The Diabetes Patient–Provider Relationship: 5 Ways to Make It Even Stronger

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Being 13 years old is hard. Being 13 years old and diagnosed with an incurable, chronic disease is almost impossible. When our family pediatrician told us I had type 1 diabetes, it seemed impossible. My little brother had been diagnosed 2 years earlier and there was no family history. At the time, our doctor assured my parents it would be almost unheard of if another sibling would be diagnosed with diabetes.

With 2 children with diabetes, my parents decided to find a diabetes specialist to manage our care. Their search for a pediatric endocrinologist led them to the International Diabetes Center (IDC) in a suburb of Minneapolis, 2 hours south of our small Minnesota town. I didn’t care who my doctor was. It didn’t seem like it would matter. But I was wrong. It made a huge difference to work with medical professionals who specialized in treating young people with diabetes.

On my very first trip to the IDC, I met an angel in diabetes nurse educator Marcia Meier. This was not the usual “doctor talks, patient listens” scene. She asked me how I was doing and then she listened. Marcia was honest about the challenges of living with diabetes and she assured me I could do it. Yes, there was a lot to learn and a lot to think about, but she promised things would get easier. I felt comfortable asking Marcia questions that were important to me.

“‐My parents are nervous about me sleeping over at a friend’s house,” I said. “How can I persuade them to let me go? Does everyone have to know I have diabetes?”

“Just because you have diabetes doesn’t mean your life is over,” Marcia counseled. “Don’t think too far ahead. Take one day, one task at a time.”

As the years passed, I continued to see Marcia and ask the pressing questions. “How and when should I tell my college roommate that I have diabetes? How am I going to refrigerate insulin in a dorm room? I’m wearing a close‐fitting, green silk dress to Christmas Ball. Where can I put my insulin pump?”

Over the past 15 years, Marcia has become a trusted confidante and mentor, in addition to being a diabetes nurse educator. She made it clear that I could ask her any question and share my concerns—that there would be no judgment. Marcia provided a safe place for me to be completely honest. She still downloads my insulin pump, and we still discuss blood sugar trends. But she also is my biggest cheerleader.
Even though I speak and advocate for diabetes as a full-time job, I am not the “perfect diabetic.” And neither is anyone else. Marcia helps me remember that I need to take one day at a time, one task at a time, just like she told me when I was a freaked out 13-year-old. Here are some tips that will help you communicate with your patients with diabetes.

1. Listen
People with diabetes often feel isolated and misunderstood. We desperately need a safe outlet to talk things out. If you listen carefully, you will gain our trust. Over time, this will allow us to open up more and more.

2. No Judgment
Diabetes is tough. It cannot be managed perfectly. People with diabetes have been lectured about good numbers or bad numbers, good food or bad food, good A1C or bad A1C, good weight or bad weight. Encouragement always trumps shaming. We understand that managing our disease is very important. But people don’t usually change behavior by harsh judgment or lecturing. It will only cause us to clam up and not share the realities of our struggle.

3. Motivate
Find out what motivates your patients. It’s easy for people to get discouraged living with a chronic illness. What are their goals? What do they love in their life? If you can figure out ways to help us attain our dreams, you can motivate us to manage our diabetes so we can get there.

4. Laugh
I can’t tell you the number of times that Marcia and I have almost fallen out of our chairs laughing about something related to my diabetes. When I was first diagnosed, I was so sad. I was convinced my life was over before it really got started. Marcia taught me that I could laugh about diabetes and the predicaments it got me into. When my prom date came close for a kiss on the dance floor, he stopped and asked if diabetes was contagious. At the time, I was furious and heartbroken. Later Marcia and I had a good laugh about it. It became the title of my book, *If I Kiss You, Will I Get Diabetes?* Marcia taught me to find the humor in the disease when I could. (By the way, my prom date is now an Irish priest and has more important concerns than “catching diabetes”!)

5. Be Informed
It is critically important that diabetes nurse educators are up to date on diabetes. This disease and its treatment are constantly changing. We rely on you to let us know what new products or protocols might help us manage our blood sugar numbers. Even though Marcia doesn’t have diabetes, she knows the disease backwards and forwards and keeps up to date with new technology, drugs, and studies. She shares the information and we discuss the things that might be a good option for me. Diabetes is definitely not a one-formula disease. Diabetes educators help us explore the possibilities.

I had often thought about writing a book for young people with diabetes or other chronic diseases. It’s the book I would have wanted to read at 13 years old. Finally, I finished the product and my book, *If I Kiss You, Will I Get Diabetes?,* was published this year. I’d like to end this article with the final chapter in the book—a letter I wrote to my 13-year-old self.
Letter to Myself

Dear Quinn,

Life is unpredictable. You can’t control this sharp turn that life has taken. Telling you that diabetes is no big deal won’t help. It is a big deal. Diabetes is a chronic, incurable illness that you will have to consider every day for the rest of your life. The good news is you still have choices. Trust me. Your parents may want to keep you safe and sound, bubble-wrapped with perfect blood sugar levels. Resist. Don’t let anyone limit your future. Diabetes cannot destroy your dreams unless you let it.

Taking off the outer protection will make you a target at times. You are different. You carry a burden. But don’t ever forget that others carry burdens too. Be gentle with them. Be gentle with yourself.

Fear can be crippling, debilitating at times. How is this going to turn out? Will I be able to (fill in the blank)? The shame you might feel after being diagnosed can be overwhelming, overshadowing your present and future. Pray. Breathe through it. It too shall pass. Diabetes will teach you that you cannot do life on your own; you will simply not make it. Most people realize this at some point in their lives. For us, we just found out sooner.

Remember your heroes. You can’t be a hero if you don’t have challenges to overcome. Your Grandpa Gordon was a great adventurer and well known for his ocean-sailing adventures. When his wife or adult children protested that it was too risky, he explained his philosophy of life.

“I could get up every morning and go down to the basement to lie between two mattresses,” Grandpa said. “At the end of the day, I would be safe and sound, but what kind of quality of life is that?” He refused to live like that. Grandpa died last year, but he lived to eighty-five years old and well-satisfied.

That’s how you live your life with diabetes. Manage what you can, but don’t refuse to participate in life because your pancreas quit. You may not be able to see it now, but you have a big life ahead of you. Ride elephants in Thailand. Dance with the Maasai in Tanzania. Blow through a triathlon. Float in the Dead Sea. Even write a book. Diabetes cannot kill your dreams. Only you can do that. CAN is a powerful word.

You may get beaten and bruised along your journey. Friends and family may let you down. Crushing challenges are forced on you before you are mature enough or strong enough to handle them. You shed tears and wonder why life has to be so hard. You think that you can’t survive diabetes. But you are wrong. You are stronger and more determined than you know. Look around. We are all terminal. Living with an incurable disease helps us focus on quality rather than quantity.

Surround yourself with family and friends who speak truth and love into your life. When you can’t take another step, they will come alongside you to help you. Fix your eyes on God and pray for the strength to walk the path before you. And keep walking.

Love Always,
Quinn

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