100 Reasons Why

we are grateful for the discovery of insulin

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CHAPTER 5

Care Partner Perspectives

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My father died of complications related to diabetes in 1968, my son was diagnosed with diabetes in 2010, and I am currently dating a man who has had diabetes for over 40 years. My feelings about being close to someone with diabetes have changed drastically over the years as treatment options improved and public awareness and acceptance enabled people with diabetes to better care for themselves. My father didn't want anyone to know he had diabetes; he stopped going out for dinner with friends, and cancelled retirement plans for travel. He didn't want to ask for help injecting insulin during a bout with the flu, which led to hospitalization and fatal complications. In contrast, my son and my partner are both better able to accept and manage their diabetes well. Knowing that they are managing their diabetes effectively greatly relieves the anxiety that I would have if they were in denial or if the methods of treatment for diabetes hadn't greatly improved since my father's time.

Marcia Russell

Care Partner to Bob

Susan Woodlief

Care Partner to husband Bruce
and daughter Alyssa

Grateful

My husband was diagnosed with diabetes one month after we were married, and over the years I became very familiar and comfortable with the challenges involved. When our daughter was diagnosed with type 1 diabetes at the age of 6; however, even though we had lived with diabetes for 22 years, her diagnosis was not "comfortable" for me. It was a shock – the kind that makes you walk around in a fog feeling like you cannot breathe and not knowing what to do. Over time routines were established, but the daily and nightly concerns were always there. Nights were the hardest and we would often set alarms to wake up and check on her. It was a habit of mine to sincerely ask for help in my prayers. I knew I needed all the help I could get. One night we went to bed with no specific worries for her, so an alarm was not set. In the middle of the night, I woke up in a panic. The thought immediately came to me: Check her. Now! I ran upstairs and quickly tested her blood. She was very low – too low. I got her what she needed. I felt grateful. Years later in college, her roommate called to tell me that she couldn't seem to get our daughter out of bed. We both sprang into action. Words can't describe how grateful I am that she was there to help my sweet daughter.

Luigi Meneghini, MD, MBA

Head US Diabetes Medical, Sanofi,
Brother to Pia

Pia, far left; Luigi, far right

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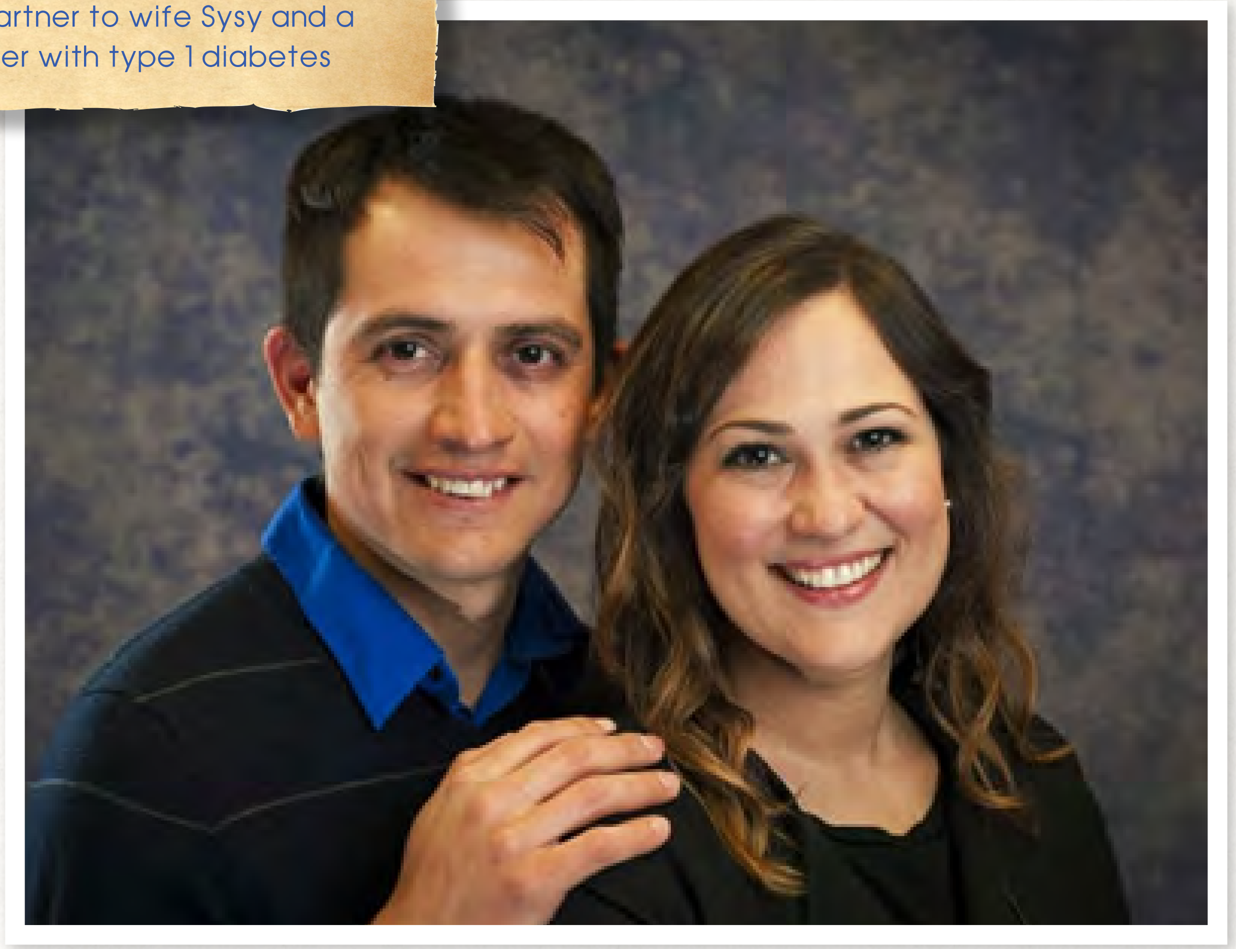
My sister was diagnosed with type 1 diabetes on a school physical exam the year we moved to the States; that summer she lost weight, was always tired and her tennis game was off (which I took full advantage of). When she was told she had to start injecting insulin, her world came crashing down. She had (what am I saying, has) an intense phobia of needles (and spiders) but is now dependent on them (the needles, not the spiders). Her journey with diabetes has been nothing short of remarkable; a true testament to the determination and grit she always displayed on the tennis court (to the immense chagrin of her opponents). Forty-two years with diabetes and no significant challenges, with the exception of her son developing type 1 diabetes when he was thirteen. I became an endocrinologist because I wanted to make a difference for my sister and all the others who struggle daily to manage this condition.

What I have learned from her on a very personal level and from the many individuals that have shared their journey with me is that diabetes never takes a vacation, never lets up, never lets go. And yet, despite this, so many like Pia have gone on to live incredible lives, filled with adventure, exploration, joy and challenge. I have had the privilege to share in their journey and every day feel humbled and blessed to have been part of their lives, and hopefully, in a small way, made a difference.

Alex Munoz

Care Partner to wife Sysy and a daughter with type 1 diabetes



I love my wife's determination to keep herself and our family healthy. She makes sure we eat healthy and cooks us delicious food. Since we have two people living with diabetes in our home, everything we do focuses on blood glucose control. My wife even persuaded me to get a dog so we would be sure to exercise each day! Diabetes is hard. I will rephrase that. It is very hard. How can I not love the determination my wife has to rise to that challenge every day?

Admiro la determinación de mi esposa de mantenerse ella y nuestra familia sana. Se asegura de que comamos saludable y cocina comidas deliciosas. Puesto que en nuestro hogar hay dos personas viviendo con diabetes, todo lo que hacemos se concentra en controlar la glucosa en la sangre. Mi esposa inclusive me convenció de tener un perro para asegurarnos de hacer ejercicio ¡todos los días! La diabetes es algo difícil. Lo diré de otra manera. Es muy difícil. ¿Cómo no admirar la determinación que mi esposa tiene para confrontar ese reto cada día?

Kathy Kenyon

Care Partner to husband Kirk

I can sum up the best and worst thing about caring for someone with diabetes with what I term "The Three H's": Hovering, Hindering, and Helping. The key is to understand each one and gain the wisdom on when to back off. Knowledge of diabetes is worth the effort, but it can lead the well-intended caretaker down a slippery slope to hovering and hindering. The challenge of achieving a healthy outcome belongs to the person with diabetes. How to be helpful without hindering or hovering lies with the care partner. Constantly reminding someone to test their blood sugar/glucose is not a helpful way to promote success. That's hovering. Asking when and how can I help remind you to check your glucose level? That's helping.

Understand, discuss, and share. Then celebrate your combined efforts and successes together!

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My husband has a metabolic liver disease. He was diagnosed with that condition almost 30 years ago. Over time, his liver continued to fail and we were advised that he would need a liver transplant in order to live. We moved to a different part of the country that would give him a better chance of receiving such a gift of life. He was placed on a waiting list and to our surprise, he received a liver very quickly… so quickly, that we didn't have time to learn what we could expect after transplant. A few hours post-transplant, a Certified Diabetes Educator came into his room with insulin to be administered. I was shocked to learn he would require insulin. Because of the transplant, he also needed a number of anti-rejection medications. The education was quick and overwhelming to both of us. After discharge a few days later, and during the first week in a rental condominium in the area, I was responsible for checking my husband's blood sugar and determining the amount of insulin I should administer. It was very stressful, and with spikes in his blood sugar, I was calling the hospital all hours of the night until his levels stabilized. We are now 13 years from that difficult time and I am pleased to say Bill is educated, confident and responsible about keeping his blood sugars at a healthy and stable rate.

Marge Ritchie

Care Partner to husband Bill

Darlene Wiley

Care Partner to husband Terry

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Diabetes is an ongoing 24/7 disease and it doesn't go away. As a care partner, I support an insulin regimen and celebrate all the successes with encouragement and love.

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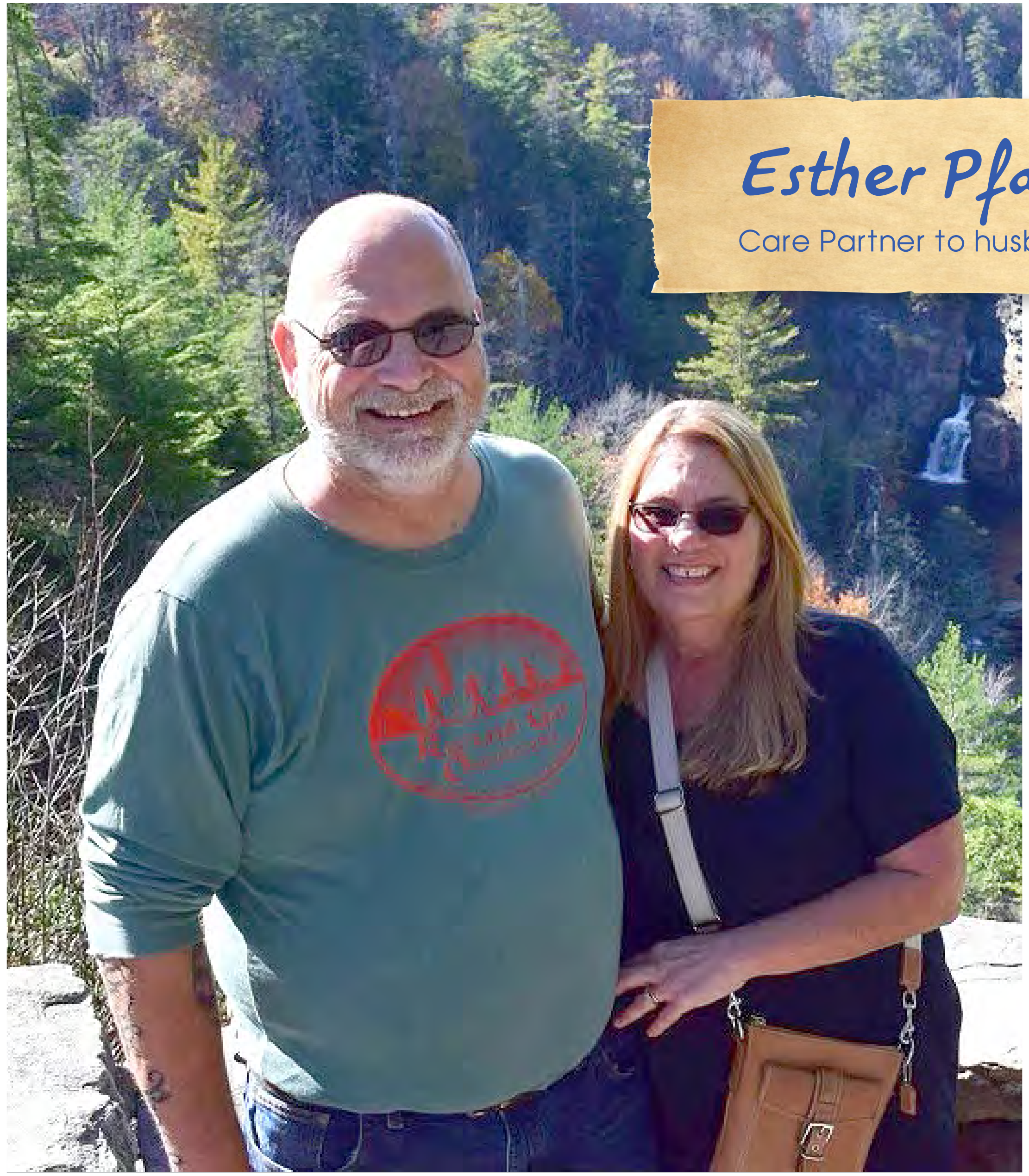
Watching the man I love go through a low blood sugar has been the worst thing about being a care partner. You can hear and see the toll this is taking on them. You have been with this person through good times and bad but suddenly, things are different. Different on so many levels. The panic and fear for that person is so much to bear and you have to be strong for them. It can feel like you are in the role of a parent to a little child, but this is your grown partner that is deteriorating before your very eyes. You just want to take away the pain they're experiencing.

Learning how to better correct these incidents with reduced panic was such an achievement that gave us both so much confidence in managing the disease. Today, we work as a close-knit team to stay on top of it. Just like we often finish each other's sentences, now I can sometimes see if he needs help before he realizes it.



Esther Pfaff

Care Partner to husband Greg

Tina Atherton

Care Partner to husband Frank

To anyone who is newly diagnosed with diabetes or who has a loved one newly diagnosed, I can only say "remain positive." It is difficult to cope with your emotions in the beginning as well as the emotions of your loved one and the reality of their diagnosis. The more you read, the more you learn. Make sure you have a true partnership with your doctor, and that you understand your treatment options, your test results and what they mean. Take advantage of working with a dietician and a Certified Diabetes Educator, and attend seminars. If you feel overwhelmed, focus on one thing at a time and work on ways to solve the issue. Keep in mind that technology is always advancing. Use it to make your life easier. My final words of advice - give lots of hugs!

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