

NEUROPATHY

By Raymond White

First of all, I am not a doctor, not a nurse, not a health practitioner of any kind. What I am is the husband of a brittle diabetic. I do not give medical advice. What you will read here is my opinions and experiences which I have gleaned from five decades of living with a diabetic. Anything you read here that you think might be useful to you, you must check with your own doctor first.

My wife, Cyndi, has been a brittle diabetic for fifty years. By *brittle*, I mean that her sugar level can move far and fast, like, for instance from 200 all the way down to 50 in two hours or less. Why does that happen? I have no clue. It's just the flakiness of her particular diabetes.

But I'm not writing this about the evils of diabetes, I'm writing this about the evils of neuropathy which, if diabetes weren't bad enough, nature tacks on neuropathy as just one more sadistic thrill, I suppose.

Here's what neuropathy is: In addition to all the other damage diabetes does, it also impairs and damages nerves. And thus the tingly feeling that diabetics feel in their toes and feet. But that discomfort is not the only problem, there is the problem of *not* feeling. Feeling, as painful as it can be, is our first line defense against injury. And when a diabetic *stops* feeling, there is the real danger of injuring their feet and not knowing it. And that can lead to gangrene and amputation which is why so many diabetics have lost their feet, which is why doctors and nurses take every opportunity to examine a diabetic's feet. The hint is: you should be paying attention to diabetic feet too.

Most diabetics know that, and their spouses as well. That's diabetes basics. But what you may not know, and I'm going to share with you, is three other hazards of neuropathy that are too often overlooked. But they shouldn't be because each, in its own way, is life threatening, and if not that, at least life debilitating.

[1] DIGESTIVE SYSTEM

As I already said, neuropathy injures nerves, and in this infirmity, it injures digestive nerves. That is: neuropathy works its way up from the feet, through the legs, and into the digestive system. This can cause incontinence both with urine and with defecation causing the diabetic to pee or poop at uncontrolled moments, like, for instance, when asleep.

Decades ago, Cyndi asked her doctor what's to be done about that, and he said that there was no known remedy. So my wife took to the internet (which was new then) and did her own research. And she discovered that there *was* a drug that helped control neuropathy incontinence. And that drug is Tetracycline. The interesting thing about Tetracycline is that's not what the drug is for. Controlling neuropathy incontinence just happens to be an unadvertised side effect.

So Cyndi told her doctor about it and he said: Hey, let's give it a try. So he wrote her a prescription, and, lo and behold, it worked! There is something in that drug that pushes back on advancing neuropathy and stabilizes her digestive system.

She doesn't need it often. It's a problem that flairs up maybe once a year if even that. But when she needs the Tetracycline, she always has a bottle on hand, and it always works.

So there you are. If you have that problem, and need a remedy, suggest Tetracycline to your doctor. And, of course, never take any medication without your doctor's approval.

[2] GASTRO PARESIS

This one is particularly nasty, and it can kill you.

One of the nerves that neuropathy attacks is the Vegas Nerve. That's the nerve that causes the stomach to pulse. The stomach, I've learned, is a bit like the heart. The heart pulses to push blood through your body. The stomach pulses to push food down and out and into the intestinal track where it is digested. The Vegas Nerve controls that.

Well, if the Vegas Nerve stops working, than food lingers in the stomach and putrefies. And the only way it can exit is straight up by convulsive vomiting which, once it starts, doesn't stop and can kill you with dehydration or starvation.

Gastro Paresis caught up with Cyndi last year. Her vicious and unrelenting vomiting bouts resulted in five trips to the emergency room and week long hospital stays.

The prognosis? Gastro Paresis caused by decades long neuropathy. The cure? There is no cure, but doctors were able to stabilize it with Reglan (through an IV). Reglan seems to cause the stomach to pulse, sort of replacing the function of the Vegas Nerve. At home, we tried Reglan as a pill but that didn't help. The pills just caused her to vomit. Then a pharmacist suggested liquid Reglan, and that worked.

Also, the doctors gave her Protonix, which, I think, reduces Acid Reflux. In any case, she hasn't had a Gastro Paresis episode in five months so I'm not going to argue with success. She's on Reglan and Protonix for life.

But there may be something else at work here. Cyndi reread a classic book that she's had for decades: *Dr. Bernstein's Diabetes Solution* by, of course, Doctor Bernstein. In it she found a discussion of Gastro Paresis that she'd never paid attention to before. It seems that Bernstein, also a diabetic, had Gastro Paresis for 17 years, and then it stopped suddenly. He claims that the Vegas Nerve *does heal*. But how can that be? Well, here's the deal, according to Bernstein (and you should get his book).

All diabetics, and caregivers of diabetics, know that too high sugar is bad and too low sugar is worse. Of the two, too low is worse because it can lead to a quick death, while too high can lead to a long lingering coma which is more easily dealt with — (it's harder to deal with being dead).

So, diabetics know that if their sugar feels wrong, but they don't know in which direction and they have to guess, it's a safer bet to guess that it's too low and take sugar. Because if you're wrong, you have time to correct. Whereas, if you bet that you're too high and take insulin, and you're wrong, you could kill yourself quickly. All diabetics know that; more Diabetes basics.

But here's the rub: That simple fact — that too low is more dangerous than too high — can lead diabetics to a false conclusion that too high is not so dangerous after all; and that's wrong. Being too high too often (I mean like 500 and above), can lead to its own set of perils, one being key-tones (ask your doctor), another being high A1C (ask your doctor). But worse than either of those, high sugar can damage your Vegas Nerve and cause Gastro Paresis.

When I learned all this, I realized that maybe I was the cause of this recent grief, that maybe I was overmedicating my wife by giving her too much sugar to quickly dance away from too low sugar and reactions.

So, what did we do? We stopped using the pump for one thing. Why? Because we can't control the settings that control how much insulin it delivers. Only doctors can set those setting

and that was unacceptable. *We*, Cyndi and I, needed to adjust the delivery on the fly, to basically experiment and get it right. We couldn't, so the pump was out. Now I control her delivery with injections and I target 150. I've always known that 100 was too low because 100 can too quickly become 50 or 40 or even 30 — very dangerous. And so I'd always targeted 250, safely away from possible reactions.

But now I realized that 250 was much too high because it can quickly lead to 400 or 500 or (horrors) 600, and *that*, I now believe was causing her Gastro Paresis. So, 150 is now my target number.

How do I insure that she doesn't drift too low and have reactions or too high and have Gastro Paresis episodes? By better diligence, and by personal management; i.e.: not trusting the pump but doing it ourselves.

Nowadays, it is rare that she is too low (below 100) or too high (above 300). Sometimes it happens, usually because I get distracted (like writing this article) and miss a check time.

Oh, and, by the way, how often do I check her sugar? Every four hours — 2:00, 6:00, and 10:00, A.M. and P.M. Why not every six hours? Because she too quickly drifts into too low or too high. Every four hours works best for us.

Okay. So now the question: Which has helped her? The Reglan or the diligent testing to avoid too highs? How would I know? All I know is that she has not had a Gastro Paresis vomiting episode since our last tryst with the hospital. It may be the Reglan, it may be the diligent testing, it may be both, or maybe it's the Protonix. What I do know is: if it ain't broke, don't fix it. (But personally, I think her Vegas Nerve is healing).

Aside: There is a doctor who advertizes on the radio that his forte is helping people with neuropathy. I don't know what he does or how good he is at it, but I think his specialty has something to do with nerves. If you want to find out, his phone number (from his radio ad) is 877-88nerve. If he helps you, please let me know.

[3] BLADDER

Everyone knows what the bladder is. It's where your body parks your pee pee before you decide to, well, pee.

What does that have to do with neuropathy? You know now that neuropathy damages nerves. And now we're talking about the peeing urge — when ya' gotta' go, ya' gott'a go. You know that delightful sensation that tells you that a restroom had better be near or you'll soon be in trouble. Well, diabetics lose that urge sensation.

Is that a bad thing? You may think that's a good thing, to be able wait longer between pit stops. But, actually, it is a very bad thing. Here's what happens:

The bladder is like a balloon. You fill a balloon up with water and it wants to discharge, which delights children as they soak each other. But if it is not allowed to discharge because you're holding it closed, the balloon stretches. And when it stretches, when it *does* discharge, it doesn't discharge everything but retains a residual that now, it *cannot* discharge. And the more the stretch, the more the residual.

In your bladder, that's pee — residual pee — that you can no longer get rid of without a catheter. That pee can cause infection in the bladder, in the kidney, and in the ureter which connects two. It can block the ureter similar to a kidney stone and cause the infected kidney to swell.

Very recently, Cyndi had a blockage symptom in her right ureter, and her right kidney got dangerously infected. Our surgeon inserted a stint into her right ureter to drain the kidney of urine and infection. He also applied an antibiotic to kill the infection. Two weeks later, a follow-up exploratory surgery revealed that there was no blockage, that the ureter somehow closed on its own. The cause? Likely, residual urine in the bladder.

That is now a new problem to have to deal with. The remedy is to pee often even if she has no urge to, and catheterize often after every voiding, and even if she doesn't void at the toilet but should. The rule is: do not leave residual urine in the bladder. That residual causes infection.

Of course you don't want to use a catheter. They're awkward, time-consuming, and yucky. Well, the solution to that is don't get in that situation in the first place. *Pee! And often!* When you feel the urge, certainly. But if you feel no urge, pee when the clock says it's time to.

Story: Cyndi and I used to drive from California to Oklahoma (a two day trip) to see our son. Then we'd make a similar trip to Washington state (also a two day trip) to see our other son. Every time we stopped for gas or came to a rest stop, I'd used the restroom to pee. And I'd ask Cyndi to do the same. Her answer was always the same: "No thanks, I don't need to." Typically, the next time she peed was at a motel where we stop for the night.

I'm no doctor but somehow that felt wrong. I now know that my big mistake was not forcing to go pee. I should have been saying at each stop, "We're not leaving here until you pee." That's what I should have done, and didn't, and now regret. My poor wife now has a distended bladder which will not shrink and it retains 500 ml of urine, and now I have to catheterize her every time she pees. Sorry, but that's our world. Maybe it will improve, maybe it won't. But take this warning. *Pee! And often!* Whether you think you need to or not. And diabetics, trust me, you need to.