

Diabetes: A Personal History

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Editor's note: This article is adapted from the address of the American Diabetes Association President, Health Care and Education, given in June 2007 at the Association's 67th Annual Meeting and Scientific Sessions in Chicago.

We all have personal diabetes histories, whether they relate to our own diabetes, the diabetes of people we love and care for, or the diabetes of our patients. Sometimes, our diabetes history relates to all of these. I hope my diabetes history helps you think about your own and perhaps appreciate it a little more.

March 1959

My diabetes story began in March 1959, when my younger sister Mary Sue was diagnosed with diabetes at the age of 9. My dad was returning from Antarctica at the time. He was a famous Antarctic researcher, and he had spent the previous 16 months as the only American at the Russian South Polar Base. My dad was famous enough to have an Antarctic mountain named after him.

My mom decided not to tell my father about my sister's diabetes until he got home. I can still remember the night of my dad's return as my younger brother and I lay awake all night, holding hands across the space between our beds, listening to our parents crying in the living room below because my sister had diabetes.

Diabetes changed our lives. There was lots of weighing and measuring and worrying. My sister had to give herself insulin with a glass syringe—no disposable syringes in those days—and she had to boil her

syringe before each use. She also spent time each evening sharpening the syringe needle with steel wool so the shots wouldn't hurt as much.

In those days, we didn't have blood glucose monitoring, so Mary Sue checked her urine for glucose. I still remember the drill: two drops of urine in a test tube, add 10 drops of water, then pop in the Clintest tablet, wait for the fizzing to stop, and check the color. Blue was good, and orange was bad.

Within a couple of years of developing diabetes, my sister had her first contact with the American Diabetes Association (ADA). She went to camp Medchi, later known as Camp Glyndon, outside of Baltimore, Md., and a couple of hours from our home in suburban Washington, D.C. Mary Sue went to diabetes camp for a couple of years, and later she was a counselor-in-training at the camp.

April 1979

Almost 20 years to the day after Mary Sue was diagnosed with diabetes, my 7-year-old son Stefan also developed diabetes. The date was April 2, 1979. Everyone who has diabetes or has a loved one with diabetes probably remembers the date of their diagnosis. I should have recognized the signs that Stefan had diabetes; he was drinking and urinating almost nonstop. I ignored these signs for a few days, but one morning I walked into the bathroom to find Stefan drinking and urinating at the same time. This might not be much of a trick if you are a woman, but if you are a guy, and you are drinking and peeing at the same time, you are either an acro-

bat, or you have diabetes. Stefan was no acrobat. We checked Stefan's urine glucose level, and sure enough, it was high.

I felt almost overwhelmed to think that I now had not only a sister with diabetes, whom I loved and felt some responsibility for, but a son with diabetes, as well. The next day we went to the pediatrician's office to confirm the diagnosis and begin our lives with diabetes. The pediatrician had been a friend of mine since we were freshmen at Johns Hopkins, and he remains one of my best friends today. That day, Dr. Bill, as he was known to my son, went through the list of things we would have to do now that we were living with diabetes. With each item on the list, I could feel my spirits sink lower and lower. Then Bill said to me, "Okay, Dick, pull down your pants, and stick yourself with this syringe to show Stefan it doesn't hurt too much."

At that moment, this crazy thought went through my mind: "Thank goodness I'm wearing clean underwear!" That crazy thought lifted my spirits a bit, and in retrospect I can say that it led to one of the most profound insights of my life: what we say to ourselves powerfully affects how we feel and how well we cope. That insight represented my first step on a path I've followed from that day to this one.

Turning Again to the ADA

Right after Stefan's diabetes was diagnosed, I turned again to the ADA. I subscribed to *Diabetes Care*, the Association's clinical research journal, which had begun publication just the year before. Many years

later, I had the privilege of serving as an associate editor of *Diabetes Care*, the world's premier clinical journal in diabetes. When my son first developed diabetes, psychosocial and behavioral research in diabetes was in its infancy. Today, we recognize the crucial role emotional and behavioral factors play in diabetes outcomes.

New Therapies for Stefan

A few years after Stefan's diabetes was diagnosed, home blood glucose monitoring was introduced, beginning with Chemstrips. Stefan would swab his finger with an alcohol swab, poke it with a device we called the "guillotine," and place a drop of blood on the strip. Then he would wait 2 minutes, wipe the blood off the strip with a cotton ball, and compare the colors on the strip with those on the tin the strips came in to see what his blood glucose level was. To save money and because it required a smaller drop of blood from my son's small fingers, I would cut the strips into thirds.

Stefan has always had really good blood glucose control, mostly because he works so hard at it, and even as a kid, his numbers were rarely high. But every once in a while when he was young, he would get a reading higher than he thought it should be. He discovered a magic trick to deal with those situations. If you take the alcohol swab you had just used on your finger and swipe it across the Chemstrip, you could make it look as if you had a reading of 80 mg/dl every time! We had a great relationship, so Stefan let me in on this trick almost as soon as he discovered it.

Insulin delivery also changed dramatically a few years after Stefan developed diabetes. Mary Sue and Stefan were insulin pump pioneers. When they got their first pumps in 1983, there were fewer than 1,000 pumpers in the whole world, and at 12 years of age, Stefan was one of the youngest. The early pumps were much bigger, bulkier, and heavier than today's models. Stefan's first pump was so heavy that it was constantly pulling down his pants. In fact, Stefan claims credit for starting the fashion statement among young

people of wearing their pants so low that you can see their underwear.

My Work in Diabetes Begins

I started seeing people with diabetes in my counseling practice shortly after Stefan was diagnosed, and I was always looking for resources to help my patients and myself. Among the resources I found was a wonderful book written in 1969 by June Biermann and Barbara Toohey with the wonderful title, *The Peripatetic Diabetic*.

In 1984, I began work at the Johns Hopkins Outpatient Diabetes Center, which was founded by my friend and colleague Dr. Christopher Saudek, a former ADA president. Within a couple of years, Chris, my long-time colleague Dr. Mark Peyrot, and I began to do research on the effects of the Diabetes Center's 5-day education program. We were able to show that this program had powerful beneficial effects on participants' emotional well-being, self-care behavior, and glycemic control. Chris, Mark, and I published the results of these studies in a series of articles in *Diabetes Care* in the late 1980s and early 1990s.

In 1985, I attended my first ADA Scientific Sessions, in my hometown of Baltimore, Md. I've attended every meeting since then, for 23 straight years. In 1986, I was in the first group to take the certified diabetes educator (CDE) exam. In 1989, I joined the National Certification Board for Diabetes Educators, and in 1991 I served as its chairman.

Writing and Research

In the early 1990s, I began writing books for people with diabetes and for diabetes health care providers. The first book was *Psyching Out Diabetes*, which I wrote in 1992 with my personal heroes June Biermann and Barbara Toohey. In 1997, the ADA published *Sweet Kids*, which I wrote with my dear friend Betty Brackenridge, and *Practical Psychology for Diabetes Clinicians*, which I co-edited with my long-time colleague Dr. Barbara Anderson. *Practical Psychology* has been translated into several languages, including Italian and Japanese. In addition,

there are two books I'm especially proud of because my son Stefan was a co-author: *Optimal Pumping*, and *101 Tips for Coping With Diabetes*, the latter published by the ADA.

At the same time I was writing these books and publishing articles on my own research, I had the honor in 1994 of becoming a co-investigator in the Diabetes Prevention Program (DPP), a landmark study that proved it was possible to prevent or delay the development of type 2 diabetes in people at high risk for developing the disease. DPP participants in the active lifestyle arm of the study were counseled to help them lose weight by eating more carefully and increasing their activity. These participants cut their risk of developing diabetes during the study by 58% compared to participants in the placebo arm, and to achieve this wonderful result, participants in the lifestyle group lost a relatively modest amount of weight—an average of only 10 lb.

I'm also a co-investigator in another National Institutes of Health-funded weight loss trial, the Look AHEAD (Action for Health in Diabetes) study. This study involves people who already have type 2 diabetes, to see if weight loss helps improve long-term health outcomes, particularly protecting people from heart attack and stroke, the leading causes of death in people with type 2 diabetes. It will take many years to determine these long-term effects, but the early results of this trial, published last year in *Diabetes Care*, are very promising. The short-term benefits of the Look AHEAD study include substantial weight loss and equally substantial improvements in glucose control, lipid and blood pressure control, and fitness.

Kids Remain My Passion

Although most of my research is with adults, kids with diabetes remain my passion. I've been involved for the past decade with an organization called Children With Diabetes (CWD), founded by two parents of children with diabetes, Jeff Hitchcock and Laura Billetdeaux, who have become close friends of mine. The ADA and CWD cooperate on a range of

youth-related activities. CWD has grown rapidly since it was founded. Ten years ago, about 100 families attended their first summer Friends for Life event; in 2007, 2,500 people from a dozen different countries attended the event.

One of the wonderful things about CWD events is that the young people get to meet and play with some wonderful diabetes role models—people like Will Cross, who completed the Poles and Peaks Challenge, trekking into the North Pole and the South Pole and climbing the highest mountain on each continent; people like Gary Hall, the Olympic gold medal swimmer; and people like Nicole Johnson, Miss America 1999. The purpose of CWD events is simple—education and support for parents and fun for kids. The kids get closer to each other, they support each other, and they grow even closer to their parents.

Improving Psychological Care for People With Diabetes

As ADA President, Health Care and Education, and as a psychologist, one of my missions has been to continue clarifying the crucial role of psychosocial issues in diabetes care and to improve psychological care for people with diabetes. Mark Peyrot and I have led a group of researchers in publishing the results of the Diabetes Attitudes, Wishes, and Needs Study. One of the most striking findings of this study, conducted among > 5,000 people with diabetes and > 4,000 health care providers from 13 countries, was the consensus among all parties that

psychological problems are very common among people with diabetes and that these problems are a major barrier to effective diabetes management. Yet very few people with diabetes receive the psychological care they need and deserve.

This led me to spearhead an effort to improve the psychological care of people with diabetes in this country. Several ADA colleagues joined in this effort, co-sponsored by the ADA and the American Psychological Association, which created a curriculum for psychologists that is designed to help mental health professionals provide the services our patients with diabetes need.

My diabetes story involves lots of travel. I've given diabetes presentations in 48 of the 50 United States and in at least a dozen countries, including Finland, Lithuania, Japan, Denmark, and the Netherlands. One of my favorite trips was one I took this past year: an ADA-sponsored speaking tour to Egypt and Dubai.

This year I had the honor of serving with three wonderful ADA fellow principal officers: Darlene Cain (our Chair of the Board), Dr. Larry Deeb (our President, Medicine and Science), and my dear friend Bill Booker (our Secretary Treasurer).

What's Next?

Now that my term as President, Health Care and Education, is over, I return home to do what I started doing long ago with the ADA: serving on my local Leadership Council. I will have more time with my family—the love of my life Dr. Karan Cole; my handsome, won-

derful son Tyler, who will be going off to college in a couple of months; my daughter Kyra and her husband Rob, two of the most creative people I know; my grandchildren, Brooks, Maizie, Kai, Tatum; Ripley the wonder dog; and my beautiful country home. And I return as well to my greatest diabetes teacher and advisor, my son Stefan.

In closing, I want to say a word about GERALYN SPOLLETT, last year's recipient of the ADA Outstanding Educator Award. Geri and I have shared a journey this year; we both developed cancer. Geri has been struggling with breast cancer, and I have prostate cancer. Geri and I have always been close friends, and we are now, as you can imagine, closer still. We talk, we e-mail, and we lift each other's spirits. Geri so wanted to attend this year's Scientific Sessions, but the timing of her treatment made that impossible. Please join me in sending healing, loving messages to Geri now and in the future. We love you, Geri.

I hope I have succeeded in getting you to think about your own diabetes story and to appreciate it more. Those of you who have been part of my story have my thanks and gratitude. I hope we continue to share our stories for years to come.

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