

DISABILITY

Even When I'm Psychotic, I'm Still Me

When my bipolar disorder caused a break with reality, most everyone in my life disappeared.

By **Susanne Antonetta**

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Last September, I believed my brain was on fire. Not in some metaphorical way. It was, as far as I was concerned, on fire.

I am bipolar and I was hallucinating. My hallucinations can be sensory, like the brain burn, but many are auditory — I know hallucinations are coming when I hear birds speak. I can tell you what the birds say, but what matters is how intensely personal it is, being shouted at by a fierce small crowd: *persist persist persist* from one, *six degrees yes yes yes* from another.

I couldn't sleep in all the chatter. Then I heard whispering everywhere, semi trucks coming to a halt right under my bedroom window. A small part of me sensed all this was not really happening, but most of me thought it was.

There's another hallucinatory change that's harder to describe, one that comes every time, mild episode or intense. The world feels malleable, like felt, or soft paper. Walls rock and steady themselves. What's around me becomes alive, air itself humming and moving. As with the birds, these changes feel intensely personal — everything around me shifts as I watch.

During the six months leading up to this brain-fire time, I'd been having milder hallucinations, on and off. I took a medication that controlled my psychotic symptoms until my cholesterol skyrocketed and kept going up. The drugs used to treat people like me — atypical antipsychotics like Zyprexa and the one I take, Seroquel — have metabolic side effects. These include soaring cholesterol and triglycerides, as well as diabetes. There may be no way out of these side effects except dropping the medication, going, as I did, from one that works to one that doesn't.

Doctors, and the occasional friend, kept telling me something meant to be cheering: “This is just a disease, the same as a broken bone or a bout of pneumonia.” As though my antipsychotic could just as easily be penicillin. I’ve heard this statement in one form or another for several decades, since my diagnosis at age 29. I don’t accept this mechanistic view of the brain, which suggests that if you pump in drugs (at levels often determined by drug company-funded research), the cogs will start working smoothly again. This model dismisses patients’ individual experience of medications, which vary wildly. It overwrites their personhood, their lived experience, the degree to which they wish to be medicated. Often at the heart of the medical model is the view that patients are the last to understand their own needs and psyches.

There’s another difference between psychosis and physical ailments: In the case of psychosis, no one is likely to stop by with a casserole. No one honestly thinks of you as having a broken bone, and no one acts as if you do. As my hallucinations went on, I had to go back on Seroquel and take medical leave from teaching. For several months I remained shaky, medication-fogged, sometimes crying for no reason, sometimes hearing birds talk to me again.

During this time in my life many people in my life disappeared. They stayed entirely out of touch or asked my husband if they should call or visit, and though he said yes, they didn’t. Mostly they were just gone. My husband, Bruce, supported me, dealt with my doctors, spent as much time with me as he could, all while still working. He needed help, too.

Even doctors showed no interest, at least not in my symptoms. They heard the word hallucination and they prescribed. I seemed to transform into some scary beast gnashing her teeth in her pen.

I don’t understand what so-called normalcy is, if it really exists, and I don’t care to try. What I wanted was to function again. This choice came with consequences. By the time these hallucinations ended in early October, I was taking so much medication that I stumbled as I walked, had hand tremors, and my word retrieval skills faltered at words like “window.” All these side effects are typical of the drugs I was taking.

As this hallucinatory time wore on, ebbed, then mostly ended, I made a decision that, for me, was radical. I told people who wondered what had become of me just what had — that I was bipolar, had psychotic episodes and had been hallucinating. I asked people who vanished why they did. In response I heard comments like “I thought you would want privacy,” as if psychosis equaled parading around naked. As if it necessitated shame.

Sometimes, from those who vanished, I got a version of “I was waiting for you to come back to yourself.” I had a hard time explaining that I’ve always been myself, maybe at this time even more myself than when I move through my day without too much auditory

interruption. Lacking many reference points with the commonly held world, hallucinations are necessarily intensely you.

I don't want to believe that my brain is on fire, and I take medication so it doesn't happen. It's frightening. I don't want trucks rumbling at me as I sleep. I want to live in a world that's quieter, that isn't always demanding my attention. None of that refutes the fact that I am still me in psychosis, and I know in some way my daily perceptions always hold those moments, those birds that speak. I can't divide myself into the ableist Sick Me and Healthy Me, or Sick Me and Real Me. Someone else can take up those metaphors. I don't want them.

I also believe that hallucinations hold truth, though a hard truth to stay with for very long. I live the world as alive with a crackling energy, open and porous, full of meaning. I don't just have delusions when I'm in that state; I re-experience. And the re-experiencing is not totally false. Air does move around us and hold us, walls are temporary, birds give voice. We just normally tune these realities out.

Dorothea Buck was a German woman sterilized by the Nazis because she was given a diagnosis of schizophrenia. She became a lifelong psychiatric activist who argued for the need to accept psychosis as meaningful. Rather than a sick state cut out of the brain by medication, she wrote, it's a personal experience meant to be understood, even and perhaps especially when treated.

My hallucinations have ended and I'm gradually returning to a lower level of medication. I'm still unpacking for myself what this experience of mine meant, how it still moves in some way inside me. It's elusive. I do know I want to peel back this isolation and forced secrecy. I must if I'm going to live honestly in the world. It's almost as disorienting as delusion, going from that crowded and noisy place of psychosis to this silence.

Susanne Antonetta is the author of the forthcoming "The Terrible Unlikelihood of Our Being Here" and "The Devil's Castle," and the editor in chief of the Bellingham Review.

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