PRINT-Diabetes Educator Learns 'Seeing' is Believing, Even for Blind Patient

Jason Huston of Keithsburg, Illinois said he was "driving in the fast lane for 41 years and enjoyed it." Now, Huston says, "I'm on the shoulder of the road with four flat tires."

The 47 year-old likes the driving analogy because that's what he used to do for a living -- he drove a truck. An introvert by nature, Huston liked the solitude and the only occasional opportunities to connect with other drivers, joining them for dinner or a quick drink after hauling a load.

As a kid, he had bouts of feeling tired and thirsty and his performance playing sports was erratic but it wasn't until he was 21 that Huston was diagnosed as having diabetes. He admits feeling "like I was 10 feet tall and bulletproof."

"I felt like I was the one. It ain't gonna get me," he said wearing dark sunglasses in the Diabetes Education Room at OSF HealthCare Holy Family Medical Center in Monmouth. "You always hear about somebody else well I'm the somebody else. I'm blind now. My kidneys are functioning at 37% now."

After Huston married and adopted a daughter, the stress and money worries began piling up. His diabetes was not under control and he didn't want to go on insulin for fear his employer would find out and he might lose his job. But Huston never imagined he would go blind from not properly managing his disease.

While on a trip in Kansas City, Huston experienced what he described as an experience that felt like a squid expelling ink in his right eye. He managed to drive home, saw an eye doctor and learned he had <u>advanced diabetic retinopathy</u>, a swelling of blood vessels in the retina caused by chronically high blood sugar. Within two months, he could no longer drive so he lost his livelihood. Since then, Huston says, "I've been trying to find my way in the world."

One person helping him do that is Tina Canada, Diabetes Education Coordinator at OSF Holy Family Medical Center. Canada says Huston's Medicaid coverage doesn't cover a continuous glucose monitor (CGM) that alerts patients when their blood sugar is too high or too low before it becomes critical. Canada was able to get a professional meter for limited use so Huston could get a better sense of his glucose levels.

When she told Huston his readings were mostly in the target range, he was skeptical and worried. So, Canada realized what is true for her other patients -- seeing is believing.

"I have found so many people when they have a continuous glucose monitor and they're able to see how their sugars respond to exercise or to particular foods, it really clicks in their mind. It's like 'I can see it now,' so I think being able to see and even if it's a tactile way to see, then it' something you really believe because you can touch it, you can feel it, you can see it," she said referring to what she calls a low-tech equivalent of a "Braille" report from his CGM.

Canada glued embroidery floss to the graph of his blood glucose line and used ribbon to mark the target range

"So on this one over here, you can feel underneath where he's in the target range, he comes up above the target range, and again back in target range," she said while running her finger along the tactile graph.

Realizing how easy it was to create and what a big impact it had on Huston's confidence, Canada recently shared her innovative, low-tech approach in a poster presentation at a recent national meeting of the American Association of Diabetes Educators.

A continuous glucose monitor has a sensor attached to the skin that can be read with a smart phone connected wirelessly to an insulin pump. Right now, Huston is challenged with pricking his finger, lining up the blood sample to his test strip plus his talking meter doesn't wirelessly transmit to his insulin pump. Jason knows the sequence to manually administer insulin from the pump for food eaten but it can be difficult to navigate while blind. He would relish a continuous monitor.

"Now, I could do it every hour. You could do it more often and adjust it and let it go versus just doing it two, three, four times a day," he said. Even more helpful, would be a wirelessly connected CGM system that also could verbally tell him his blood sugar level so he could be reassured his disease it under control.

Huston lost his mom, his dad, and his brother to heart disease and he's now divorced. His main support comes from a personal assistant who helps him three hours a day. He has bouts of depression and Huston admits he doesn't want to venture out without a personal assistant because he's afraid of failure. Canada has tried to be encouraging and she's sympathetic.

"Using our public transportation, the Warren (County) Achievement Van, there's no one there to help you on and off even if you have a disability so actually he fell a couple of times by not realizing they were at the curb so it's made him very self-conscious about using the van," she shared.

Canada has supplied Huston with smart-phone apps such as <u>Be My Eyes</u> which has volunteers who through live video connection help navigate new spaces, read expiration dates, instructions, or, whatever challenges can be solved through video support. Always the optimist, Canada would like to get Huston to attend a support group she hosts for people with diabetes. She knows social isolation is contributing to his sometimes negative outlook. But Huston is reluctant, fearing any positive experience from being a part of the group will be fleeting.

However, Huston was recently connected with an independent living advocate at the <u>Stone-Hayes Center for Independent Living</u>, a non-residential non-profit that empowers people with disabilities to improve their lives and live on their own. Canada hopes his advocate there can add to the support she's limited in providing as a diabetes educator.

Common symptoms of diabetes:

- Urinating often.
- Feeling very thirsty.
- Feeling very hungry—even though you are eating.
- Extreme fatigue.

- Blurry vision.
- Cuts/bruises that are slow to heal.
- Weight loss—even though you are eating more (type 1)
- Tingling, pain, or numbness in the hands/feet (type 2)

See a medical professional if you are experiencing symptoms to get a proper diagnosis.