

Fifty Years of Living With Type 1 Diabetes

Nora Williams

I have had type 1 diabetes for 50 years. *Fifty* years. At the time I was diagnosed, way back in 1968, I was told that I shouldn't expect to live past the age of 35 years. Now, as I approach 58 with all my toes intact, I welcome the opportunity to look back at the decades, the changing technologies, and the many clinicians who have crossed my patient path.

I was there for the replacement of porcine insulin with biosynthetic human recombinant analogs. I had one of the first portable glucose meters, which required a small suitcase to lug around. I was there when sugar stopped being the big enemy (although most of us who had had the disease for a while had figured that out *long* before you admitted it to us). And I'm still astonished by the difference the insulin pump made in my life. Wearing my first insulin pump almost 20 years ago allowed me the opportunity to "forget" for the first time that I was diabetic, even if only for a few hours.

I was first diagnosed with diabetes during a bout of what my parents were certain was the flu. My pediatrician put me in the hospital and made the diagnosis. He was one of those pediatricians who really loves children, and he paraded me through the hospital halls on his shoulders, telling me about the disease, introducing me to the staff, and telling me how we were going to keep me healthy. The joy and the optimism he expressed made an enormous difference in how the diagnosis affected me, and as long

as I live, I will never forget how fully he seemed to be in my corner. I'll grade him on how he made me feel, so we can refer to him as "Dr. A."

Alas, I aged and eventually left my pediatrician behind. My next experience was with an endocrinologist for whom nothing I did seemed enough. I failed, and failed, and failed. My A1C results were never good enough (not that that means as much as he thought it did); my diet was never perfect enough; nothing was *ever* enough. I was too young and too inexperienced to realize that there is no way to perfectly manage diabetes, and that is triply true for adolescent diabetics. Then, the disease defined me to him, and my failures defined my relationship with him. I wanted nothing more than to receive no more "care" from him. He not only wasn't in my corner—he was my opposition in the ring. Let's call him "Dr. F."

When I left North Carolina for university, little did I know how many years I would spend in academia. I received an undergraduate degree from Princeton, a master's from Harvard, and then a Mellon fellowship from Johns Hopkins University. One thing I was spared by spending such a lengthy time in academia, during which most of my medical encounters were with clinicians associated with those universities, was being treated as though I just couldn't be very smart.

Goodness knows, I've experienced that often enough in the years since. Do some of you treat your patients

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this way? Are your diabetic patients usually not bright? Is it that few modern physicians have time to deal with the complexities of the disease and find it easier to treat us as simpletons? Is it that the predominance of the patients with diabetes that any doctor sees are those with type 2, where socioeconomic and obesity prejudices may come to the fore? I simply don't know. I do know that I've wished I'd brought my diplomas with me to many a first visit with a clinician.

Over time, it has become easy to recognize the Dr. Fs. It took a few of them to teach me the tricks for getting the prescriptions I needed with as little nagging as possible. You're all figuring it out by now. You can fake a good A1C with lots of highs when there are also lots of lows. Patients may also try some unproven tricks they can find online that may skew A1C results (for example, excessive vitamin C or vitamin E intake or having *very* low blood sugar when the blood draw is made). These are tricks I never tried with doctors whom I felt were my partners in this struggle. I only used such tricks with doctors who made themselves my smug, irritating enemies. They did me harm—and I did myself harm—under what I can only loosely call their “care.”

The experience I had in my youth with the first Dr. F, and later with others of his ilk, left me feeling that the more a doctor felt he or she knew about diabetes, the less willing that doctor was going to be to listen to me. It turns out that nothing could be further from the truth. I've had endocrinologists who were always learning more and were willing to

learn from my experiences. These are the doctors who changed the shape of my relationship with the disease and to whom I'll always be grateful. Unfortunately, I've also had doctors with little or no experience with diabetes who were certain there was nothing they could learn from me. In one instance, I removed myself from a hospital in fear for my life (and advised the doctor there to look up the Somogyi effect).

The key from my perspective isn't the doctor's degree, or the area of specialty. It's the doctor's willingness to listen and learn *with* the patient, to always make the patient welcome, and to care about the struggles every patient undergoes.

I've met *way* more Dr. Fs than Dr. As throughout my 50 years as a patient with diabetes, but the Dr. As have all made such a positive difference in my life, and I've stayed with them for years, until a move or the physician's retirement have forced a change.

My advice to you? Table your assumptions about your patients before the first visit. Let your patients teach you their limitations. Be someone they want to share their struggles with. Be as supportive as you can be, despite their struggles. *Know* that you don't know their lives and don't know the hurdles they face each and every day, both as people and as patients with diabetes.

You are going to have patients who fail to do as you feel they should. You are going to have patients who are their own worst enemy, so believe me, they don't need *you* to become their worst enemy, too.

If you just can't bring yourself to actually care, hide your lack of caring better; fake it better. If you have a patient who can understand the research, share it. If you find yourself having difficulty empathizing, live as if you were a diabetic for a while, and see how long you can be perfect. Humanize yourself, and let your patients become fully human in your eyes, too.

I am heartened by how much the medical emphasis has changed—more teamwork with the patient and less antagonism, more support and less judgment. I'm also heartened by the increasing focus on bringing multiple disciplines into the treatment of patients with diabetes, including podiatrists, opticians, nutritionists, cardiologists, and others. I'm heartened by the existence of programs such as the Family Medicine Chief Residents Summit on Intensifying Diabetes Management, an annual event through which senior and chief residents from around the country meet for a weekend of intense study and live as diabetics, with a pump, carb counting, and glucose monitoring. As one participant put it, “I had no idea how hard this was!”

You may already know how hard it is to be a diabetic. I do. It's almost as hard as finding a Dr. A.

Duality of Interest

N.W. is employed by the Primary Care Education Consortium, which, with the Illinois Academy of Family Practice, sponsors the Family Medicine Chief Residents Summit on Intensifying Diabetes Management. No other potential conflicts of interest relevant to this article were reported.