correspondents at large

Learning from Blindness

CHRIS MOUNSEY

ONLY WHEN MY FRIEND KEVIN SAID, IN AN ASIDE TO HIS WIFE I WAS NOT MEANT TO HEAR, THAT I WAS STILL GRIEVING FOR MY LOSS OF SIGHT did I realize that I was and had been for the past seven years. When a friend or family member dies, it is an obvious time to grieve; when someone you love dies, you have to get on as best you can without them. But when you are confronted with a disability, it is as if a part of you has died, and the rest of you has to get on as best it can. Learning how to come to terms with the change in your day-to-day life disguises the need for grief. So, seven years on, let me give you an inkling of what happens when one of your senses dies. The metaphor of death (or perhaps it's *not* a metaphor) is convenient since it leads to a framework for my explanation. Elisabeth Kübler-Ross, in *On Death and Dying*, explored the ways we come to terms with death through five emotional stages: denial, anger, bargaining, depression, and acceptance.

Denial

I was in denial about the problems with my sight for so long that I even learned to drive a car, and my lousy driving caused most of the major arguments in my life. I suppose it could be said in my favor that since I've always had the same pair of eyes, I have never known what it is to see properly. On the other hand, the fact that I used to cover my left eye in order to read and would never drive more than forty miles an hour might have told me that there was something wrong. But denial becomes an emotion that colors all your life. You convince yourself that it is better for your concentration to read with one eye and that you are the only safe driver on the road. "It's not me! Everyone else is doing it all wrong." Denial is an angry emotion that puts your self at the center of the universe as the master of it. A color-blind friend of mine bought an electric-blue suit for his graduation thinking it was charcoal gray and refused to believe what he'd done. When I first met him, he was wearing bright-green shoes and got really upset when I joked about them. It was a year into our friendship

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before he confessed to me that he was color-blind. But then *I* could see his mistakes, so there could be nothing wrong with *my* eyes.

Anger

Now it is I who am fed up with answering the question, "What exactly can you see?" Partly because it is no one's business but my own, partly because no one can make sense out of my usual answer. You cannot see through my eyes, and I cannot see through yours. So don't ask, and I won't tell. Suffice it to say that for the past seven years I have not had sight enough to read books, and sight correction does not work and never has worked for me. The first response of other academics to my situation was, "That is awful!," meaning, "That is a career-ending injury!" But academia is not a football field, and in the United Kingdom, as in the United States, there are laws (the British Equality Act and the Americans with Disabilities Act) to protect those of us who meet with disabling conditions, laws that demand "reasonable adjustments" in our working conditions to accommodate our disabilities. But laws that are meant to protect and serve can and do transform superficially mild-mannered academics, boiling with the internal rage of denial, into harpies.

The years of lonely self-justification in a world that just didn't understand me burst forth in righteous anger derived from having the law on my side. It did not take long to learn from government officials telling me that something I had requested was a "reasonable adjustment" how to make all requests into requirements. When and where I taught my classes, the location of my office, and the way rooms were set out changed from requests into requirements. I became exacting. Woe betide the people who did not come up to my very high standards. They would be met with the bald statement that because what I required was a "reasonable adjustment," it had to be done—yesterday. Here and now I apologize to everyone I've upset with my intransigent stare through the hard surfaces of my sunglasses, looking at you as though you're not there—but then I really *can* see right through you to the wall behind.

Bargaining

Exacting standards do have a positive—or apparently positive—side to them. Exasperation at not having things immediately, another life-coloring emotion, is aimed not only at what others can do for me but also at what I can do myself. For a professor of English, not being able to read is a frightening proposition. But it is possible to meet fire with fire. So here's the bargain: if I can see half as well, I'll work twice as hard. And so I have done for the past seven years.

I get up at 5:30 a.m. every day and am the first in my local coffee shop, so I've done my day's work (aside from face-to-face work with students and colleagues) before 8:00. Well, that is to say, if I didn't do any more writing that day then I'd still be satisfied that I'd fulfilled my commitments. But I *always* work more. I've just finished rewriting all of my teaching materials and I've published five books in the past three years.

How? I hear you ask. This is where technology comes in. The most interesting thing about sense impairment is the way you learn to rely on the other senses and the way they do not so much take over as rebuild what was formerly there, and with unexpected results.

My usual way to address text now, whether I'm reading or writing, is through a text-to-voice computer program that has advanced from a breathless monotone that avoided punctuation to Apple's Alex, who (which?) breathes for different lengths of time at commas, periods, and paragraph ends. Alex even speaks in well-rounded phrases, approximating a human voice.

It took me two years to learn how to *listen to* rather than read text. Because Alex can be

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speeded up as you learn to speed-read without skimming, I now grade essays at a speed you probably cannot even hear as words, and I *hear* spelling mistakes and solecisms as well as concepts. This reading speed also allows me to understand the arrangement of ideas more clearly than I could if looking at the page, and it led me to write a book about essay writing to teach students how to organize their thoughts into clear prose. I make comments with the usual word processor function, and students receive my suggestions and grades in this form.

Speed-reading without merely skimming is also invaluable for reading academic articles during research. I use a PDF reader that allows me to take electronic notes and copy quotations directly into my work. The program even provides the page references. If it could put them into the style required for the journal or publisher I am writing for and prepare the bibliography, it would be even better, but there is always room for improvement.

Speed-reading without skimming is also invaluable for writing. The text-to-voice technology has improved the style and content of my writing. When I write, I listen to what I've typed over and over again and listen to the shape of the sentences and paragraphs as they develop, hearing my words in *someone else's voice* as though I were reading someone else's work. This allows me to be much more ruthless with my phraseology as it is all at once *not* my phraseology. Alex says something unintelligible, and I need to disentangle his ideas from his words so he is clearer to me. It helps that it wasn't my mistake: Alex said it.

As far as content is concerned, listening to, say, a novel through text-to-voice gives equal weight to every sentence, and there is no hurrying to find a quotation or a useful incident to cite in an essay or lecture. There is no skimming, no avoiding the boring bits, no cheating. But also there are no fortuitous discoveries to be made in the layout of the words on the page. No way to admire the architecture of a sentence, going back over just part of it because it is so beautiful. No fun in finding something by accident.

Being a supercrip is not all it's cracked up to be, however good the technology, however productive you are. Lindsey at my coffee shop calls me "a machine," but the machine is running down. There are always two sides to a bargain, and the other side of the working-twice-as-hard bargain is exhaustion and the depression and sadness that go with it.

Depression

It must be that I've not had a holiday in seven years or that I work every weekend. My lie-ins are limited to 8:00 a.m. on Saturdays and 9:00 a.m. on Sundays, the weekend opening hours of my coffee shop. I'm fifty-five years old, so I can't be slowing down yet. But when all I do is weep when I see a finished project in print, even *I* have to acknowledge that something is wrong.

There is little more awful than the objectifying pity that seems to go hand in hand with disability. I remember many years ago standing outside the British Library before it opened, one day when it was pouring rain, and one patron (Betsy Surbiton we called her) said to no one in particular, "But what about the disabled?" I said to my friend in a clear voice, as if in reply, "Heavens to Betsy! They'd get wet. Like all the rest of us." We'd all be in it together. But the refusal of any quarter to yourself leads only one way: to suicide.

There are support groups for alcoholics like Alcoholics Anonymous and others for drug abusers and even for sex addicts. Support groups for disabled people do exist, but they always meet during working hours. Well, I work. That's the point, isn't it—to work? not to give in to your disability?

Doctors in Britain's National Health Service are generally unsympathetic. I've never been abused so heinously in my life as by doctors who believe they're giving you their ex-

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pertise for free. Things get worse when they think you might be a fascinating new case, but then you fall outside their expectations or interest, and you discover they don't know or care anything about *you*. Then they say in your presence, "Pfff! Discharge him at his next appointment." (Why the *next* appointment?) But when you realize that you've just got to get on with it and sort yourself out, don't assume that counseling is available from the National Health Service. You do get one session free, to diagnose the fact that you're screwed up and clinically depressed, but the cost of the follow-up sessions ("You'll need two sessions a week for at least three months!") is way beyond the income of even a full professor.

Perhaps that's why I decided to work so hard. But when you work to stave off the fear of grieving, the cycle of depression spirals ever downward.

Acceptance

All that work I did to stave off depression was not useless. Hey, read the books; I think they're quite good. But that's not what I'm saying. As an academic, I worked in the field of sexuality for years, trying to find a way of accepting myself as a homosexual. Now I begin to work in the field of disability, using myself as the model again, hoping to accept my new self and put behind me my grieving for the old self.

That takes friends, who are by far the best counselors. At a conference on disability, called VariAbilities, that I organized with Paul Kelleher in summer 2013 at Emory University, a subtext arose among those of us who were disabled about what we called "Crip Time." What we meant was that we all needed some respite. The deaf needed a rest from noise; those with speech impediments needed a rest from talking; the blind, like me, needed a rest from light. We all were tired of pushing ourselves harder than those who are not disabled.

I've tried being a supercrip, and my five books got me a full professorship. But now I've realized that I don't have a Lycra suit in my bottom drawer and can't leap about the city at night like the comic book hero Daredevil. Just like you, I whinge when I think about how things could be better. There is always a better place I could be: a place where I can see.

So now maybe I've got to the really emotional part of being disabled. Or maybe I just didn't want you to think that I'm a model of stoicism. Or maybe I'm simply telling the truth about being disabled. Whatever—acceptance of myself as an impaired person leads me to end on a positive note. The most important thing text-to-voice technology has taught me, and that I want you to learn from me, is that texts are a shorthand for voice. That means *every* text, including this one, ought to be read out loud in order to be understood clearly.

When I was a child, I was told to stop moving my lips when I read because it made me look unintelligent. Now I know that I moved my lips so I could follow the words one after another without losing my place, because I have always had problems with my sight. Can you really run your eyes silently over a text and claim you've read it? Let me tell you how much more you can get from a text if you say the words and feel them in your mouth, how much more you can get from a text that whispers its secrets in your ears. How erotic it can be to have someone else's words in your mouth, their sounds in your ears! Did you ever think that learning about being disabled could be so sexy?

Work Cited

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