylor & Eisele, 2003, p. 4). I am more accepting now of my body's new terms and more connected with other sufferers; I do not yearn to return to the
frantic, fear-driven pace of my earlier way of life. I marvel at the financial and physical drain of multiple visits with speech, physical, massage, and cognitive behavior therapists; with an acupuncturist, chiropractor, internist, gastroenterologist, pulmonologist, gynecologist, cardiologist, ophthalmologist, and otolaryngologist; and monthly energy shots, compounded prescriptions, and intravenous infusions of a special cocktail of vitamins, minerals, and anti-viral medicines at an Atlanta clinic specializing in fatigue and fibromyalgia. My health gradually improved as symptoms abated, but I continue to experience flare-ups of symptoms that sometimes lead to relapse. At these times, I cancel plans and retreat to the bedroom until the fog lifts, pain subsides, and hand-eye-foot coordination returns.

During my 16 months at home, my partner and friends drove me to appointments without complaint as I gazed out the window, "irresponsible and disinterested and able, perhaps for the first time for years, to look round, to look up—to look, for example, at the sky… If we were all laid prone, stiff, still the sky would be experimenting with its blues and its golds" (Woolf, 1930, 2002, p. 12). Finally, I was able to pause and look up. Practicing slow, deliberate looking, Woolf says, either up at the sky or "down at something very small and close and familiar, we shall find sympathy" (p. 12). When I was able to read again and ran across Woolf's *On Being Ill*, I resonated with her Buddhist exhortation to look deeply to find sympathy. From my bed beside windows overlooking a pond, I observed spiders, skinks, turtles, rabbits, and birds of every sort busy themselves through the seasons. The only writing I did, other than recording my daily intake, output, meds, and symptoms for the fatigue specialist, was a haiku about the star magnolia outside my window. In the span of a year, the poem evolved into what I call a "quadku," four stanzas consisting of four haiku each, focusing on the sentient life I could see from my bed across four seasons.

Without realizing it, I was enlarging my capacity for empathy and my ability to dwell in *being* rather than *doing*. Could anything other than catastrophic illness have kept me still and quiet for so long? I had participated in many silent meditation retreats, but even there we had structure, bells, routines, and rules. Disability was different; one long afternoon in bed I kept eyeing the red numbers on my digital clock: 3:20, 3:23, 3:28, 3:31. No one was coming or going. Nothing was happening. What difference did the hour make? Suddenly, I got it: Nothing better or worse would happen later that was not happening already. Walt Whitman was right in refusing to delineate or attach to beginnings or endings:

> There was never any more inception than there is now/ Nor any more youth or age than there is now,/ And will never be any more perfection than there is now./ Nor any more heaven or hell than there is now.

("Song of Myself," 1965, p. 39, stanza 3)

At last, I understood my job: breathe in, breathe out, be present. Eat dinner. Pet the pups. Curl my now-bony, 106-pound frame into my partner's soft flesh, and close my eyes. Rest. I no longer qualify to give blood.

**Back to School: To "Pass" or "Come Out?"**

I slowly regained the use of my limbs, voice, and mind after months in bed and in clinics. I returned to the classroom in January 2009 minus one-third of my body weight and my confidence and cognitive quickness. As I drove the seven miles to campus that first morning—yes, I drove! —I sang along with Leonard Cohen's "Hallelujah" and celebrated the blue sky and red-winged blackbird I noticed on the way. I was consciously exhilarated to be returning to work, to be of use again. I had fresh perspectives for my Writing and Healing class and was happy to be among them. It would be a rocky semester in which I returned to the fluorescent-lit hospital scene where my brother, Tim, developed pneumonia related to quadriplegia. My mother and I cradled his body as he drew and released his final, labored breath.
Mother and I cradled his body as he drew and released his final, labored breath after midnight on March 1.

I made it through the term and collapsed, then recovered in the now familiar push-crash cycle of CFIDS. Two students hit me with the most hostile comments I have ever received in course evaluations: "She is very confused at times and it makes the class confused and then she is just all out of wack[sic] from that point on and it sucks." For improvement, the professor should "stop using her sickness as an excuse why things are out of order every time something does not go as planned." Is that what I was doing? While most students wrote positive comments and were sympathetic about Tim's death and my subsequent memory lapses, I zeroed in on the negatives and sweated them, literally, for days. The other student writes: "Towards the middle of the semester Dr. Milner[sic] organization skills began to simmer. At points we, the students were confused about what was due when. I do understand that uncontrollable circumstances come up ... it just really became chaotic." Neither student mentions death or disability. Their comments could be taken out of context and used against me in annual or post-tenure reviews, in which case I would explain, with crimson face, the circumstances. I wonder if I told my students too much or too little about my situation; I wish I could have named for them what was at stake in my brother's death and my presence there, the tough choices a person with CFIDS makes and the consequences of those choices. But I did not.

With every new class, I now face two decisions related to "coming out:" Do I tell students I have a disabling virus that flares up and temporarily rearranges how I think, talk, and move? Do I answer their "Are you married?" question with my 25-year relationship with a woman? How much will I disclose, and how can I be sure my disclosures are relevant and appropriate to what we are learning? Like any rhetorical challenge, I decide and proceed in the context of each moment, each symptom, and each situation. The marriage question seems easy now compared to divulging my disability, a decision that could erode my students' faith in my ability to teach them and my confidence to continue.

I have been coming out as lesbian in class for ten years, typically during an introductory activity in which we bring an object that symbolizes something about our values or identity. In a normative rhetorical move that minimizes disruption, I typically share a photograph of my partner and dogs beside an outdoor fire or her high school class ring that I wear. I pass around the photo or ring and say a few light words as a member of the circle, then nod to the next person. Sometimes my coming out seems to invite others who are "different" to do the same, and by semester's end, students have learned as much about valuing diversity from knowing each other as they have through texts we have read and written. In Writing and Healing last spring, I disclosed my VCD in a written response to a quiet student's detailed description of her throat-closing episodes, difficulty speaking, and frustration with doctors who fail to diagnose or treat her "problem." She quickly found VCD online, and her symptoms and history matched the medical definition. Her relief was palpable in both her smiles and her email to me about her gratitude for having a name for her malady and for knowing another sufferer.

My decisions to pass or come out are influenced by the foundational work of Linton in Claiming Disability (1998) and of other teachers with disabilities—visible and invisible—whose essays appear in Disability and the Teaching of Writing (2008). I agree with Mark Mossman that "telling stories, in the social context of disability, articulates the rhetoric of social change" (p. 165). Mossman describes what happened when he wore shorts to class for the first time on the last day of spring semester, revealing his prosthetic leg to surprised undergraduates: "I did not want to be a super-crip, to be heroic or brave for simply being the professor at the front of the room, for doing my 'normal' job with my 'abnormal' body. I needed to take control of my body, to share in its story, in its social meaning" (p. 168). Students were familiar with his "pronounced limp" but had not seen his misshapen legs. After
were familiar with his "pronounced limp" but had not seen his misshapen legs. After
an uneasy start, he told the class the short version of his medical history:
anomalies at birth, several surgeries, kidney failure, and now a possible transplant.
He assured them it was all fine, and they shifted to the day's assignment.

Through telling his body's story, Mossman negotiated "difference and abnormality"
and claimed "inclusion and recognition as 'normal'" with his students. A larger
benefit was "an undermining of stereotype, the construction of a new story of
disability" which evolved as he allowed his body to become "a vehicle for social
change" (p. 168). By showing his legs and telling his story, he demonstrated "that
physical abnormality does not equal powerlessness and helplessness, or heroism
and bravery, or anything else necessarily, but rather that disability equals normality
and sameness" (p. 168). He concludes that "we need to authenticate disability, to
make it a real, viable perspective on the world" for our students by allowing all of
them to participate fully in discussions and by giving all of them "a normalized
status" (p. 169). When teachers make themselves transparent and vulnerable,
students often feel safe enough to follow suit, and learning is more likely to take
place.

From Personal to Political to Testimonio

Autobiographical narratives, by definition, require self-representation, and "the self"
or self-image of a chronically ill or disabled person is always at risk of being
obliterated by disease, loss, or authoritative figures assuming to know and speak
for the person. Couser (2008) sees three obstacles that interfere with a disabled
person's narrative coming to light: "having a life, writing a life, and publishing a life"
(p. 191). Too often, he says, "those who accept society's devaluation of them are
less likely to consider their lives worthy of autobiography. Stigma serves to silence
the stigmatized" (p. 191). People who connect with others who have been similarly
stigmatized or oppressed increase their chances of writing not only a narrative, but
a testimonio, which John Beverley defines as autobiography that affirms individual
growth and transformation "in connection with a group or class situation marked by
marginalization, oppression, and struggle" (p.196). In testimonio, the [illness]
narrator speaks not only for herself but for a group of marginalized individuals with
similar circumstances, offering political critique that emphasizes "the prejudicial
construction of a normative culture" rather than representing disease as a personal
flaw or lack (p. 196-197). Connecting with others is crucial for testimonio and for
political and social advocacy. In doing so, we acknowledge and respect our
differences and privileges—such as mine as a highly educated white, tenured,
associate professor—and speak alongside, not on top of, others in similar
circumstances.

Through fragments and fog, fits and starts, my testimony demands utterance not
only for myself, but for others with CFIDS, VCD, and/or traumatic histories of
sexual abuse by perpetrators who continue unabated. Like Frank's wounded
storyteller (1999), I am "trying to survive and help others survive in a world that
does not immediately make sense" (p. xiii), a world which offers less compassion
to those whose dysfunctions are perceived as self-inflicted or psychosomatic and
more to those who were "born that way" or inherited a genetic predisposition.
Either way, those of us with visible or invisible disabilities want to be recognized as
fully human, not elevated as heroes or denigrated as weirdos. In sharing how
CFIDS and VCD—and in my case, a history of sexual abuse and traumatic injury—
are transforming my life and work, I "assume responsibility" for my life (p. xii) as I
reject being silenced or defined by events I could not or cannot control, past or
present.

Disease and disability are arguably personal, even private experiences. A survivor
who decides to write and/or tell about her body's experiences may have multiple
reasons for doing so, such as political, social, educational, financial, or
spiritual/religious. Whatever her reasons, "writing is a political act" (Vick, 2009, p.
“the story of women’s illness narratives is the story of the personal made public, or, if you will, made political” (Dasgupta & Hurst, 2007, p. 5). Whether written for publication or delivered orally, narratives of illness and disability are “inherently social and usually presuppose an audience,” be it a friend, family member, physician, support group meeting, newsletter, scholars, students, or the wider public who may read the story online or in print (p. 5-6). Once made public, the stories enact Mossman’s (2008) “rhetoric of social change” as we see in Foster’s (2007) story of chronic fatigue. She wonders: “When does a medical narrative become a political narrative? When does a disease move from the biological to the cultural? And does this … add another layer to the patient’s suffering?” (p. 111). I share Foster’s curiosity and ambivalence; perhaps an illness narrator’s level of suffering after going public depends on her rhetorical and bodily situation, which is fluid, not fixed. Foster learns from extended periods of exhaustion and years of hiding her illness at school that her time on the couch has humbled her. She discovers that “vulnerability has no inherent politics. Politics comes through creating a narrative. Politics is embedded in the struggle for recognition. Politics is inevitably about whose narrative of suffering and success gains recognition. Will it be yours or mine?” (p. 114). I, too, wonder whose ethics and interests are considered in the decisions of which stories “play” and which writers get paid, and in what light, on network television, in daily newspapers, weekly or monthly magazines, or academic journals and books? Would a healthy heterosexual mother’s allegations of childhood sexual abuse be taken more seriously by judges and juries than those of a childless, chronically ill lesbian academic? Could I have written, much less published, this story for a more straight-laced English studies journal?

Personal and Social Benefits of Voice Giving

Having grown up in the 1960s in a southern culture that taught girls to smile, submit, and stay quiet, I now aim to “not only recover [my] voice,” but to “become a witness to the conditions that rob others of their voices. When any person recovers his voice, many people begin to speak through that story” (Frank, 1999, p. xiii). I have witnessed firsthand the benefits of bearing witness in the Writing and Healing course I teach every spring. It is not uncommon for one student to disclose rape, another incest, another abandonment or injury or betrayal. By semester’s end, we are rowing together rather than floating along in isolation. By then we realize that “the narrator of personal disaster … wants not to whine, not to boast, but to comfort” (Mairs, 1994, p. 127). Such writing requires emotional, intellectual, and physical fortitude, especially if the survivor is reaching for a public audience:

Choosing to speak publicly about affliction is risky for both [genders], but for different reasons: for the woman, because the behavior (public utterance) is culturally impermissible; for the man, because the condition (physical or mental weakness) is proscribed. Clearly, the woman who undertakes to publish a book about her miseries, or about anything else, has already decided to transgress, at whatever cost, the taboo on female speech. (p. 128)

Mairs insists that writers who “seek to console and hearten” must “make themselves and their anguish wholly transparent, revealing not illness as metaphor but illness as illness, in order to persuade the skeptical reader, through the very writing, that survival (at least till the last page) is possible” (p. 129). Though the trajectory of my disability differs from Mairs’ multiple sclerosis, I, too, have learned that “it is possible to be both sick and happy. This good news, once discovered, demands to be shared” (p. 127). I have abandoned my body long enough, and I am listening to her now, inviting shoulder and jaw to speak.

In a September 2007 email to an old friend who has published two mystery novels, I connected the vocal cord dysfunction to my history of sexual abuse in church after the pulmonologist who diagnosed it said that one-third of those diagnosed with
the pulmonologist who diagnosed it said that one-third of those diagnosed with VCD were molested or abused as children. I wrote to my friend: “I’d like to send [the molester] my hospital and therapy bills now!” She wrote back immediately that I must write the story, write it all the way out and through, something I could not begin to do until now. A month later, I found myself in speech therapy at 47. I hissed and hummed into a microphone as green lines danced across a screen indicating the depth of my breath, the strength of my vocal signal. In my final session, the therapist asked me to read aloud a section from Thoreau’s Walden, measuring breaths and regulating pauses as she had encouraged me to practice at home. My eyes stung as I delivered the familiar words audibly without faltering: “I went to the woods because I wished to live deliberately … and not, when I came to die, discover that I had not lived.” Finally, I had learned to breathe from the diaphragm, this time successfully because the teacher/therapist kept her hands to herself. My body and voice were beginning to belong to me again.

I agree with Griffin, Mairs, and Frank that writing an illness or disability narrative is both personal—finding words for a malfunctioning, inarticulate body—and social, telling the story to an actual audience. The narrative’s structure is shaped by the rhetorical moves I internalized as a medical journalist hearing patients and doctors describe sickness and death in such disparate terms, patients using metaphors of “fighting” and “conquering” while doctors were careful to couch diagnoses and prognoses in disembodied terms of percentages and to remain silent on matters of soul or spirit. As an adolescent visiting grandparents and older relatives, I witnessed interminable family “organ recitals” and vowed never to waste a sunny day indoors complaining for hours of headaches, heartburn, or heat rash.

It is no surprise that speech often fails when doctors ask, “What brings you in today?” and expect us to elaborate on the evidence the body now presents. I learned to pen my symptoms in advance, over a period of days, so that I could hand the list to practitioners when words dried up: throat, ears, head, heart, arms, elbows, wrists, back, gut, vagina, knees. Body parts won’t do as they’re told. The one who could answer the question is apparently not home. Instead: insomnia, inertia, dizziness, stumbling, stool, urine, drip, drainage, discharge. Woolf refers to “the poverty of the language” in describing illness, how English “can express the thoughts of Hamlet and the tragedy of Lear, [but] has no words for the shiver and the headache” (p. 6). We reach for romantic poets to express love, “but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry” (p. 7). Fortunately, my general practitioner remains patient and reaches for my list when words stagger around haphazardly or stick to my tongue. She asks questions, and I nod. We usually find our way, if only to compassion and forbearance.

**The Power of Positive Recognition**

My story is “not just about illness” and is not just about me; it is “told through a wounded body” (Frank, 1995, p. 2), as stories of death are not just about the person lost, but are told through a survivor’s grieving body. I persevere. I come in, go out, rest, and return. As I’ve learned from my students for years, telling and listening do not come easy, but both are worth doing: “As we witness to the past and as we serve as witnesses for others, we may begin to see how the cords of one story link to the cords of another. This recognition … enables a reconnection between people in the present” (Steele, 2000, p. 9). Recognition is key in reducing shame and blame and engendering compassion for ourselves and others. Griffin (1999) goes one step further: “If a story is good enough, everyone will see their own lives reflected in it” (p. 101). She acknowledges that “mingled, stories more than double in value. When one story meets another, the consequences can be surprisingly intense” (9). Reading Griffin and Foster’s accounts of CFIDS let me know my illness was real, that I was not imagining the symptoms. Their stories reflect and expand my experience to a community larger than the one I inhabit.
geographically. Earlier in my illness, I read other CFIDS narratives such as Laura Hillenbrand’s “A Sudden Illness,” Dorothy Wall’s *Encounters with the Invisible*, Floyd Skloot’s *The Night-Side*, and Peggy Munson’s essay collection, *Stricken*. I knew that I could survive and perhaps thrive and create because these writers had done it.

Relief from the shame of a malfunctioning mind and body comes with recognition of its complexity, especially after a period or a lifetime of self-blame and desire for visibility. The pleasure of finding words for one’s illness experience along with other writers and teachers who share it, then locating the story within the framework of disability studies, outweighs the pain of days and nights at the computer. The satisfaction of finally having said something to someone who might hear it is worth the energy drain required to say it. Woolf (1930, 2002) named the dynamic precisely: “There is, let us confess it (and illness is the great confessional), a childish outspokenness in illness; things are said, truths blurted out, which the cautious respectability of health conceals” (p. 11). Perhaps our unpredictability or outspokenness—along with ubiquitous denial of aging, death, and disability in families, schools, churches, and advertising—is part of the reason why society spends enormous energy and money “keeping people with disabilities sequestered and in subordinate positions” and why universities try to “justify that isolation and oppression” by ignoring or marginalizing disability studies (Linton, 1998, p.3). With illness or loss of function comes a tendency by doctors, family members, teachers, and friends to medicalize or infantilize the person, to over-protect, silence, or ignore our truths, blurted or otherwise. In the early stages of a disability, according to Jacqueline Rinaldi (2008), those impaired “feel an acute sense of displacement, living as they do in a culture that privileges strength, beauty, and health over frailty, deformity, and illness. They correctly perceive that cripples generate discomfort, that wounds disturb, that damaged bodies affront” (p. 200). These feelings and perceptions intensify shame, which only improves with internal and external recognition of one’s worth and value.

Before the Americans with Disabilities Act was passed in 1990, people with disabilities were hidden in institutions, attics, basements, and “special” schools, classrooms, and buses to be segregated and erased from view of the so-called able-bodied (Linton, 1998, p. 3). Now that more people of varying abilities are participating in public life, Linton says, “we disrupt the social order. We further confound expectations when we have the temerity to emerge as forthright and resourceful people, nothing like the self-loathing, docile, bitter, or insentient fictional versions of ourselves the public is more used to” (p. 3). In her efforts to make disability studies part of humanities curricula, Linton refuses “the medicalization of disability” and reframes disability as “a designation having primarily social and political significance” (p. 2), a reframing that reinforces what Foster, Griffin, Mairs, and Frank say about the social and political power of illness narratives.

In his foreword to Linton’s *Claiming Disability* (1998), Michael Berube acknowledges the difficulty in defining and distinguishing between disability and illness. Defining either is “inevitably a matter of social debate and social construction” (p. viii). Berube credits Linton with showing, convincingly and repeatedly, that “humans have defined normal in as many ways as there are human cultures” (p. viii), and that humanities curricula in universities should include more humane representations of disability if we are to create a more humane society. He writes: “Even though I knew that gender, race, and sexual orientation were unstable designations, subject to all manner of social and historical vicissitudes, I had yet to learn… that disability is perhaps the most unstable designation of them all. Surely I was in denial, as are so many nondisabled persons” (p. xi). Many in American culture will live and die without disrupting designations of their own race, gender, or sexual orientation, but almost everyone will experience changes in the extent to which they are “able,” temporarily or permanently: in a flash, gradually, or recursively with aging. The hand, eye, or knee
that serves us now may give way, given the inevitability of sickness, aging, and death. Why pretend otherwise?

The House of Shame and Creativity: A Call to Testify

References to shame appear frequently in illness and disability narratives and narratives of sexual abuse, especially when the writer can be blamed for her or his condition. In his foreword to *Scenes of Shame* (1999), psychiatrist Donald Nathanson paraphrases Leon Wurmser: “Creativity requires the heroic transcendence of shame” (Adamson & Clark, p. vii). Nathanson notes that most stories of scientific, political, romantic, or economic success feature courageous people whose effort “was carried along on a wave of enthusiasm sufficient to wash away potentially stultifying shame” (p. vii). Wurmser distinguishes between shame and guilt, saying that shame stems from a violation of the self, and guilt from a violation of others (p. 25). Mairs, Griffin, and other writers of disability narratives must know that admitting shame is “an indispensable part of human growth” and “defends against the destructive consequences of unconscious feelings of shame … that may push one to violate the other’s physical or personal boundaries” (Adamson & Clark, p. 27). Furthermore, the ability to experience shame and guilt openly and to claim its psychic or bodily consequences “serves as a defense against egotism and coldness, unconscious defenses against shame that result in a betrayal of the other’s trust and love.” Just as coldness and egotism are often common denominators among rapists and child molesters, so is a history of childhood abuse or neglect. As they were treated, so they treat others, as long as their shame and guilt thrive under the skin, under the brain’s conscious radar.

Perhaps unacknowledged or repressed shame motivated my egotistic music minister and psychologist to violate boundaries and betray trust. Even now, as I prepare to testify in depositions and hearings before a state licensing board and a civil court judge about the long-term damage done by these men’s sexual improprieties, both perpetrators insist on their innocence. Despite testimony from young women in the choir he directed until two years ago—students for whom he held the power of their grades and the power of their scholarships—the voice teacher insists that “the girls” conspired against him to create lies about his sexual misconduct. My emergence as a witness provides evidence of a pattern that has led to his termination without pay; although he is fighting the termination, our combined voices bear witness to what our bodies have endured by his hands. On April 1, 2011 at the Colbert County Courthouse, the choir director agreed to a settlement before Circuit Court Judge Henry Allred that he will never teach college again.

Likewise with my first therapist, despite the evidence consisting of love letters he handwrote and delivered to my apartment while I was his patient and my detailed calendar of events from that year, he claims he is not guilty of any wrongdoing and the board is out of line to litigate. Meanwhile, he continues to see five or six clients a day, a reality I can no longer afford to ignore. His boundary-crossings thrive between my aching shoulder blades and in my unsteady gait and gaze during viral flare-ups, just as the voice teacher’s violations linger in my chronic sore throat and shallow, exhausting breathing. Distrust rumbles in my relationships with anyone in a helping profession, complicating treatment and recovery. Knowing now that “the prohibition against therapist/client [or minister/congregant] sexual involvement was first codified in the Hippocratic Oath almost 3000 years ago” (Flynn, 2003, p. 23), I write and speak out against such violations. I plead for personal agency, especially for girls and women who grew up as I did in a culture that privileges white male authority figures and discounts the female voice, body, and brain. I hope, in practicing the arts of self-reflection and testimonio, to avoid inflicting pain on my students or other relations with whom I have a power differential.

Just as unacknowledged shame can lead to coldness and boundary violations, the inverse is also true. Adamson and Clark (1999) note: “Shame is an important motivator of positive behavior.”
Adamson and Clark refer to the "often compulsive relationship between shame and creativity" and its relationship to writing: "Writing is potentially an act of the most dangerous exposure ... but writing, precisely because it allows one to hide and reveal oneself at the same time, also allows for an intimacy and trust to be established with another or others, perhaps, in a way that no other situation provides" (p. 28). Whether writing in a classroom, journaling in a café, or typing alone on her home computer, “the writer seeks some degree of display, even when she is hiding, and must be able to trust in an audience, in the willingness of others to see her as she is without undue fear of overexposure or invasion or rejection.” She trusts that her words, a representation of herself or her experience, will be seen and heard by empathic readers who will recognize her (pp. 28-29). Writers seek, through communication, to surmount the destructive aspects of shame, and “such a surmounting is the goal of both love and creativity” (p. 29).

Without communication, shame and self-loathing continue to churn in a sea of "what ifs" and "if onlys," unless and until we speak up and change the pattern. Since stepping into the light of testimonio, my fog has (mostly) cleared, my pain and insomnia have (mostly) dissipated, and my voice has become (mostly) viable and reliable. For these side effects, I am grateful.

Closings and Openings

At the risk of misleading readers into thinking mine is a conversion narrative, I must tell how 16 months of relative immobility moved me closer to my brother. I was too weak to travel to see him the first Christmas I was ill, but a year later, we sat together at his slightly elevated kitchen table in the glow of colored lights while everyone slept. I wanted to ask how Tim had managed to drive again after his accident, return to college to complete GIS (Geographic Information Systems) certification, and go to work as a part-time city planner. I wanted to know how he had adjusted to his loss of privacy (he had lived with our mother and stepfather since his accident and divorce 14 years earlier) and his new dependence on others to help him bathe, dress, and manage bladder and bowel functions. Sober he was not a big talker, but he was a kind listener, a gentle, thoughtful person.

As we sat alone at Tim's table, I acknowledged, somewhat awkwardly, that I had not begun to fathom his situation until my own body seized up. That I respected his perseverance, his pilgrimage, his strength. Of course, I said, I can still walk and may recover most of my abilities, so I'm not equating my chronic fatigue with your quadriplegia. I stopped. He nodded and smiled: "Go on." But I couldn't. My face dropped into my hands, then down into my arms folded against the table. Not one to show emotion, he surely wanted to back away from the table and motor down the hall to his room, but he sat still. He waited as I wept, then handed me a tissue. I lifted my face and muttered that I wanted to know how he does it, how he goes to work and comes home without railing against his limitations or drowning in self-pity. How? I asked. And why? In his most serious, quiet voice, he looked into my eyes and replied: "Patience. You learn to be patient."

Less than three months later, he spent 12 days in the intensive care unit where he was placed on, then off, and almost back on a ventilator. When I asked what he wanted, he said, "No more." He wanted more time, but his lungs and body were...
wanted, he said, "No more." He wanted more time, but his lungs and body were spent. He told his sons, 18 and 24, how proud he was of the men they had become. He called a meeting of family and friends and entertained us with memories and hallucinations. When his lungs began to fill and collapse again, we moved him out of ICU and into a private room. At his request, I bathed his face and combed his gray hair, reassuring him that we would remain with him. He nodded and smiled. Morphine and oxygen eased the way. Not long before his final exhalation, he said: "I'm ready to get out of this chair!" We cheered him on.

Now, two years later, I grieve over conversations we never had. What might I have done differently to engage him, to invite speech? What rhetorical strategies might have worked to open our hearts and loosen our tongues in moves toward connection and away from the isolation and shame that disability—or the able-bodied person's reaction to it/us—sometimes imposes?

In the creative exercises of writing and revising this illness narrative and in preparing to testify publicly on behalf of others, I experience an unfamiliar strength of body and mind. I agree with Alice Walker (1993) that creative activity becomes a kind of "spiritual alchemy" that promotes health and well-being. When we create a poem, a sculpture, or a loaf of bread, we focus on something outside ourselves, and in the process, our grief begins to lift; when we share our poems and loaves with others, we open ourselves to healing connections for ourselves and our communities. Griffin (1999) similarly acknowledges that whether we are ill, well, or in the murky middle, "getting and spending are crucial to surviving in modern times" (p. 9). Sometimes we give away material objects or cash that would be useful to us if we kept them, "but there is one gift that has no value until it is given. And that is a story" (p. 9). She compares the decimation caused by CFIDS to "a dilapidated house whose every system fails" (p.37), a simile that works well for me. Mairs (1994) turns the house into a metaphor for any autobiographical writing: "If I do my job, the books I write vanish before your eyes. I invite you into the house of my past, and the threshold you cross leads you into your own" (p. 120). Indeed, she names my experience in reading her work along with Griffin and Woolf: crossing into their worlds, I dwell more deeply in my own and am able, slowly, to create a broad path forward for my rickety, rambling body.

Yet, I am compelled to echo Whitman's cautionary words from "Song of Myself," stanza 26: "Writing and talk do not prove me./ I carry the plenum of proof and every thing else in my face" (p. 16). Words, whether designations of disease or declarations of love or betrayal, cannot signify permanent, locked-down reality, as he says in stanza 46: "I …was never measured and never will be measured" (p. 75). Neither can our bodies be measured or contained; Whitman continues in stanza 52, "You will hardly know who I am or what I mean,/ But I shall be good health to you nevertheless,/ And filter and fibre your blood" (p. 80). In coming home to dwell in the body, we meet spirit(s); in bearing witness to the woes and triumphs of human flesh and heart, we are buoyed by the stream of human compassion where we mingle, drift, and occasionally make waves in our attempt to avoid drowning. Together, we keep each other afloat on a sea of intermingling stories.

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1 to give something as a gift He gave away most of his money to charity. (informal) Check out the prices of our pizzas—we're virtually giving them away!
related noun giveaway.
2 to present something The mayor gave away the prizes at the school sports day. 3 to carelessly allow somebody to have an advantage They've given away two goals already.  give something/somebody away. Add to my wordlist. jump to other results.