

There's no such thing as a medium apple...

The misadventures of a Diabetic

navigating her way to a happy, healthy life

Talking to medical professionals and reading a couple of books can make you feel that, while managing diabetes should be pretty simple. Just test your blood sugar before and after meals, eat the appropriate amount of food to go along with the insulin you're taking, and you'll live a happy, healthy life.

Well, I guess that's true on paper. If a person had nothing to do but to be diabetic, then it would be simple. But the fact is, if you have anything going on in your life like a job, a spouse, kids, social life, your life does not fit into the neat little boxes of a blood sugar log and food diary.

When I was first diagnosed with Type 1 diabetes at age 24 in 1985, I wasn't all that alarmed. My mom has Type 1, and I had seen her live with it. In fact, there had been many advances since she was diagnosed in 1976, so I approached it with a pretty positive attitude. What I've discovered is managing diabetes is simple, but it's not easy, and it's a lot easier when it's not your own.

Profile at the time of diagnosis

I was a relatively happy 24 year old working as a radio DJ and assistant music director at a popular new radio station. I weighed about 110 pounds and loved being thin. I wore a size 3. I ate whatever I wanted whenever I wanted.

My favorite breakfast was sugary cereal, but other than that, I didn't eat a lot of sweets. I typically ate 2 to 3 meals per day, always at different times. I smoked close to three packs a day, and drank alcohol, primarily beer, with zeal.

My favorite food type was starch, noodles with butter being the top favorite, followed closely by rice, potatoes, etc.

I was a somewhat impulsive person, living with spontaneity, and enjoyed the freedom with which I lived my life. I was a bit of a rebel, no one was going to tell me what to do, and I was brought up with a belief that I could do anything if I wanted to badly enough and was persistent enough. I was pretty scattered, someone disorganized and forgetful.

I did no formal exercise, not much informal either for that matter.

Here is some of what I remember of my first 6 months of having diabetes.

Other people's comments:

My friend Danny who worked for the local Blue Cross carrier. "Hey good news, Blue Cross now covers kidney transplants for diabetics." (I didn't even know kidney problems were something to worry about.)

My Aunt Mary. "Wow, you have to be a scientist to be able to deal with all this, with the testing, understanding the impact of food, exercise."

My friend Joanne - "Be careful of your feet. My uncle just had his leg amputated."

On the ADA Diet

The dietician told me how much I could eat, and the way I would have to eat. At breakfast, 1 meat exchange, 1 bread exchange, 1 milk exchange, 1 fruit exchange. Lunch 2 meat exchanges, 2 bread exchanges, 2 vegetable exchanges, 1/2 fruit. Dinner, 3 meat exchanges, 1 1/2 bread exchanges, 2 vegetable exchanges, 1 milk. Snack - 1 bread exchange, 1/2 milk.

My friend Jerry - "Can you still drink?"

My answer to Jerry - "One beer counts as a slice of bread."

My reaction to the ADA diet.

"Who eats vegetables at lunch?"

"I'm not cooking an egg every morning!"

"Peas and corn count as a bread???? That's not fair? 1/2 cup of corn is one bread? I love corn, this is a rip off!!"

"If I'm going out with my friends, then I'll end up having a loaf of bread's worth of beer."

"How do you count the ice cream bar you had to treat a low."

I followed it religiously for about two days and fitfully on and off for 10 years .

On testing blood sugar

Initially, I found it interesting. But keeping track of results soon became a pain. Back then, the best of the machines took 2 minutes, and you had to pay attention and wipe off the strip after one minute. Plus, my life did not fit the schedule the little log books had preprinted. Who eats dinner at the same time every night? What about weekends? What about when I want to sleep in? What do you mean I can no longer sleep in? What about when I'm out late partying? What do you mean I shouldn't be out partying?

On taking insulin

They showed me how to take injections using an orange as a example. I can't imagine anything less similar to one's leg or stomach than an orange. I don't know if they still do this.

On my first insulin reaction

I was in the hospital, and the nurse's aide didn't know what was happening. Neither did I, when I ended up starting to pass out, she decided to call in the reinforcements.

Over the course of 20 years, I have been taken to the ER about 8 times unconscious due to insulin reactions. About 4 of those times were when I was pregnant.

On exercise

Exer-what? "I'm 24 and 110 pounds. I don't need to exercise. Plus when you're on insulin it can cause your blood sugar to go low, so all the more reason not to."

On other people

All of a sudden people I barely know are telling me what to do."You can't eat that." "You have to exercise more."

On my social life

There was nothing I was invited to do that fit in with the lifestyle I was supposed to be living. Meals were never timed according to when I was supposed to eat. Meals never had the right mixture of food available. So essentially, I just ignored everything.

The following chronicles my first 20 years with Diabetes.

After 1 year - 1986

Somewhere I got the idea that I should have a baby sooner than later, before I had diabetes for too long, so I got pregnant. That didn't give me much chance to get used to the disease, or to learn ahead of time about the impact of pregnancy on Diabetes. What I learned once I found out I was pregnant is that they don't go well together.

There were no books out at that time about the two conditions together. My OB/GYN gave me some copies of his medical books, which essentially said if you were lucky enough to live through it, you could have a baby with severe physical anomalies (I didn't even know what an anomaly was, I had to look it up.)

Then there was the problem I read that babies could die in the last week or two of pregnancy. They also talked about babies being born extremely large. Before I had much chance to worry about that, I started having all sorts of highs and lows and overall the pregnancy was pretty difficult, and included some very bad hypoglycemic reactions that required hospitalization. My doctor wanted me to attempt to keep my blood sugar between 90 and 185 at all time, which was pretty difficult, but I did the best I could.

In the end, thankfully, I gave birth to a healthy baby boy of perfect weight, 7 pounds 7 ounces.

Not long after that, financial issues caused me to go back to work. I remember my husband getting angry with me because I wouldn't take my blood sugar tester to work with me. I was embarrassed to, be-

cause I didn't want to call attention to myself, and because back then the machines were big and you couldn't just sneak one into your purse.

One day, my husband actually took the trouble to bring it to me at work. I was so angry because I saw it as a criticism of me, and an attempt to control. In looking back, I realize the poor guy was just concerned about me and was doing a caring thing.

At this job, I met my friend Ellen. I was in the HR department, and she had come to ask me a question about her doctor's visit, with none other than Dr. Harris, my endocrinologist. She's been diabetic since she was 13. We developed a long-term friendship.

After 3 1/2 years - 1989

As time went on, the novelty of the disease wore off and resentment took over. I am a rebel by nature and always resented anyone telling me what to do. Spontaneity is probably my strongest character trait, and I always had enjoyed doing what I want, when I wanted it, regardless of any risk.

I was not organized enough to have diabetes, and at times not financially organized enough. I sometimes did not have money for strips or syringes, or forgot to order them in time.

Before developing diabetes, if I needed to lose weight, I would just skip lunch for a couple of weeks. I loved drinking, loved smoking and did both as often as I could.

I began to hate the fact that diabetes affected every part of my life and got in the way of doing things I loved. I had to consider it when deciding what to eat, when to eat, what to drink or not drink. I had to stop and consider what my blood sugar was before any activity, including sex. As each day, I hated it more and more. I felt guilty every minute of every day, because I felt I was always doing things that were wrong for my diabetes.

Every way I turned I felt deprived.

Eventually, I became so overwhelmed that I kind of barreled into a depression. My marriage broke up and I started drinking heavily again, thrilled to have the relief it provided. Unfortunately, I knew that I was putting my life at risk with drinking while on insulin, and that took much of the fun out of it.

I was worried I would die from a bad insulin reaction while drinking and leave my son motherless, so I went to a rehab to deal with the alcohol problem.

After 6 years - 1991

With the alcohol problem now under control, I was left with the depression brought on by the diabetes and probably from a life of partying too. Thankfully, I found a therapist who helped me, and introduced me to another patient of hers named Phyliss who is also diabetic. This person was much more accepting of it, and we became good friends for several years.

This therapist was the one who helped me put into words how angry I was about being diabetic and how I resented how much it limited me.

My control was semi OK, using NPH twice daily with Regular insulin with breakfast and dinner. I had a lot of lows, and found myself drifting off at work particularly at lunch time.

One time I didn't have enough to eat at lunch and drove home from work. I don't remember much about the drive home, but apparently I hit a car and drove away. A cop showed up at my door and I explained about my diabetes. I had just eaten something, but was not quite right, and poked him in the stomach, teasingly suggested that he lose 20 pounds.

After 7 years - 1993

Technology was helping treatment of diabetes grow by leaps and bounds, testing was so much easier, and each day machines came out that tested in less than a minute and did not require wiping the strip. The insulin pump was also becoming more readily available. My doctor was very enthusiastic about it. I told my friend Phyliss about it, and she ended up transferring to my doctor, and getting a pump.

It was great to see what an improvement it made in her diabetes, which had been very difficult to control.

At that time, I wasn't interested in the pump, because my insurance wouldn't cover it, and it all seemed pretty overwhelming. My doctor continued to mention it to me occasionally.

During this time the results of the DCCT came out and proved what everyone knew all the time, that tight control of blood sugars greatly reduced complications.

It was around this time that my doctor put me on what he called the "poor man's pump" which was Lente Humulin once per day and Regular Humulin for meals. I learned to count carbohydrates and embraced the freedom this gave me. My lunchtime lows all but disappeared, and the biggest problem I had was accurately matching my meal time doses to the carbohydrates I was eating.

I went into the hospital so they could get it set up and I learned to measure food, and became frustrated with books that claimed to tell you carbohydrate values. For instance, a medium apple is 19 grams of carbohydrate. Well what is a medium apple. Looking in the really good book from Jean Pennington "Food Values of Portions Commonly Used" you can discover that a medium apple weighs about 138 gram. For me that meant I should take 2 units of insulin.

I challenge you to find an apple of that size in the supermarket. Most weigh in the neighborhood of 150-170 grams, or about 22 grams of carbohydrate which according to my dosage would be 2.2 units of insulin. You need a stinking math degree just to figure out that part at all.

Well, with syringes there is no way to take 2.2 units, you can try, but there is no way to be exact, so your choice is, under dose, or eat more, essentially chasing the insulin dose with food.

This is the kind of compromise and frustration that happens with every meal that doctors and dieticians don't realize. You can't just pick up a darned apple and eat it!!!

Because of this kind of thing, I still had relatively frequent lows, in the neighborhood of 10 per week. I refused to treat them with glucose tablets, and used reactions as an excuse to have candy bars.

My A1Cs were in the sixes, but mainly due to the overabundance of lows.

Even with those frustrations, my mental health improved. I was thrilled to be able to have an extra cracker or two, or dessert, if I felt like it and not feel guilty, but instead just take a bit more insulin.

I loved that I had some choice in my life again.

I remember Roberta, the CDE talking to me about exercise. It seemed so complicated to manage that I just said "It's too complicated, I'm not going to exercise at all."

I always knew I should, so I just had this constant background guilt.

Years 10, 11 and 12 - 1995 through 1997

I continued to read everything I could about diabetes and various treatments and came across Dr. Bernstein's book. I loved reading about it because of his story. He is a diabetic who became a doctor so he could get better treatment. We can thank him for advocating for the availability of blood sugar testing in the home. Believe it or not there were plenty of medical professionals who didn't think it was a great idea. In reading his book, he struck me as a bit of a rebel and a smart guy who wasn't going to let anyone tell him what to do, and wasn't going to let diabetes beat him.

I also related to him with how he acted when his blood sugar went low. He talked about throwing a glass of orange juice. Many times, when someone would suggest I have something to eat, I would get angry, and refusing to eat. It seems that low blood sugar accentuated my base level characteristics, which were at the time, anger and the 'no one's telling me what to do' attitude.

He also talked about glucose tablets, and why they are the best way to treat a low. He said that the tablets don't need to digest before they start working, as opposed to other forms of carbohydrate. As soon as they hit your cheek, they start working. I found this interesting and it got me to buy them anyway.

Finally, I was interested in his method of treatment. His prescribed treatment calls for a very low carbohydrate diet, similar to the Atkins diet and very precise blood sugar tracking. I talked to my doctor about it, who said "Let's give it a try." I did, and got much better control with fewer lows. I followed this for the better part of two years, and all of a sudden missed bread so much that I realized that the lack of carbohydrate was causing me to be unhappy. I was always full, but never satisfied.

I sort of had a rebound effect and ate every starch and sugar in sight for a while. I also started traveling a lot for work, eating out a lot and gaining weight.

I also got married again in 1996 to a wonderful guy who really took an interest in my diabetes and helping me manage it. He witnessed a couple of bad lows, which was pretty scary for him, and caused him to watch carefully over me, nagging me to test etc.

At this point I had also developed hypoglycemic unawareness, and could be down to 50 without any signs like sweating, etc.

After 15 years - 2000

I began to consider the Insulin Pump again. I got on the active list for Insulin-Pumpers.org, which has a great email list where I learned a lot from pumpers and their families.

Even so, I was really hesitant about it because I had a very busy work schedule and didn't think I could take the time out to learn how to use the pump, etc. Someone in my department had gotten one in 1998 and was required to be in the hospital for 5 days to get used to it. I didn't want to take the time. I also didn't want to be tethered to something all the time. I liked the freedom of taking shots when I wanted etc. However, I talked to a lot of people who loved having one, so I decided to get one.

It was a great time to do so because I was covered by two insurances at the time, so my out of pocket expense would be less than \$100.

But then, there was a mixup with the provider and my insurance company, and the order didn't get in before the end of the year when one of my insurances was dropped, so I decided to skip it.

Besides I had just started a new job with even more responsibility, and couldn't take the time.

After 17 years - 2002

It took me two years to realize that the job and the company would always be there, and that I was the only one who could put myself and my health first, so I decided to get a pump. This time, it worked out great.

I bought John Walsh's Pumping Insulin Book and read it cover to cover several times.

I loved the book and learned a lot about pumping. I got my pump on December 3, 2002 and took 5 days off from work to get used to it. I went to the doctor and/or CDE each day for 14 days to monitor numbers. I tested by blood sugar before and after meals and in the middle of the night for two weeks to fine tune the dosages. Through all of this, we discovered my insulin to carbohydrate ration is much higher for breakfast than it is for dinner. I was also able to eliminate the dawn phenomenon by increasing my basal between the hours of 4:30 and 6:00 a.m.

The pump has brought an amazing improvement to my life. The first time I 'bolused' at a business dinner, it was wonderful. I never realized how much I hated shots and the syringes until I didn't have to use

them anymore. I was always worried someone would see me and think I was shooting up. I was worried about dropping one, I worried my son would get poked by one, etc. etc. etc.

The ability to take portions of units (for instance 3.7 units to handle the 21 carbohydrates in a large apple) has all but eliminated the lows) has made my life immeasurably easier, reducing my insulin reactions to once a week instead of once per day.

Not long after I got the pump, I was on Amazon ordering Walsh's book for someone else, I saw the little message that says "People who ordered this book also ordered a book called "Diabetes Burnout, What to Do When You Can't Take it Anymore" by Dr. William Polonsky. I decided to order it.

When I got the book, I couldn't put it down. I was floored about how much he understood diabetics. I loved all the case studies. I got something out of every paragraph I read.

I had spent 17 years feeling guilty about not doing things right, and it was such a relief to know about others who felt the same, and were 'non-compliant.'

I was impressed that the book also provided worksheets that helped you develop solutions to long standing issues. For me, the biggest issue was my weight was sneaking up due to the way I was eating, and the fact that my main exercise was walking from my kitchen to the car in the garage 5 days a week.

I had the opportunity to meet with Dr. Polonsky who helped me put some of my newly gained insight to practical use. I felt that my life was too unpredictable to have a regular exercise schedule. Other things that worksheets revealed was that going to a gym was inconvenient, I love music, and the only time in the past year I had enjoyed exercise was when I had done an 8 mile charity walk.

We came up with a plan that I would buy some CDs of David Bowie, Elton John and other favorites that I would listen to **only** when I was on the new treadmill we bought. This was an interesting twist on "I'll listen to music when I exercise," but instead "I will only listen to this particular music when I exercise." It marries something I love, music, with something I need to do, exercise.

We also agreed that I would walk two miles per week. If I did that in one day, fine, if I did it over the course of 5 days, fine. In any case, before my head hit the pillow on Sundays I would have made it two miles, either on the treadmill or on my lunch hour that previous week. We also agreed that I would find charity walks to do, and maybe someday do a short run.

These changes caused a remarkable change in my attitude. I began to enjoy exercise. I stuck with it for a good while, but every now and then, I felt like I would go “on strike.” I couldn’t get myself to exercise if my life depended on it. These times were relatively short lived, and eventually I’d start up again.

It was in 2003 my blood pressure started to get dangerously high, and I was put on blood pressure medicine. My cholesterol numbers also went up, and I was prescribed medicine, but convinced my doctor to let me try to control it with diet and exercise.

I made a couple of feeble attempts to get moving, and I started eating that buttery stuff that supposedly helps lower your cholesterol.

Years 19 and 20 year- 2004

Through a series of synchronistic circumstances, in October of 2004 I became General Manager of a large fitness center. Now this seems like an odd job for someone who had to be bribed into exercising.

Having left radio and having a great career in information systems, I had developed a pretty solid business management background, and I certainly had a lot of book knowledge about the effect of exercise and diet (or lack thereof) on a person’s health.

An amazing series of changes has happened due to this great opportunity. In June of 2005, I noticed a flyer on our bulletin board that said there would be a 3 mile run on Labor Day. I decided to do it. I was pretty out of shape by that time, so I hired one of our trainers to help me get ready. My only goal was to finish. I was able to finish, completing the course in 33 minutes. My brother said to me “Were you actually running?” Well, it was more of a jog, but I jogged the whole way. I finished 7th from the end.

Then, in November 2005 we decided to do an indoor triathlon to help the Leukemia and Lymphoma Society. This event would include:

- a 400 yard swim
- 7 miles on the stationary bike, and
- 2 mile run on the indoor track

As an experienced ‘runner,’ I teamed up with my husband and a friend and we participated as a relay team. My goal was to finish the run in under 20 minutes. I did it in 17:24!

I did three more 3 mile runs, one that included a lot of hills, never breaking any speed records but always improving.

Then, in November 2006, our fitness center again hosted an indoor triathlon, this time to help the American Diabetes Association. This time, I decided to do the whole thing myself. Now, keep in mind,

I couldn't really swim. Technically, I could. If an alligator was chasing me, I could make my way across the pool. But the swim required 20 laps!! The impulsive part of me is still alive and well, and the lack of swimming experience didn't really occur to me when I said I'd do it.

Again, I hired one of our trainers, and got ready. I read and re-read the section on exercise in John Walsh's book, and as my exercise increased, I lost some weight and my muscle tone improve, I made adjustments in my basal and bolus rates. This was not easy, and I did experience more lows and highs as I made changes.

On November 3, 2006 I was able to complete our indoor triathlon in 55 minutes. I had set a goal to finish it in an hour and 10 minutes, and was happy to improve that. Had I been better on the swim, I could have done even better. Next year, I hope to improve my swim to under 10 minutes.

During the event, I tested before and after each event and bolused as needed.

Where I am now

At my most recent doctor's appointment, my blood pressure was 117/70 with no medication. My bad cholesterol numbers are low, and my good cholesterol numbers are high. My doctor is amazed. He had moved away for two years and come back. He said "You've done all this through diet and exercise??"

I weigh about 132 pounds, and can squeeze my way pretty comfortably into most size sixes.

I'm still off cigarettes and alcohol and grateful that I'm not being dragged down by either.

I keep glucose tablets in my car, at work and at home, and most of the time keep them well-stocked. I keep an eye on my supplies, and haven't run out of anything in a long time. I can't tell you the last time I used a candy bar to treat a low.

I exercise between 3 and 5 days per week, depending if I'm 'training' for some event. Even working in the greatest fitness place in town, I still sometimes have a hard time getting myself moving. I do better if I'm working with a trainer, or if I have a running date with a friend.

I eat pretty much what I want, when I want to, because the pump allows for that. Because we have a lot going on, we eat out about 4 times a week. I have dessert when I want it, taking the necessary insulin to cover it.

I have conducted weight loss seminars at work, and at other locations, using cases from Dr. Polonsky's book, helping people focus on what they *can* do, rather than what they can't. We use some of his worksheets in our Health Coaching program too. I don't hate my diabetes anymore. I don't love it, and I don't love having it, but the anger and hate towards the disease is gone.

I am still happily married, and am proud mother to a 20 year old college student. Both of them are a big part of my support system.

My husband and son love Dr. Polonsky's suggestion about dealing with a diabetic who's having a 'low.' Don't tell them to have food, he says, instead try this: "I'm having a glass of orange juice, would you like one too." Even though I know it's from the book, somehow I don't resist it.

Summary

- My rebellious nature, impulsiveness and spontaneity caused real problems in dealing with my Diabetes. But interestingly, the rebel in me also pushed me past unnecessary limitations. My nature didn't let me take this sitting down.

- For the most part, Diabetes hasn't stopped me from doing what I've wanted to do. I've travelled all over the world, explaining my pump in the best Spanish I could muster up for the security people in the Dominican Republic. I've skydived, had surgery, run races, given speeches, been on stage in theatre and comedy shows, and all sorts of other things I didn't think possible. There's always the background worry of having a low blood sugar, but having a small 5 second tester that fits in my pocket makes a big difference.

- If I have to be diabetic, I'm glad it's been between the years of 1985 and 2006. Since my diagnosis, it seems every day there are improvements in testing and treatment. I'm now considering going on a pump that has a continuous glucose monitor, which would improve my control even more.

- My endocrinologist is wonderful because he listens and is willing to let me try anything that will help me deal with the disease. My GP is also great and supportive.

- If someone came to me today and said "We can get rid of your diabetes today" would I do it? It depends. There are a lot of things in my life that are only here because of my diabetes.

What I've gained:

- My friend Ellen. I only know her because of my diabetes. We've become great friends because it turns out we have a lot of other things in common, like a love for the New York Times Crossword Puzzle, independent movies and a lot more.

- The insight I've gained into myself, what drives me, what holds me back. What I've learned about myself because of my diabetes has helped me in every area of my life.

- The opportunity to help others. Fighting against the limitations of this disease has driven me to help others who feel as stymied as I did. I hate to see others struggling with it, and am heartened when my experience can help someone else.

- A healthier lifestyle. I am healthier than I've ever been in my life. If I get one cold a year, it's a lot. I used to get bad bouts of bronchitis once a year, not to mention digestive system issues, so much that I took Zantac daily. Diabetes was another driving force in getting me to quit smoking.

- A sense of peace. If I hadn't developed diabetes, I don't know if I would have felt as compelled to get help with my alcohol problem. Getting help with that opened my mind to getting help with dealing with the psychological impact of diabetes.

If I didn't have to give these things up too, then I'd say yes, take my diabetes away. If you had to take these things away too, I'd say no, I'll keep the diabetes and deal with it.

If I were running the show

- Doctor's would pay more attention to treating the psychological side of diabetes before anything else. If that isn't dealt with, the medical piece will be handled in a mediocre manner at best.

- GPs would refer diabetics to endocrinologists as a standard operating procedure. It's a complicated, complex disease and deserves specialty treatment.

- Every endocrinologist, internist and GP would read Pumping Insulin and Diabetes Burnout.

- Every endocrinologist, CDE and dietician would follow the treatment plan they expect their patients to follow, every day for two weeks. This includes eating, stopping to test, taking a pretend shot, etc.

- Every endocrinologist's office would have a bi-weekly support group run by a staff member that would feature education, behavior modification, food information and a party every now and then. Treatment of diabetes is not a once a quarter event. The staff person would also hook up newly diagnosed people with a 'buddy,' someone who has had it for a while.

- This is a successful technique in treatment for addiction. It helps the helper and the one being helped.

- Psychologists/psychiatrists who see diabetics would read Diabetes Burnout.

- Every endocrinologist's office would put out a bi-monthly newsletter about diabetes, including success stories, and reality-based case studies.

- I'd somehow get into every diabetic's head that they can live healthy, enjoyable lives and they shouldn't necessarily believe everything they hear from well-intended people. We are the ones that control what happens to us. It's up to us to do the research to figure out what works in our individual lives, speak firmly to all involved parties about what's realistic, and continue to push for improved treatments.