



“YOU HAVE DIABETES”

These Words Don't Have to
be a Punch in the Stomach

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uncle or auntie.’ ”

When I heard the words, “You have diabetes,” I felt like I had been punched in the stomach. That’s how it was for me and how I think it is for many Native Americans. Everything changes. The word “diabetes” is devastating. We think, “This is it. It’s over. I’m going to suffer just like my mother, grandmother, uncle or auntie.”

Diabetes has a different meaning for Native Americans. What is different for you and for me is that we have a dark history with diabetes. In some ways, diabetes is the current enemy. It can be a very frightening enemy—one that we cannot

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see. It can slowly and painfully take our health. It has taken our loved ones and can take us.

We have recent memories of how diabetes has hurt our people. When I first heard the words, “You have diabetes,” I thought about the person I loved the most who was hurt so badly by diabetes: my mother. I want to tell you the story of my mother, so you can think about your own parents or grandparents or anyone else who was hurt by diabetes. Maybe you will understand why your reaction to having diabetes is so strong.

MY MOTHER WAS A PROUD AND STRONG NATIVE WOMAN

My mother grew up on the Bishop/Paiute Reservation. She was a typical Paiute woman: proud and strong. In the Paiute culture a woman is absolutely needed in the family and community. Paiute women have an overwhelming desire to be useful. That’s the way my mother was. She was the foundation of the family, the center, the strength. She had high self-esteem because we needed her so much, and she knew it. She never had fancy things—she was happy because we needed her, because we loved her and because she was useful to us.

My mother was one of the strongest and most giving persons I have ever known. She was very active, always taking care of her family and her home. She baked delicious pies, cakes and biscuits. She was an excellent seamstress. She made all the clothes for me and my siblings. When we were young, she made dolls and stuffed toys for us. For hours she would look through the Sears and Roebuck catalog to get ideas of what to sew. Then she would stay up all night sewing.

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If she had some money, she bought cloth, but most often she bought second-hand clothes. Then she disassembled the clothes and remade them to fit us. She could make something beautiful out of someone else’s throwaways.

My mother made quilts. They weren’t fancy or intricate. She cut simple squares and stitched them together. She had a way of communicating through her quilts. She had theme quilts, some for boys, girls, graduations, etc. She chose colors that usually do not go well together. But in her quilts, they were beautiful. She made some bright, happy quilts that made you think of flowers. They were messages without words.

She had a way of showing love which required no money. Along with my father, my mother often called the local radio station and requested songs be dedicated to my sisters and me. When we heard the announcer say our names and play a special song, we would jump around with excitement.



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Our family may not have had much money, but because of my mother and father, we never felt a lack of love.

HIDING HER DIABETES

I think my mother was in her forties when she found out she had diabetes. She hid this from us for 20 years. I think being told you had diabetes back then was like being told you had AIDS when AIDS was first discovered. No one talked about diabetes. There were no examples of people surviving it. Unlike today, there were no walking groups, diabetes talking circles or healthy eating programs. The only examples my mother knew of how people lived with diabetes were bleak: people with amputations, blindness and on dialysis.



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If I could ask my mother now how she felt for those 20 years, I think she would say *afraid*. I think my mother was afraid of being needy, and even worse, being useless. How could she be proud and giving if she was needing attention and care because she had diabetes? How could someone on dialysis or in a wheelchair be useful to her family? Having

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diabetes was an assault on my mother’s core identity. It took away the very thing that defined her as a Paiute woman.

For 20 years, my mother did not talk about this frightening thing called diabetes. We did not know she had it. She didn’t exercise or change her eating habits because she was busy taking care of her family. She didn’t check her blood sugar or go to regular medical appointments. I’m not sure if she was prescribed diabetes pills, but I never saw her taking medicine. She pretended she was fine. But during all this time, diabetes was harming almost every part of her body.

SUDDENLY EVERYTHING CHANGED

One day she became very ill and soon had to go on dialysis. We knew then that she had diabetes. I think we had a hint that being on dialysis was serious. But we denied that diabetes had harmed her body so much. We said, “Oh, Mom needs a little help because she is on dialysis.”



I went from believing my mother was fine, to finding out she had diabetes and renal failure which meant she was in the end stage of her life!



Then one day I picked up some papers that had come from the dialysis center. On them I read, “*End stage renal failure.*” I was in shock! The paper said *end stage!* That’s how fatal kidney failure was!

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In a few short weeks, my reality was changed forever. I went from believing my mother was fine, to finding out she had diabetes which meant she was in the *end stage* of her life! Having diabetes and coming to the end of one's life were linked! It happened shockingly fast.

How many Native Americans' experiences with diabetes are the same as mine? We find out someone has diabetes, and before we know it, they have a diabetes complication like kidney disease. They go on dialysis, then they are gone.

Suddenly we found ourselves driving our mother to the dialysis center. Three times a week, we drove four hours each way to a dialysis center. We left at five in the morning and returned home at five in the evening. It helped a lot when the tribe started providing van transports to the center for people who needed dialysis.

My mother tried to be cheerful during the rides, but the entire thing was so depressing. She said, "Why do I have to be like this?" She hated having to depend on us and not being able to be strong for us. Over and over she said, "I'm so useless." She had been so strong and active during her life, but could not be strong about diabetes.

COMMON SCENARIO OF HIDING DIABETES

Our family's experience with diabetes was similar to many other people's on our reservation. A common scenario was this: A person had diabetes, but told no one. Suddenly the person was flown to a hospital out of the area. That's when family and community members first realized the person had diabetes. When they came back, they were weak. From then on, they just wasted away. They had amputations, became

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blind or went on dialysis. Then they passed away. The time between hearing a person had diabetes, to the person passing away, was short. It was often a few, short, horrible years.

That's why, when my mother heard the words, "You have diabetes," she didn't tell anyone. Because there were no examples of people living well with diabetes, she didn't take steps to avoid complications. Later, when she had kidney disease, she gave up.

And that's why, for you and me, the words, "You have diabetes," *can be* like a punch in the stomach.

I purposely say the words *can be*. Hearing the words "You have diabetes," *does not have to be* like a punch in the stomach!

THE WORDS THAT CHANGED EVERYTHING

I will always remember the day in the clinic when the doctor said, "You have diabetes." I thought of my mother. I thought, "I will need all sorts of help. I will need to depend on people. I will no longer be able to take care of the people I love."

I began to cry. The doctor closed the door. He looked at me and gently said, "*Your diabetes does not have to be like your mother's or anyone else's. You can make something good out of having diabetes.*"

Your diabetes does not have to be like your mother's or anyone else's. You can make something good out of having diabetes.

I believe the Creator, my mother, my grandmother, my uncle and my aunt were in the room with my doctor and me. They helped the doctor choose the exact words that would help me.

He said, “...*make something good.*” I thought, “Yes! I can make things!” Just like my mother making beautiful quilts out of mismatched color squares. Just like my mother making perfectly fitted clothing out of someone’s throwaways. Native women make things! I can take the rough, raw thing of having diabetes and recreate it so it is like a beautiful quilt.

The Creator and my ancestors continued to speak to me. They told me having diabetes is like being told of a scary place, like a deserted road in a dark forest. You are frightened when you drive through the darkness. And when your car breaks down there, you are terrified. But you get out of your car. You summon all your courage and walk down the road to get to a better place. You come out of the dark forest. You are okay, and the forest is no longer terrifying.



*You summon all your courage,
and walk down the road to
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My ears were opened to what the doctor was saying. My heart was opened and my tears stopped.

This is a different time than the time of my mother. Things are not the same as they were in the 1960s or 1980s. Just like music, fashion and technology, diabetes treatment has changed. There are new medications. There are new ways to eat healthy foods and be active. There are proven ways to avoid complications. Having diabetes and going on dialysis, having an amputation or becoming blind are no longer our absolute destiny. If you are going to have diabetes, now is the very best time to have it.

My mother was speaking to me. She said, “*Barbara, you can do what I couldn’t do.*”

MAKING DIABETES POSITIVE

My mother could not fight diabetes because there were no examples of people surviving it, so she didn’t try. She was a woman who could put a positive spin on anything. She could make a quilt out of scraps. She could make pot holder Christmas gifts out of worn-out jeans. She could make a delicious meal out of a few potatoes and leftover hamburger. But she could not put a positive spin on having diabetes.

What diabetes did to my proud and able mother made me angry. My mother should have lived longer. For awhile, I was angry at people who still had their mothers. “Why do they have their mothers, and my mother was taken from me!?”

I was mad at what diabetes did to my mother. But with the help of her words, I knew that I did not have to follow in her footsteps.

I believe diabetes is our new enemy. We are Native Americans. Show us the enemy and we will fight it! Unlike my mother’s years, today we are no longer hopeless.

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We have the tools: the medications, the clinic staff, the exercise, the eating habits, the sense of community, the extended families, the prayers, the connection to Mother Earth. Look around! There are many examples of people living well with diabetes. We have the knowledge and wisdom to fight diabetes and win.

We have many of the things that our grandparents and ancestors did not have. It is our duty to them not to give up. In fact, we must lead the charge against diabetes. We have to do this. We have to defend ourselves against diabetes. In doing so, we are defending our families.

It is our duty to our children and grandchildren. They are looking at us as examples. They love us and depend on us. Not only must we keep ourselves as healthy as possible, we must live as long as possible. My mother left me when she was in her 60s. I still needed her wisdom and love. Her premature passing left a huge hole in my heart, in our family and in the entire community.

It will be different for me.

I plan on living until my late 90s. I might even see 101 or 102. I plan on staying healthy with diabetes. I've had it for over ten years and have no major complications. My blood sugar readings are usually 113-120.

By living a long, healthy life, I can carry on the Paiute tradition. I can be generous and useful to my family and community for many years. That is my mother's wish for me. She knows I can be useful, like she so desperately wanted to be.

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THE PROMISE I MADE

Toward the end of her life, my mother was legally blind due to diabetes. But she kept making quilts. She needed our help to thread the needles on her sewing machine and cut out cloth squares. We described the colors of the fabrics to her. We helped her arrange the squares at the sewing machine, so she could sew the straight lines.

Some of my mother's quilts are carefully folded and put away in my hall closet. Sometimes I take them out, smell them, feel the textures of the squares and take in the bright mix of colors. My mother put her spirit into these quilts. They are simple, bold, beautiful, strong. I wrap myself up in them. I am protected and comforted by my mother's strength and generosity.



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The quilts remind me of her struggle with diabetes: The disease tried to engulf her in hopelessness, and it almost did. The quilts were her statement, her proof that she was useful. Every stitch was her silent, determined way of saying, “See, I have not completely given up!”

Warmed by my mother’s quilts, I made a promise to her, and to my grandmother, uncle, aunt and the Creator, that I will never give up.



Wit & Wisdom

I asked myself:

**How have my loved ones
been affected by diabetes?**

**Do I know anyone
living well with diabetes?
How are they doing it?**

**How can my experience with
diabetes be different than my
mom's? aunts'? uncles'?**

