



DIALOG with the DEVIL

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Diabetes has made my body broken in ways I don't readily admit, but I am sometimes forced to acknowledge. People talk about my daughter's chances of developing the disease and they always give me what they think is a comforting comment – "At least it would be the devil you know," – but that doesn't ease my boxed-away fears and I usually end up saying, "Yeah," through gritted teeth because I don't know how to explain that this disease isn't the devil I know. It's the devil that I think I know, but it still tricks me and the road takes unexpected turns.

Diabetes communicates with me all the time. It tells me things through my glucose meter, and my retinal screenings, and my insurance company co-pays. A glucose meter reading that's out of range feels like a jab at my ego; an A1C in the same vein feels like a judgment on my worth as a person. Every bit of feedback I receive from my disease feels like one I have to consciously reposition, reminding myself that my job is to do my best, and its job is to minimize my efforts. And talking about this part of diabetes can be hard for me, at times, because I don't want anyone feeling bad or thinking I'm looking for attention when I communicate some of the challenges of life with diabetes, but at the same time, I am looking to be heard.

Because diabetes isn't just in my pancreas. Or on my lab work printout that gets mailed alongside my electric bill and the leaflet about lawn service. Diabetes gets right into my head, into my mind, and frays the edges of my emotional health. I feel happy and healthy the majority of the time, but diabetes does play a huge role in the moments that make me feel vulnerable.

Sometimes communicating about diabetes doesn't go very well, and those moments are disappointing. When I was diagnosed with diabetic eye disease two years ago, my retinal specialist made the diagnosis to his computer screen. "You have macular edema," he said almost casually, the click of his mouse button marking the "IDDM, Complicated" button in my electronic medical record. I had been living with diabetes for 26 years at the time, and this was my first marked complication. I was so disheartened to hear this news. I felt guilty and scared. But I couldn't convey anything that I was feeling, or even ask the questions I needed to ask, because my doctor never turned around to acknowledge me. I was a routine moment in his day of seeing patients with diabetes. So much was communicated in his lack of desire to literally face the patient he was diagnosing.

It goes without saying, but I'll say it anyway, that I wished he'd looked me in the eye and made me feel like someone human.

Sometimes communicating about diabetes goes remarkably well. Like the first time I tested my blood sugar in front of my best friend, while we were working at the same breakfast restaurant. "My mom has type 2 diabetes," she said. "Oh really?" I replied, finishing up my test. "Yeah. And you have type 1, right? I'm in nursing school so I'm learning. Do you want to take the earlier start or the later one tomorrow morning for the Sunday shift?" And that was that. She let me know she was educated, that she didn't critique me, and that we had more to talk about than diabetes. Her ability to ask questions without making me feel judged has been

some of the best discussions about diabetes I've ever had.

And there are times when I communicate about diabetes, despite my desire to keep it quiet some moments. Like when I'm low in a public place and profoundly unsettled, drawing me to the nearest stranger so I can tell them my name and what I might need if I'm unable to keep myself upright.

Communicating can be hard, but even the hard discussions are necessary – maybe more so than the easy ones. I wish that doctors knew how their words can make or break an interaction. It can be hard to tell your doctor that you don't like the way they talk to you, but what if they are unaware? I feel very lucky that phrases like “this is your fault” and “non-compliant” haven't ever been uttered by my endocrinologist, but so often these phrases are common parts of routine medical appointments. I wish my doctor knew when I was lying about the things I'm doing, or not doing, so she could be armed with the right information to help me work through issues I'm not quick to admit.

I wish my friends knew how being able to shoot up at the dinner table without our conversation skipping a beat means so much to me. Or how much I appreciate when my husband doesn't make any arguments about my daily trips to the running trail. Or how my grandmother always made an attempt at creating a sugar-free dessert for me at family gatherings. Diabetes is not an often discussed topic, but it's not taboo. It's discussed as often as everything else, which helps bring it to a baseline of normal.

It's this weird dance, the one between feeling like diabetes profoundly affects my day-to-day health, both emotionally and physically, and the feeling that diabetes is just a blip on my daily radar. It's even weirder to try and articulate those feelings.

I am fine. I think? That's part of the dance – feeling and seeming fine and actually being fine, even though my body is dealing with something serious every moment of every day. Is it an invitation for a pity party? Nope. But it's a reminder that even though I feel fine, and I mostly am “fine,” there's a part of me that permanently needs tending to, and ignoring it only leads to tougher roads. The lows, the highs, they feel like ships passing by, but what they may be leaving in their wake scares me.

It doesn't mean I want people to ignore the severity and pervasiveness of this disease. I don't want people who

might be thinking about donating their time, energies, and finances to type 1 research, funding, and advocacy to be deterred by the fact that sometimes we look fine. What those outside of this condition need to understand is that this perception of “fine” is all relative. One day you can be fine, and the next, things can be deeply and profoundly changed.

Why talk about it? Because it's there. It's there all the time, even in the moments when I want to pretend that it's not. I walked down the aisle on my wedding day with an insulin pump carefully hidden in my wedding dress, a careful pocket added among the folds of fabric. I gave birth to my daughter, and as the sound her of first cries hit the air, a flash of “Am I still too low to hold her?” raced across my mind. I wonder if I'll ever be without it. I wonder if hard work always pays off with good health. So many emotions are encased in a disease that I don't want but I still have, and my life goes on, despite this diagnosis that continues to and forever will mark every moment I experience. It is the first thing I think about when I wake in the morning, and it is the caboose in my last train of thought each night before bed.

Talking about something that frightens us like the “devil” removes its stronghold over us and for those around us. I can't make diabetes shut up, but I won't let it out talk me or take over my life.

Diabetes will be in headlines and on television shows, and health and mainstream media websites will occasionally turn their attention on the disease so many of us live with and care for every day. It's in those moments when we need to show the world that even though we seem fine, we still need better treatments and a cure for this mess. We need to talk about it. Sharing our stories is important, and we can make a difference in diabetes in our lifetimes. Fine is status quo. Fine is tolerating stereotypes instead of changing them. Fine is waiting patiently for things to change, or keeping the things that bother us under wraps.

But we can do better. We must talk about it. By communicating with one another, with our healthcare teams, and with the societal ecosystems we inhabit, we can change perspectives, minds, and the world. Together, we can do better. ■■■