JCI The Journal of Clinical Investigation

Trials and tribulations of diabetes: a patient's perspective

Mary M. Meyer

J Clin Invest. 2019;129(11):4556-4557. https://doi.org/10.1172/JCI132144.

Viewpoint

I was 38 years old when I was diagnosed with type 1 diabetes. I have lived with this disease for 34 years and have seen many changes in treatment during this time. Although daily management has improved and become more convenient, the confusion, pain, and devastating effects of living with this illness remain the same. The spring that I was diagnosed was a very long one, filled with many doctors' appointments to treat infections that would not go away. I was always thirsty and needed to urinate frequently. There was only one symptom I was happy with: weight loss without dieting! It never occurred to me that these were all signs of the onset of diabetes. My gynecologist diagnosed my disease after almost six months of dealing with so many confusing changes in my life. I was very surprised because no one in my family had ever had diabetes. The doctor suggested that in my case, the disease may have been caused by a virus, although there was no test to definitively support this theory. I immediately decided that I needed to find an internist who could help me with this new disease about which I knew nothing. Fortunately, my blood sugar levels were not terrible at that time, and I did not need to be hospitalized, thank goodness. My […]

Trials and tribulations of diabetes: a patient's perspective

Mary M. Meyer

I was 38 years old when I was diagnosed with type 1 diabetes. I have lived with this disease for 34 years and have seen many changes in treatment during this time. Although daily management has improved and become more convenient, the confusion, pain, and devastating effects of living with this illness remain the same.

The spring that I was diagnosed was a very long one, filled with many doctors' appointments to treat infections that would not go away. I was always thirsty and needed to urinate frequently. There was only one symptom I was happy with: weight loss without dieting! It never occurred to me that these were all signs of the onset of diabetes. My gynecologist diagnosed my disease after almost six months of dealing with so many confusing changes in my life. I was very surprised because no one in my family had ever had diabetes. The doctor suggested that in my case, the disease may have been caused by a virus, although there was no test to definitively support this theory.

I immediately decided that I needed to find an internist who could help me with this new disease about which I knew nothing. Fortunately, my blood sugar levels were not terrible at that time, and I did not need to be hospitalized, thank goodness. My internist prescribed an oral medication, although this treatment did not control my blood sugar well enough. After almost a whole year, my doctor and I decided that I needed to start giving myself injections of insulin once or twice a day — a difficult and time-consuming task. First, I practiced injecting an orange before building up the confidence to inject myself. I also slowly learned to count carbs and made better food choices with the help of a dietician. Finally, I felt better and was confident that I had the disease under control. WRONG!

Thank goodness a friend told me about the Diabetes Education Program, which she had just completed at Johns Hopkins Hospital. I signed up, and my mother and I spent an exciting week learning about diabetes management. Through this class, I learned how complex a disease diabetes is and how little I knew about it. Not only is it important to keep your blood sugar controlled, you also must not ignore your eyes, foot circulation, and kidney function — all affected by the progression of diabetes. During the program, I learned how to prick my finger to test blood sugar, which was a wonderful help to me. I learned how to manage my diabetes with more determination — and I learned the importance of a good sense of humor to cope with diabetes 365 days a year. There is no vacation from this disease!

One of the most important takeaways from the patient education program was the need to see an endocrinologist to help me manage the disease. At every visit, my doctor stressed the importance of the A1C blood test to oversee the management of the diabetes and has helped me to use new technologies to improve my care. During the last 30 years, I have gone from testing my blood sugar twice a day and using two to four shots of insulin to using an insulin pump and glucose management system that reads my blood sugar levels and sends the results to my smart phone.

Even with improvements in insulin formulations and glucose monitoring technology over the past three decades, management of the disease still falls on me and impacts my lifestyle. There are many issues I deal with each day. Physical activity, such as walking and occasionally golf in my case, lowers blood sugar levels, and it can be hard to know which foods will raise my glucose levels in dangerous ways. Blood sugar monitoring is a constant activity. Both lows and highs can cause complications and hospital visits — and I want neither!

Although my disease has not always been easy to deal with, I have been fortunate to have the support of amazing doctors, friends, and family. I have never had to wonder when and from where I would get my test strips, needles, insulin, or help should an emergency arise. Many diabetics are not as lucky. Despite all the advances in diabetes research and technology, most patients in the United States are facing skyrocketing insulin prices and need to ration their insulin supplies, or go without insulin treatment altogether. Many patients with diabetes do not seek medical care until they lose eyesight, a limb, or kidney function, or suffer other major complications of diabetes.

I am an advocate for people suffering from diabetes, especially those who are new to the disease or are not as knowledgeable as I have become about the disease progression. Through comprehensive patient education, support, and research, we can help people with diabetes lead robust lives. I have encouraged many of my friends to go to an endocrinologist for the first time and to sign up for a diabetes educational program. It is also important to share trials and tribulations with friends and family, and throw in lots of humor. The government has an essential role to play in diabetes management by providing healthcare infrastructure and support for patients who cannot afford insulin and other supplies and lack access to educational programs and other necessary medical services because of cost or transportation. The economic and social burdens of diabetes would be lower if we could help people manage their diabetes rather than treating amputations, blindness, kidney failure, and heart disease.

Authorship note: The author is a donor to the Johns Hopkins Diabetes Center with which the *JCI* editor in chief is affiliated.

Conflict of interest: The author has declared that no conflict of interest exists.

Reference information: *J Clin Invest*. 2019;129(11):4556–4557. https://doi.org/10.1172/JCI132144.

One of the ways I advocate is through support of the Johns Hopkins Diabetes Center. Once I received my diagnosis, my family was willing to do anything they could to help me manage my disease. After witnessing the kind of care I was receiving at Johns Hopkins Medicine, my family made a significant gift to create the Hugh McCormick Family Diabetes Center in order for us to give back to our Baltimore community through diabetes research, education, and support, especially for those without resources. A number of years later, my family created the Hugh P. McCormick Professorship in Endocrinology. I personally support the Center today and take pride in the work our great physicians are doing.

It is so important that we all support the medical research that is required to find a cure for diabetes. Doctors and researchers are up to this challenge, but they do need financial help from private individuals and the government. My wish for the future is that diabetes will become a disease of the past! I still have a lot of living to do, and I am equipped to do the best I can with my "mess," as I often call my disease. As long as we continue to make progress in research and apply new findings toward improving the management of diabetes, I have hope that future generations of children and adults will not have to deal with the scourge of diabetes.