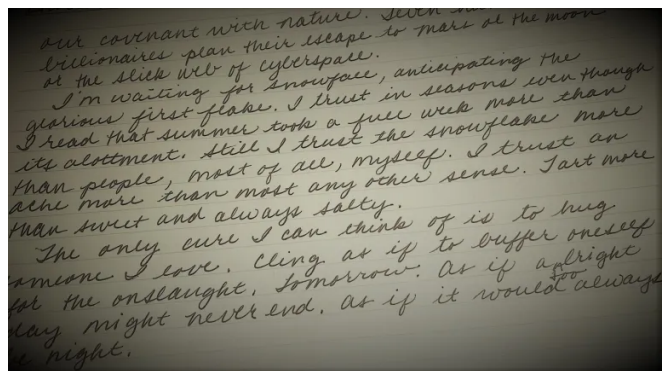


The welt under the eyelid appeared today as it did on Friday, and on Tuesday. The week before and the week before that, going back not months but years. Officially diagnosed as idiopathic angioedema, the swelling happens in either eye, and in my lips, changing the whole look of my face into something not quite recognizable to me. It is both my face and not my face.

This is just the next step on a medical journey that started in the 1990s when I was diagnosed with rheumatoid arthritis (RA). I might as well own up to the fact that the diagnosis was also the catalyst that brought me to a life of writing. The poet Sharon Olds said in a Q&A for *Literature and Medicine*, “Someone said that artists generally have a gift and a wound—the gift, which makes them able to write, and the wound, which drives them to feel they have to do it” (243). I often wonder how Olds’s view applies to me. I readily recognize where my work lands in that filling of the wound category. More importantly, how does my illness directly relate to how I craft?

Louise DeSalvo writes in *Writing as a Way of Healing*, “Narrative about living with illness, disease, dying and disfigurement...must supplant falsely hopeful triumphed-over-all narratives as norms of our culture” (198). DeSalvo feels closer to my experience than the lofty Olds. As my body deteriorates under the weight of RA flares, my experience on the page feels more like preservation than filling a wound with art: “Writing when we are living with wounded bodies is a primary vehicle for resisting cultural prejudices about who we are, what is possible and what wellness and wholes mean” (DeSalvo, 195). With this new facial-deforming swelling, even as it isn’t permanent, it erases what I know to be my physical face, replaces it with a different one. Like a persona on the page, it is part of me and not all of me. Maybe I get a glimpse of the personas I create on the page when my facial features swell, accurate and not at the same time. To experience the change back and forth, though, feels unwieldy, chaotic, beyond my comprehension and my grip.

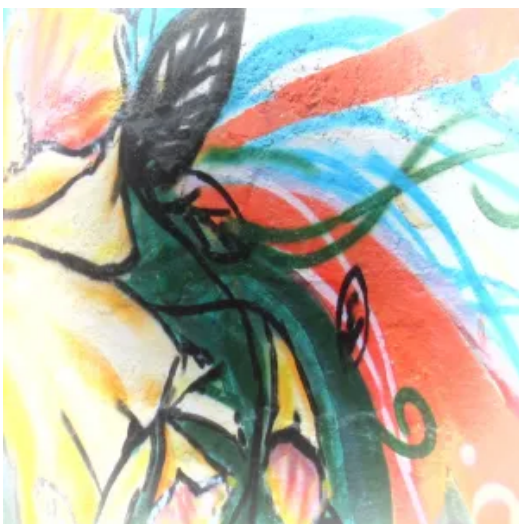
Writing organizes this temporary chaos. And those who live with permanent disfigurement might approach the page differently than I do. If my writing is an act of restitution, that restorative aspect may be very personal to my set of circumstances. As DeSalvo notes, “Writing helps us assert our individuality, our authority, our own particular style” (183). Another writer, with different experiences and afflictions, would necessarily find their own individuality, authority and style. I find the voice I reach for shapeshifts from draft-to-draft or from piece-to-piece. I struggle with a single writing voice—which may not



be due to changes inflicted by my illness. Still, I think the constant flux might also account for these persona shifts. How could they not show up in the writing in some way or another?

Then there is the medical encounter, which also impacts my craft. As I try to explain my dilemma to my physicians, something insidiously sinister happens. As we test and try medications, and as they fail to explain or remedy the situation, a medical-gaze starts to happen. Are these episodes that I bring to their attention really that bad? They must be caused by allergies, even though they happen overnight, correspond with hormonal fluctuation, and show other indications that the angioedema may not be allergy induced. Somehow, the focus shifts to how my perception of my changing, medicalized self is to blame. This is partially because of the ways we train doctors to think: “Medical education is still by-and-large rooted in the positivist-empiricist model of knowledge. This view requires methods of analysis that are precise, logical, and systematic” (Shapiro et al, 234). What the medical encounter does, based so much in this empirical stance, is undermines my own sense of voice, sense of self. It cuts my confidence in the one thing I should feel the most confident in, which is my own lived experience.

However, medicine’s messages seek to undercut what feels particular and serious to me. I come to the page carrying doubt about my own circumstances, and part of my writing challenge is to tamp the doubt down, to not let that medicalized voice infect my writing by undercutting its authority. “Our medical system cannot handle me and would like me to go away,” writes Sonya Huber in *Pain Woman Takes Your Keys and Other Essays from a Nervous System*. “Some doctors have given up on me merely because I wasn’t an easy win for them” (27). These encounters leave a mark, and for me, it’s something I work out on the page by not following the sure and pat “rules.” My narratives take on a disjointed quality because I am out of joint. Figuratively and literally.



It’s no wonder that writers suffering chronic illness or other disability come to the page hoping to reintegrate what is disintegrated. As my face fluctuates from that which I know intimately to that which is distorted, I am sure the page helps bolster a sense of who I am and what I am beyond this physical context. I also see it in the work of others. Sonya Huber writes, “Pain woman has a different voice. She has a kind of messianic confidence that I do not have in my normal writing or even my normal living, and this is the most shocking thing” (101). Huber allows the

space for this Pain Woman voice to emerge and, in some parts of her book, to take over, the way that pain does. It’s one of her voices, but not the only voice. Here, form and art merge. DeSalvo describes this process: “The shape of our work will contribute much to its meaning, and paying attention to its form can teach us much, too, about how we’ve come to understand our experience” (143). She discovered this process in writing about the onset of severe asthma:

*In writing Breathless, I discovered I was no longer writing long sentences punctuated by semicolons, containing lots of dependent clauses. I started writing very short sentences. Then fracturing my sentences.*

*Because my body and writing were different, my writing was different. Sentences that chopped and sputtered, I discovered, were the only ones I could write (DeSalvo, 201).*

We see clearly that the form something takes has a direct, embodied relationship to the physical being of the writer herself. The two cannot be cleaved apart, and nor should they be separated. The power in the writing is that it sprouts from the body itself, and the form reinforces the impact lived experience must bring to the page. I think about this in terms of my own writing, and the way rheumatoid arthritis and associated auto-immune issues that are less concretely diagnosed continue to leave my physical self both temporary disfigured and more permanently fractured. It continues to form and inform who I am on the page.

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