A Week at the Hospital With My Diabetic Wife

By Raymond White

There are times when hospitalization is necessary; that is, of course, if you want to live. But when that time comes, meaning no disrespect to the medical profession, expect accidents and oversights to happen. They do, you know, even in hospitals. Therefore, when your special someone is in the hospital and is not lucid and completely vulnerable, for safety's sake, you should remain as close to her, or him, as possible for the duration.

My wife, Cyndi, just spent five days in the hospital and I have a story to tell about what happened while we were there. She is a brittle diabetic and has been for 44 years. What "brittle" means is that her sugar level can go crazy up or crazy down to dangerous levels frighteningly fast regardless of what we do — (for example, a month ago, her sugar fell from 350 to 50 in just four hours). So, keeping that fragileness in mind, here is our scary story from just a week ago.

I'll not be ragging on hospitals, or doctors, or medical staff — they did their job, they saved my wife's life yet again. But I will be pointing out how important it is for the patient's support person to be alert and willing to speak up. Your loved one's life may be in your hands.

[1] Getting Sick

On Thursday morning Cyndi's sugar was over 600 and she was vomiting. Through that day and that night I worked to get her sugar down (more and more insulin) and I finally did. The following morning, Friday, I had gotten her sugar down to 300, but she was still vomiting. And so frequently that I knew this was something I could not fix by tweaking insulin and sugar. So, over her objections, I got her into the car and into Intensive Care where she and I spent five days.

Some background: Here's what can happen to a diabetic and what happened to Cyndi: When sugar gets over 600, two bad things happen. First, no insulin means sugar is not being digested, so the diabetic is starving. But second, although her sugar is not being digested, there is sugar — it's just not being handled and so it backs up, floats free, and becomes acid eating her body. That is called Ketoacidosis which puts the patient dangerously near a coma. Correcting that is more difficult than merely balancing her sugar — it requires getting several numbers back in sync which only a doctor and a medical team can do. So my wife very soon found herself wired up with several IV's and a blood draw schedule which was painful but necessary.

But none of that is the story I am trying to tell. All of that is standard fair for a brittle diabetic. The real story is the mistakes along the way, and why it was important for me to stay there by her side through the duration. I never left her. I remained constantly with her, and at night I slept on the floor. Without that vigilance, she might have died. Now: the real story —

[2] Incidences: Sugar and Insulin

First Incidence: Around midnight, Cyndi's sugar was about 280, and her sugar was being checked by the nurse every half hour, or was supposed to be. So Cyndi ought to have been safe. 280 is a good number because it's a long way from danger in either direction — (above 400 or below 90 are dangerous).

But then, around 3:00 A.M., when the nurse measured Cyndi's sugar, it was 500. Whoa! How did that happen? I said to the nurse, "You need to turn off her dextrose (i.e. sugar) *now*."

But she didn't. Instead, she went to a phone and spent a half an hour trying to get a doctor on the phone to get permission to turn off the dextrose. Finally, she got that permission, returned and turned off the dextrose.

While the nurse was out of the room, I tested Cyndi's sugar with her own test kit (which we're not supposed to do) and got a whopping 600+. In other words, we were right back where we had started: super high sugar, Ketoacidosis, more vomiting, but now also an IV dangerously feeding her sugar — and a nurse who could not (or would not) act decisively to do the necessary common sense thing without a doctor's instruction. In other words, during that half hour while the nurse was on the phone, my wife could have gone into a coma and died. And for what? For the sake of a protocol.

Now, I have three questions: [1] How could my wife's sugar have gone from 280 to 600 in those two or three hours when she was (supposedly) being checked every half hour? They were either using a *lot* of dextrose or they weren't checking. [2] Why is a nurse not permitted to immediately relieve a dangerous situation that is so obvious? And [3] Why would the doctor's instructions to nurses not say something like: "If the patient's sugar rises above 400, turn off the dextrose. Or if the patient's sugar drops below 90, turn off the insulin. *Then* call me."?

Second Incidence: It was virtually impossible to get any nurse to hear what I was saying. I was politely harping on this singular message: "Cyndi's sugar can rise or fall very far very fast." I was saying that over and over but nobody was listening. So when her sugar tested at 139, I said to the nurse (different nurse), "You really shouldn't be giving her insulin." So, what did they do? Of course, they gave her insulin.

An hour or so later, the nurse tested Cyndi again and she was down to 101. This time, at my suggestion, the nurse did turn it off.

I suspect that the reason she turned it off is because a few hours earlier Cyndi tested at 87 and I complained then and got the nurse to reduce the insulin. In any case, this time the nurse did the right thing.

But what was a bit odd, I thought, was that she spoke of 87 as if it were normal. For healthy people with a working pancreas, perhaps 87 is normal. But for Cyndi, 87 and 101, might be moving rapidly to dangerous territory, so I was pleased that this nurse stopped the insulin.

Third Incidence: My wife's sugar was around 110. For Cyndi, that's danger so I asked the (male) nurse what he intended to do about the insulin. He said he reduced it from 3 to 1. Exactly what that meant I wasn't sure, but a 66% reduction sounded safe to me so I did not say what I wanted to say which was: "Why don't you just shut it off?" Instead, I deferred to his medical judgment. He had, after all, taken an action in the right direction.

However, at the next reading, Cyndi was down to 90 and on her way, I'm sure, to 50 and lower. So I said to the nurse, firmly but respectfully, "turn of her insulin." He did. Good for him. Then he stepped out and called a doctor. Then he came back and said harshly to me, "I don't take orders from you. You have no right." I said harshly back, "My wife's life *gives* me the right."

Well, that spat didn't last long. We made our peace quickly and had no more incidences in Intensive Care. But then —

Fourth Incidence: The day finally came (day 4, Monday) that Cyndi, nearly fixed up, was transferred from Intensive Care to the regular hospital. We were there two days: Monday and

Tuesday. Now we had a new flock of nurses — all sweet and wonderful but again not paying much attention to what the husband had to say about Cyndi's rapid sugar changes.

So: Sometime after midnight Cyndi's sugar tested at 115. The nurse put her on an insulin drip — why, I cannot imagine. I knew that would be trouble and said so. But the nurse said she'd test again around 3:00 so I let her proceed.

The nurse returned, not at 3:00 as promised, but at 3:30. And Cyndi's sugar? It had dropped to 40! The nurse said, "Oh, my goodness!" I said, "I knew it! I knew it! Damn!" I should have tested her sugar at 2:00. To the nurse's credit, when I then said, "Stop the insulin," she did, and started dextrose.

Now, what if the nurse had returned at 4:30 instead of 3:30? Cyndi's sugar could have been zero and her dead! That realization was and is frightening.

So those are the incidences involving insulin and sugar level. But there were two more incidences of a different nature — the first involving fluids, the second involving a tube.

[3] MORE INCIDENCES: MISCELLANEOUS

Fifth Incident: On Tuesday in the regular hospital, Cyndi was fine, or nearly, and was discharged. But not without another incidence.

Two nights earlier while still in Intensive Care, Cyndi started complaining about trouble breathing. I just chalked it up to pain and trauma. But the next day a savvy doctor got word and ordered an X-ray. Turns out that with all the fluids being pumped into Cyndi to un-dehydrate her, well, she had long prior been successfully un-dehydrated (as her swollen hands were showing) and excess fluids were moving into her lungs. In other words, all the IV fluids were giving her pneumonia. I had no idea that could happen.

To basically dry her out, they gave her a diuretic injection which caused her to pee a lot. But what makes no sense to me is that they also continued to give her fluids until the very last day which kept her struggling for breath. Why they did that, I have no idea.

Finally, on the last day, Tuesday, in the regular hospital room, we met the hospital doctor who was seeking to discharge her. He asked us if we had any questions. I said, "Yes. Don't you think it's time to stop the fluids? I mean, since they're giving her pneumonia." He looked at his charts, then at the drip and said, "Of course." He turned to the nurse and said, "Stop the drip." And she did. Just like that. But I was left thinking: why not two days earlier?

Well, now I know. That's one more thing to watch out for in the hospital. While un-dehydrating you with fluids, they can accidently drown you. If a patient says she's having trouble breathing, believe it.

Sixth Incident: Back on day one when she was first admitted, there was blood in her vomit. The doctor explained to us that the blood needed further evaluation but was not necessarily serious — blood often comes up with persistent vomiting. But sooner or later they'd have to find out for sure if there was something serious to be concerned about.

So two days later, they decided to investigate that. They attempted to push a small tube into Cyndi's nose down to her stomach. However, somewhere in her throat, the tube ran into an obstruction. The nurse tried again with the same tube, then a third time with a smaller tube but to no avail. The tube could not pass and each attempt hurt Cyndi severely. I explained to the doctor

that years ago Cyndi had broken her jaw and maybe that left some kind of obstruction. That of course was speculation; I couldn't possible know. But the doctor said let's not try again; we can always worry about blood in the vomit later if need be.

But what that tube did do is it gave Cyndi a persistent sore throat so that she could not easily eat anything including Jello.

That became a major problem because eating was exactly what Cyndi needed to do to get well and leave the hospital. Finally, on the last day the soreness subsided enough where she could eat chicken noodle soup. But today, a week after discharge, her throat is still sore and she has trouble eating bread. She does say though that her throat is healing but slowly.

I do wonder though, why wouldn't they include a camera in the tube so they could see an obstruction prior to bumping into it so that they could avoid trying to push past something that could cause a serious injury? I'd think that would be standard procedure. But that's just me.

[4] DISCHARGE

Anyway, finally, on the sixth day, Tuesday, Cyndi was discharged and we went home.

Before parting, I had a friendly conversation with our final nurse and we talked freely about these incidences. She said something very encouraging. She said that the hospital (maybe all hospitals, I don't know) are planning to install large screens in every room so that anyone, including the patient, can see what's going on. Perhaps that means that medical people have finally arrived at a conclusion that they themselves are *not* the final arbiters of common sense, and that patients and their loved ones should not be kept in the dark but should have some say in what goes on. That I was allowed to stay with Cyndi through the duration was itself good judgment. In decades past, that was not allowed. But I think hospitals now understand the benefit of a present and vigilant loved one.

My message to nurses is: When a spouse says to you, "I think that may be too much sugar or too much insulin," you really should take it to heart. I know you have a lot more experience with medicine, but that spouse has a lot more experience with *that patient*.

My messages to doctors is: Nurses may need a bit more training so that they're a bit more confident to make common sense decisions. Also, a longer leash might help when it comes to sugar level in brittle diabetics. Common sense and some permission to use it might save a life.

But my most important message is to spouses of patients. Had that last nurse returned at 4:30 to find my wife dead, that would have been *my* fault. *I* was there, *I* had a test kit, I should have used it an hour sooner because I was suspicious. That I didn't was nobody's fault but mine.

To spouses, I'll finally say: [1] Be there! Don't leave. Your loved one's life may depend on your presence. And besides, your loved one is suffering. Your back rub, your squeezing a hand during a blood draw, your adjusting a pillow, your escorting them to go pee, your taking their side in a dispute with a nurse, and so forth, really do help — especially in mitigating the terror. [2] Observe. Pay attention. Ask. [3] Do. But courteously, of course. It doesn't accomplish anything to bully people. Nurses do want to help. They don't want to imperil their patients. Remember, you and they are on the same team. Don't be offensive. But it is not offensive to ask, "Please test her sugar." You don't have to tell them you just did.