

## HOW I CARE FOR MY DIABETIC WIFE

By Raymond White

Hi. I'm Ray and my wife is Cyndi. I am not a doctor, or a medical practitioner of any sort, I am just a dutiful husband with a diabetic wife who has been tasked by fate and love to keep my wife's sugar level as even as possible so she can continue to live and enjoy life to the fullest extent. I'm going to share with you what I do.

Disclaimer: Nothing in this essay is advice. I wouldn't presume to tell anyone what they ought to do for their medical condition because, as I said, I am not a medical person. For medical advice, you should go to your own doctor.

### [1] OUR HISTORY: WHAT "BRITTLE" MEANS

I'm 70. Cyndi is 67. She's a brittle Type 1 diabetic and has been for forty years. What "brittle" means is that her sugar can fall from 200 to 50 (normal is 100) in two hours without warning. That's a frighteningly rapid descent and very dangerous, and, if her sugar level fell even further, could be fatal.

The lowest I've ever measured her sugar was 34, an extremely dangerous level. But the lowest ever was off the chart (unmeasurable so I don't know the number), and she became unresponsive, not lucid, staring blankly at the ceiling, and could do nothing to help herself. So it was entirely up to me to save her life. That was the most frightening day of my life; I thought I had lost her.

But thank God for 911, and a very responsive paramedic team (we were surrounded by a medical team in five minutes from my call), and for Kaiser Permanente. I cannot say enough about Kaiser who, over the decades has saved my wife's life at least a dozen times. I'm just telling you this story so that you know what you're dealing with. Diabetes is not to be trifled with, death can come quickly.

There was one other time. About thirty years ago, we were living in the mountains of Frazier Park, California which was a mistake as we learned from this incidence. We were at church when Cyndi fell into a deep insulin shock (meaning very low sugar). We were 50 miles from the city and medical help. There were no paramedics in our area, but there was an ambulance service.

The problem was, however, that although there was an ambulance service in town, its one ambulance was not in town. It had just left the hill with another patient, so we were stuck.

So, what did I do? I put Cyndi in the car to chase down that ambulance which was somewhere along the 50 mile stretch of the 5 freeway between Frazier Park and Santa Clarita. Our good friend Terri Hart, who was also a Type 1 diabetic, bravely came too. In the meantime, our good friend Ken Mazantti, who was the local CHP sergeant, called his office and alerted all black and white units that they were to let me pass without interference. Also, they alerted the ambulance that we were coming. I drove 100 miles per hour (the fastest I've ever driven), and passed one police car (they moved out of my way), and caught that ambulance waiting at the side of the freeway for us. They administered immediate assistance and saved Cyndi's life.

The moral of that story is: if you're a brittle diabetic, don't live in the mountains, or anywhere where you might not be able to get immediate help.

Enough of history, it's time to deal with now.

## [2] WHAT IS DIABETES?

The normal, healthy human body constantly keeps its sugar level at about 100. It is the pancreas that produces insulin. It is also the pancreas that acts as a kind of thermostat, producing just the right amount of insulin to exactly balance the sugar to maintain that 100. Too high means too much sugar, she needs more insulin. Too low means too much insulin, she needs more sugar.

What exactly is diabetes? It's when your pancreas stops working, stops producing insulin either entirely (Type 1) or partially (Type 2). When you no longer produce insulin, your body can no longer synthesize (digest) the sugar that you take in from eating. In other words, you eat, but your body cells starve to death for lack of sugar, and you go into a coma and die. The only solution is to receive insulin from another source; pills or injection. Type 2 diabetics may get along with pills, but Type 1 diabetics — whose pancreas have ceased to function entirely so that there is no insulin at all — require injections. There is no other way.

But here's the quirky thing: too low is more dangerous, much more dangerous, than too high. 100 is, of course, perfect, where we all ought to be all the time. But 200 is not so bad. At 300, a diabetic might begin to feel sick, but not realize why. At 400, a diabetic knows that she is not right. At 500, she is pukingly sick and need insulin right now. At 600 or above, she may be vomiting regularly and, if so, probably needs to go to the hospital. But my point is: from 100 to 600 is a long trip and takes several hours to get that high. And much of that trip up is not particularly dangerous unless it's ignored. The danger is *remaining* too high for too long which at some point invites a coma.

The opposite, however, is much deadlier, much quicker. A diabetic (particularly a brittle diabetic) can fall from 100 to 50 in less than an hour. And in that below-50 range, death is threatening. She needs sugar immediately, instantly, at this moment — *now!*

Therefore, if it happens that she feels sick and you don't know if she's too high or too low (which happens if you're out somewhere and forgot to bring her test kit), always bet that she's too low. If she's too high and you bet wrong (you give her sugar when she needs insulin), that can be fixed. But if she's too low and you bet wrong (you give her insulin when she needs sugar), then you've may have just killed her. So, if you don't know (and shame on you if you don't) and you have to guess, give her sugar, get her home quickly, and test. But better is: never leave home without her test kit. That's a simple enough rule.

Now, having just said that too low is more dangerous than too high, I must point out that there is one other problem from being too high too long: Ketoacidosis. That's where unprocessed sugar (because there is no insulin to process it) backs up, turns to acid and starts eating the body. That generally causes uncontrolled vomiting. And once that starts happening, a trip to the hospital is unavoidable, Ketoacidosis cannot be corrected at home.

## [3] KEEPING IT BALANCED

Okay. So, how do I regulate this? How do I keep her sugar and insulin in balance?

Fortunately, Cyndi is now on an insulin pump, which is manufactured by that marvelous company Medtronic. Decades ago, before we had the pump, I had to give her injections about twice a day — sometimes three times — and hope that it and her sugar intake somehow balanced each other, which didn't always as you just read in our horror stories above.

That pump is a God-sent — thank you, Medtronic. With that high tech gadgetry, Cyndi is now on a permanent insulin drip which is *much* easier to regulate. Now she is stable *most* of the time. But not absolutely always. As I said, her sugar can descend quickly, very quickly, and we still sometimes get caught off guard

#### [4] TESTING

To learn what her sugar level is we do a “lancet” (also called a finger stick or finger prick). That is, we use a lance (a device with a sharp blade) to draw a drop of blood from a finger tip, place that drop onto a test strip which has been inserted into a pump, then the pump calculates and displays her exact sugar level.

The temptation is to test her sugar (do a lancet) every two or three hours. But it hurts of course, and the more you do it the more callused her fingertips become which creates its own problem: the more callused her finger tips, the more difficult it is to get a blood drop for the sugar test. So, my goal is to test her sugar hopefully just three times a day and hope that gets the job done. So, with that goal in mind, here is how we do it.

We want to do a sugar test (a lancet) as few times in a day as possible. My goal for her is three times a day. More may be necessary, of course, but if we can keep it to just three, that’s a good day. The three necessary times are: 6:00 A.M. (or 5 or 4, whenever I wake up), 10:00 A.M. (breakfast), and 10:00 P.M. (or 9 or 11, bedtime).

Here’s my reasoning:

In the early A.M. — 6 or 5 or 4, whenever I wake up — she’s been asleep for 8 hours and her sugar has been drifting in either direction for who knows how far. So we have to know which direction and how far so we adjust with sugar or insulin to correct.

In the late A.M. — 9 or 10, breakfast time — we face a second high-risk-span because she typically sleeps till noon. That being the case, I have to again *know* her sugar situation and to once more get it on track, and to know what she ought to have for breakfast.

In the late P.M. — bedtime, 9 or 10 or 11 — we need a final number before going to sleep, to adjust as best we can for 8 hours of sleep.

Those are the three times I get involved. Through the day, from breakfast to bedtime, she pretty much takes care of herself because she’s awake and feels what’s going wrong. But at sleepy time, she’s vulnerable so I kind of manage things.

#### [5] WHAT IS “NORMAL”?

As I said, for a non-diabetic, normal is 100. But the problem we face is that she can slip from 100 to 50 very quickly, sometimes in a half an hour. So, while 100 is normal for a normal person, it is a very dangerous place to be for a brittle diabetic.

So then, what *is* normal? Meaning, what is *her* normal?

Well, below 100 is dangerous and above 400 is dangerous, so anywhere between 100 and 400 is sort of safe. So, since midway between 100 and 400 is 250, that seems to be the safest place to be, where her sugar can drift 150 in either direction before she’s in trouble.

Yes, 250 is very high. I know that. But I also know that she can fall from 200 all the way down to 50 in just a couple of hours or less, so what am I to do? I’ll take our chances on the high

side to protect her from the low side as best we can. So, for my brittle diabetic wife, her *normal* is 250, or thereabouts.

Now, that doesn't mean that I go crazy with it, absolute precision is impossible. If at bedtime she tests at 230 or 280, I may just leave her be. Or maybe at 230 I'll give her some protein to stabilize. And maybe at 280 I'll give her a *little* bit of insulin but not what the pump is asking for. If it is asking for 1.7, I'll give her maybe .6, not to get her down, but to keep her from going up. But if it is right at 250, I'll definitely leave her be, I don't care what the pump says.

#### [6] MY TOOL KIT: THE JUICE

In years past, before we had the pump, I gave her orange juice. But thawing out a frozen can was a dangerous time waster. These days, we've settled on box drinks and Kerns fruit cans.

There are two sizes of juice boxes: large (6.75 oz by Juicy Juice) and small (4.23 oz, Hansen's Junior Juice). Cyndi prefers the Fruit Punch flavor.

There are also two sizes of the Kerns, large and small. She prefers Peach and Apricot.

By my experience, I figure a small juice box will raise her sugar about 40, a large box about 60, a small Kerns about 60 and a large Kerns about 160. Don't count on those numbers, those are *my* numbers not *your* numbers. I have no idea what the real science is, those are just my estimates from my experience, and those numbers have worked pretty well for us. You work out (calibrate) your own estimates, don't use mine. And of course you should talk to your diabetes doctor. As I told you, I'm not a medical practitioner, just a struggling husband.

#### [7] A HAZARD: THE CANULA

The biggest single problem is the pump failing because the canula (soft needle) now and then gets crimped. When the canula is crimped, insulin does not feed into the diabetic, the sugar goes up, and up, and the diabetic doesn't know why. Well, you can guess why (it's likely the canula) but you don't *know* for sure until you remove the canula and examine it. And once you remove it, you have to re-insert a new one.

So the diabetic does what the pump says to do; that is, request more insulin. And you and she do that, request more and more insulin. But the sugar keeps going up.

This cycle can continue through the day and through the night into the next day. When her sugar rises above 500 she'll start feeling sick. Now you can bet that it's the canula. Remove it, examine it and very that that is indeed the problem, and replace it.

So she puts in a new site and all is well. Well, not necessarily. Here's the next problem.

When she changes her site, she can never know *for certain* that *that* canula, the new one, isn't *also* crimped. Almost always it is okay, but on rare occasions, the process fails and the *new* canula is crimped from the beginning. That is why when she periodically changes her site, usually once a week, we always change it in the morning. That way she has all waking day to notice that it's okay or not right and needs to change it *again*. If she changes it at night and it's bad, she won't know it's bad until she wakes the next morning and that's too late.

But now, in the situation we're discussing, her sugar is very high from a full day of not getting insulin, she's just changed her site, so now what? The problem is that since she just changed her site, she doesn't *know*, not for certain, that the canula is okay. Now normally that's okay because she has time to assess through the day that her sugar is under control and fix it if it

is not. But now her sugar is above 500 heading to 600. What should she do? She cannot take the risk of her sugar rising still higher so instead of trusting the pump, she'll take the required insulin *with a syringe*. That way she *knows* that she's getting the needed insulin and she can watch her sugar drop to safer levels through the day giving herself additional injections as needed. When her sugar is safely below 300 heading to 200, *then* she can trust her pump knowing that if anything is amiss, she now has time to change the site yet again.

The point is: Never trust a new canula until you've paid attention for a few hours to make sure that your sugar level is behaving right. If your sugar level is badly wrong, way too high, use a syringe. That way you *know* you're getting the insulin you need.

### [8] ADDITIONAL HAZARD: THE FLU

For most people, the flu is an uncomfortable and yucky inconvenience. For a diabetic, the flu can be deadly. So, of course, every year we get flu shots.

Balancing a diabetic's sugar and insulin is always tricky no matter how good your calculations and diligence are. But now, add to that chaotic mix uncontrollable vomiting from being sick with the flu, *now* how do make sense of it all? It takes constant vigilance, and maybe constant pleading with my diabetic wife to *please eat something* even though she feels crappy and it will likely come back up anyway. But if she needs sugar, she needs it now — I can't afford to let her sugar get low. That's of course true anytime, but it's doubly true when she has the flu and is vomiting because once her sugar is too low, it will be the devil to try to get her to drink or eat anything when she is vomiting.

The danger is two-fold: First, the sugar she needs has just expelled so her insulin will not be balanced by any sugar at all. And second, because she's lost that precious sugar, she'll need to ingest something to make up for it. But because she's sick, she's in no mood to eat or drink. So, what I need to do is to keep working at it. Apple juice may be the best I can do, if she can take even that. Tomato soup is also easy on the tummy. If nothing else stays down, I try beef bouillon soup.

But, before anything else, I do need to test and get her sugar level to see what the deal really is. Is she high? Low? Or somewhere in the middle. If she's low, obviously, don't give her any more insulin and try to get her to eat or drink something. If she absolutely won't, you can try honey under the tongue which absorbs quickly without swallowing. I learned that trick from a paramedic. And those little packets of honey from KFC are ideal. And in the refrigerator, apparently, they last forever, or so I've heard said.

If all that fails, and her insulin is dangerously low, she needs to go the E.R. *right now!* What they will do is give her a glucose (sugar) drip I.V. Yes, it hurts, and yes, she'll feel like crap, but her life is at stake, so I have to do whatever it takes to balance her insulin and sugar.

There are anti-vomiting pills that reduce the urge to vomit. We have tried those and they work. If she vomits a pill up, I try another. But I've gotta' get her vomiting under control, one way or another, in order to stabilize her sugar/insulin balance. And I'll be testing her sugar much more often than usual, maybe every hour until her vomiting subsides. I've got to keep track of her sugar level and where it's heading: up, down, or stable.

What's particularly nasty about all this is that the flu's urge to vomit is compounded by high sugar (400+). And also, my force-feeding her and bullying her into eating *something* makes

her feel even crappier still, and makes me the villain. Well, so be it. But what can you do? It's her life on the line.

### [9] FINAL THOUGHTS

Don't you dare take anything I've said here as gospel truth. If you've a mind to do something like what I do, show this to your doctor first. It's his or her advice you ought to be taking, not mine, and, in fact, nothing I've said here is advice, nothing like a recommendation. It's just history and personal experience — what I've done and what we do to make life good, or at least tolerable.

I have a wish list of two.

First, I keep hoping that someone will invent a way to test sugar level without a finger prick. It will happen. And when it happens, it will likely be Medtronic who invents it.

That's plausible for the reason that an exact number is not necessary. Off by ten is acceptable in my opinion. Such an estimate will at least tell a diabetic which way to go. Right-on-point precision is not necessary. If we know that she's too high or too low, we can correct.

And second, of course, I hope some brilliant researcher will cure diabetes, to jump start the pancreas, and make a "dead" pancreas return to life. Either that or a new pancreas grown from adult stem-cells — kind of an Avatar pancreas.

That's all. Have a happy life — anyway.