In your own words
Reflections on living with diabetes

Edited by Ellyn Spragins
People with diabetes write back to their younger selves, to share personal insights and reflect on their experiences of living with diabetes and starting on insulin therapy.

## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction from Ellyn Spragins</td>
<td>5</td>
</tr>
<tr>
<td><strong>Letters</strong></td>
<td></td>
</tr>
<tr>
<td>Aida</td>
<td>8–11</td>
</tr>
<tr>
<td>Ashley</td>
<td>12–15</td>
</tr>
<tr>
<td>Brian</td>
<td>16–19</td>
</tr>
<tr>
<td>Charlene</td>
<td>20–23</td>
</tr>
<tr>
<td>Cindy</td>
<td>24–27</td>
</tr>
<tr>
<td>Fatima</td>
<td>28–31</td>
</tr>
<tr>
<td>Mario</td>
<td>32–35</td>
</tr>
<tr>
<td>Nadege</td>
<td>36–39</td>
</tr>
<tr>
<td>Renira</td>
<td>40–43</td>
</tr>
<tr>
<td>Rishma</td>
<td>44–47</td>
</tr>
<tr>
<td>Warren</td>
<td>48–51</td>
</tr>
<tr>
<td>Wayne</td>
<td>52–55</td>
</tr>
<tr>
<td><strong>Closing remarks from</strong></td>
<td></td>
</tr>
<tr>
<td>Professor Anthony Barnett</td>
<td>56–57</td>
</tr>
</tbody>
</table>
Most of us, probably. This desire is so common that we have shorthand for it: 20/20 hindsight. Who knows better than you exactly what your younger self was struggling with—and that perfect piece of wisdom that would have smoothed the way?

For me, this yearning for the insights that lay in the future became a creative project. What if I asked smart, accomplished people what they would say to their younger selves if they could somehow post a letter back in time? Even better, what would they say about a critical or challenging moment in their lives?

These questions led to three books filled with letters that I collaborated on and a speaking career which allowed me to bring the *Letters To My Younger Self* experience to life for hundreds of people in seminars and workshops. From the letters that emerged, I learned that everyone, even the seemingly invincible, has struggles. I discovered that what is difficult has as much to do with the fears and beliefs surrounding a particular obstacle as it does with the obstacle itself. Wonderfully, the lessons in the letters felt very approachable because the letter writers were not lecturing the reader—they were addressing themselves at a younger, less experienced age.

Very few letters, however, were about a physical or health problem. And yet, wouldn’t it be extremely helpful to know how other people have handled—or mishandled—a health challenge, so that we could gain from their experience?

“The letters that emerged, I learnt that everyone, even the seemingly invincible, has struggles”

The letters in this book have been written by people with diabetes and edited by Ellyn Spragins. The views and opinions expressed are not representative of Novo Nordisk and should not be considered as treatment advice.

Novo Nordisk has permission from all participants confirming their consent to use their letters and personal details in the *In Your Own Words* book.
At the very least, it seemed to me, reading about someone who has faced a condition like your own would make you feel less alone and better equipped to move forward.

This is the thinking that led to In Your Own Words, the book in your hands. It contains 11 letters from people with diabetes, and one letter from a daughter of a man living with diabetes. It won’t surprise you to find that their experience with diabetes varies tremendously. Some were diagnosed quite young, while others came to the disease later in life. Some have suffered serious complications, while others have not. Some have found it easy to manage their blood sugar but others have had to search painstakingly for the right combination of diet, exercise and medication that works for them.

One of the most important elements that emerges: a diabetes diagnosis is almost always wrapped up with layers of other emotions connected to a person’s values, background and identity. I’m thinking of Warren, who was so sure that his active, large family would criticize him for having diabetes, that he did not tell them about his diagnosis for years. Or career-driven Mario, who anticipated that he would be stigmatized in his corporate work environment. He ignored his condition. Shame or embarrassment, the sense of being different from other people—and not in a good way—was common.

Many people mentioned being shadowed by fear. Cindy was afraid that being diagnosed with diabetes, with all its potential complications, might tip her back into a depression from which she had only recently emerged. Others, such as Nadege and Ashley, worried constantly about ongoing, frightening hypoglycemia episodes.

A key moment for many letter-writers was being told that it was time to go on insulin. It seems to signal failure and deterioration. For Brian, his doctor’s suggestion that he begin using insulin indicated that his disease had progressed, that he was getting worse. He wasn’t keen to use needles either, so he argued at length with his physician before beginning to use insulin.

So, the challenge of diabetes, as shown in this book, is not just the significant set of physical issues. It’s recognizing the emotional hurdles that may cause you to deny the problem, ignore doctor’s advice or skip testing and medication.

The good news is what the letter-writers learned from their missteps and misconceptions. Their letters offer encouragement about persevering, as well as practical advice about how to handle stress, for example, or a fear of needles. Just as important, many of the writers believe that the changes they made because of diabetes improved their lives beyond what they expected.

As Charlene wrote to her younger self at a time of deep despair over her condition: “From this moment will come a brand new, unexpected opportunity to speak—and to be heard. You will help other people with diabetes, by giving inspiring speeches. Your self-esteem, which has been squashed by so many set-backs, will start to grow and bloom.”

I’d like to offer my thanks to all the people who were willing to open up about their experiences in In Your Own Words. I hope their valuable insights will help others with diabetes, and their family members, live fuller, healthier lives.

Ellyn Spragins
Malvern, PA
“Mom!” both Aida’s son and daughter protested, with more than a little accusation in their voices. The Canadian family was on vacation in New York City a few years ago, about to enjoy a delicious meal in an Italian restaurant. What was the fuss about? Aida, who has type 2 diabetes, had revealed to her family that her doctor had recently told her that she needed to add insulin to her treatment plan to manage her blood sugar levels. But at the restaurant she had just ordered a decidedly unhealthy pasta dish. Her adult children pointed out that there were plenty of healthy choices on the menu. They were very upset that she was not looking after herself properly.

Unfortunately, not looking after herself with regard to food had become a long-ingrained habit. It started when she was an underweight, young-looking teenager growing up in the Philippines. Food was a tool for gaining weight and looking older. When her parents sent her to university in New York City, a cornucopia of packaged and prepared foods paraded through her kitchen: TV dinners, frozen foods, potato chips, sweets. “I think my love of chocolate cake for breakfast started there,” recalls Aida, now 67.

When Aida was diagnosed with type 2 diabetes 11 years ago, at 56, she was reluctant to change her diet. In fact, at the beginning, she was so resistant to accepting it that she did not tell anyone in her family about it. Aida continued to eat as always. She had no symptoms and so it didn’t feel necessary to make any changes.

It took seven years and three more visits to the doctor before Aida was told to begin using insulin. During that time she did tell her family about her condition, but continued to eat irresponsibly. “My kids and my husband would nag me, which was annoying,” Aida remembers. “Sometimes I did the opposite of what I should have been doing.”

The consultation that finally caused Aida to change her ways was with a dietician who managed to impress upon Aida how much careful attention to her diet and exercise would improve her long-term health. Today, Aida’s blood sugar is well controlled through a combination of diet, exercise and medication, including insulin. Now retired, she’s a passionate advocate of medicines becoming equally accessible to everyone, particularly those with few financial resources.

Aida wants to be a champion of wellness, not a victim of disease – and to confront it head-on. This radical shift in her mindset transpired because of a few key elements that she wishes she had known about earlier. Here is her letter to her younger self at 57, a year after she was diagnosed with diabetes.
Dear Aida

Secrecy is your mandate. Don’t let them know at work and don’t let them know at home. You have no pain. It just seems easier this way. I know.

But Aida, there’s something going on here besides sheer inertia. You have a big stubborn streak that is preventing you from truly taking care of yourself. You just don’t want to be told what to do – by anyone.

Education is what you desperately need. Read books and attend seminars. The more you actually know about diabetes and how it works, the less you will be reacting rebelliously against your beloved children’s and husband’s suggestions and reminders. Knowledge is power.

Unlearning a lifetime of bad habits and making lifelong change is not easy. The information out there about managing diabetes can be overwhelming – but you can figure out what works for you.

Here are some tips and tricks.

At social events, eat before you go. Don’t go there hungry, which will cause you to snack on the wrong food. You can still chat and tell stories with a drink in your hand. Just make it water with a lemon slice.

Believe it or not you can learn to eat things, like celery, that you never could stomach before. Eventually you’ll put turmeric on your food, drink lemon water in the morning and make smoothies containing kale. Yes, kale! As much as your taste buds seem to insist on chocolate cake and béarnaise sauce, they can learn to love other foods.

The final tip: exercise. It’s honestly going to be a great experience for you, especially once your kids give you a gym membership as a Mother’s Day present. Proper nutrition, exercise, learning to handle stress and maintaining spiritual health are the key tools to successfully manage your diabetes.

A champion of wellness,

Aida

“The more you actually know about diabetes and how it works, the less you will be reacting rebelliously”
Ashley

Though she is only 27, Ashley has been living with type 1 diabetes for a long time. She was diagnosed on her tenth birthday. Instead of a day filled with anticipation about celebrating with her family after her parents got home from work, Ashley woke up feeling very sick. Her older sister found her crying in the hallway and alerted their mother, and little Ashley was whisked off to the hospital.

“I was so scared. I had never been to the hospital before. I was being pricked, tested and wrapped in blankets,” she remembers. “Suddenly the doctor came in to speak with my mom and told her that I have type 1 diabetes. My mom instantly started crying.”

Ashley had no idea what type 1 diabetes meant, but she started crying too. Though her life changed dramatically on that day, she credits a very supportive family with helping her to adjust to her condition. As a keen soccer player, she continued to play in a league during most summers, but certainly had many “Why me?” and “It’s so unfair!” moments as she grew up with the disease. Now working in sales for an e-commerce company and living with her boyfriend in Toronto, Ashley recognizes that the emotional hurdle of accepting her diagnosis was among the biggest that she had to surmount.

An even larger one, though, was physical – hypoglycemia. She has experienced a handful of frightening episodes, two of which required that she be rushed to the hospital. The first time it happened, she was 22 and still living at home in Oshawa. She had slept late and awoken in a dream-like state. Ashley, whose family nickname is “Bratley,” was so out of it that her sister, who was visiting home at the time, assumed that she had been out partying the night before and was still a little drunk.

Then Ashley’s boss called, wondering why her normally punctual employee had not shown up for work. The ensuing conversation was so unintelligible that her boss, knowing Ashley has diabetes, figured that something was not right and called an ambulance.

Ashley is writing to herself at this moment, when she is lying on an ambulance stretcher, racing toward a hospital.
Dear Bratley

You have just been revived and the paramedics have told you what happened. Your blood sugar dropped very low. The last thing you remember is going to bed last night and now the implications of what happened are sinking in.

I know what you are thinking. Could I have died? What would I have done if no one was home to help me? What would have happened if my boss hadn’t called?

These thoughts will never leave your mind. Before going to bed you will always be wondering: what if it happens again?

I am writing to prepare you for the struggles that lie ahead. You are going to learn about something called hypoglycemia. You will learn about it by experiencing extreme cases of it. This was the first, and I’m sorry to say there will be more. One time you will be taken to the hospital and told that your blood sugar dropped so low in your sleep that you were almost unconscious.

Because of your fear of another hypoglycemic episode, you’ll decide from time to time to run your blood sugar high before going to bed. This seems like a good solution, especially once you move out to your own apartment. After all, who would help you if you were to have another episode? You always worry that maybe one night you won’t wake up.

But, Ashley, please don’t do that. Running your blood sugar high is going to impact your health in the long run. Work with your doctor to monitor your glucose overnight and change your treatment to prevent the extreme lows you are experiencing at night.

There will come a time when you are ready to start your own family. Naturally, you’ll be scared about how your diabetes will impact that process. If you start taking care of yourself now, that won’t be an issue.

I will end this by saying that it is okay to be different. You won’t be shunned or judged. In fact, instead of hiding it, embrace your condition. It is not going anywhere.

You got this!

Ashley

“There will come a time when you are ready to start your own family. Naturally, you’ll be scared about how your diabetes will impact that process. If you start taking care of yourself now, that won’t be an issue.”
In many ways, Brian, 53, was perfectly positioned to tackle type 2 diabetes when he was diagnosed seven years ago at age 46. He runs his own advertising agency outside of Toronto, Canada, which focuses on the pharmaceutical industry. He studied for an MSc in nutrition and biochemistry, so he comprehends how many diseases work. And he understands numbers: after learning about his condition, he tested his blood sugar levels eight times a day for a week, created a spreadsheet and charted his daily fluctuations for his doctor.

“Diabetes is a game of numbers and I can track those. It was a way for me to take control,” he asserts.

Beyond his own skill set, he’s supported by two well-informed relatives: his wife, Janice, who is a veterinarian, and his sister, who is a dietician. What’s more, diabetes was not a completely foreign condition; both of his parents had it in their later years.

However, sometimes a deep reservoir of knowledge and support doesn’t suffice when you’re confronted with an unexpected development. That’s what happened to Brian three years ago when his doctor told him that he should begin injecting insulin to control his blood sugar levels. He dragged his feet, insisting on several detailed debates with his doctor about alternative medications or dosages. He says: “Sometimes a little knowledge can be dangerous. You may know the right thing to do but still resist it.”

Here is Brian’s letter, written to himself at this time.
Dear Brian

Hey, 50-year-old me, What’s the big deal? Why are you stalling? You started off being so diligent, taking care of your diet and getting more exercise. But I know you think rice is a God-given right… and maybe corn chips, too. Life has been getting fuller, with three teenage boys and a growing company, and your walks have been getting shorter. Your doctor has been talking about adding insulin to your treatment plan for a while, but you’ve resisted at every turn.

While you dig in your heels, I’ll tell you what’s going on. First, in your mind a move to insulin is a loud signal that your disease has progressed. If you need more drugs and medication, it means your body is less able to do what it’s supposed to do. In other words, you’re getting worse, right? That’s sobering and scary. It feels like your path is getting more slippery and other unpleasant developments lie ahead.

Second, you really don’t want to inject yourself with a needle. It just seems repugnant. Period. I get all that – how could I not? But come on, Brian. You’ve been worried about your high blood sugar levels every morning for far too long. You know something has to change.

Dig into what you know about diabetes. The more you know, the better off you will be. The most fundamental fact: it can be an insidious disease. It doesn’t make you feel different. You don’t look different. But over the course of a decade or two it can result in significant health issues like organ damage, cardiovascular problems or losing a limb. It lies low and then one day your kidney is failing.

Your most potent armour against those dangers, as you know so well, is managing your blood sugar with all the vigilance you can muster – and the best tools. Your doctor has recommended insulin because he thinks it’s the best tool for you, and one of the most natural and direct ways to control your blood sugar levels. You don’t need to be afraid. Adding insulin to your treatment plan doesn’t mean you are seriously sick, nor is it a sign of weakness.

And those needles? Janice can help you with the injections. You’ll be surprised how rapidly you get used to them. You’ll be doing it yourself, no problem, within a week. Here’s the good news. Seeing your numbers fall into the right range will be such a relief. It will motivate you to do even more – to eat a little better, walk a little more and lose a few pounds. Stay motivated.

Brian

“Seeing your numbers fall into the right range will be such a relief”
Imagine regularly waking up in the middle of the night confused and disoriented, holding a juice box in your hand. This is Charlene’s experience at least twice a month, when she suffers through an episode of hypoglycemia.

“I live alone. I have everything I need on my bedside table to help manage hypoglycemia, but when my blood sugars drop to potentially dangerous levels I am so confused and disoriented that I get up and I lurch toward the kitchen,” she explains. “So now I load the kitchen up with juice boxes… which means I have to put that little straw in the box while feeling totally out of it!” She usually wakes up with the refrigerator door open and a juice box in her hand.

She hasn’t exactly gotten used to severe hypoglycemia, but she knows she can live with it. A gregarious 63-year-old who lives in Ontario, Canada, Charlene walks with a cane due to neuropathy, a long-term complication from diabetes meaning that she has little sensation in her feet. But she swims laps four evenings a week and is 50 pounds lighter compared to what she weighed five years ago. She’s also become a fervent advocate for effective, affordable diabetes medication, often speaking at Diabetes Canada events. In 2018 the organization presented her with the Inspirational Award for Ontario.

No one would have predicted this role for her, least of all Charlene. When she was diagnosed at age 19, she was given no medication and no instruction. No one among her family or friends ever mentioned it. “It was something you didn’t discuss, a taboo subject. Sometimes, in the early years when I tried to talk about it and find out if anyone else had diabetes, it was shameful, like I was talking about a sexually transmitted disease,” she remembers.

Over the years, while raising three daughters, she has confronted a host of personal and health challenges, including divorce, two bouts of cancer and many surgeries. But the most soul-crushing moment came five years ago, when she was in her endocrinologist’s office trying to find a diabetes treatment she could afford. In frustration, the doctor dismissed Charlene, saying she could do nothing more for her.

Charlene just looked at her and said: “You’re kidding…?”

Charlene went to her car and sat in it, tears streaming down her face. “On my way home, through the tears I wondered, what do I do now? I have endured so much but these words were the worst I had ever heard,” Charlene says. She wondered: is there nothing or no one that can help?

Here is her letter written to herself at this moment of despair, when she felt she was being told that she no longer mattered.
Dear ‘Charles’

I know over the years you really didn’t think too much about this diabetes thing, and that you let it go because you really didn’t think it would make that much of a difference. Well, it does.

If I can say anything to you, Charles, it would be to be more aware of your body and yourself. Learn its rhythm and nuances. Know who and what you are. Begin to recognize your native part; your grandmother’s Algonquin heritage has played a big role in your experience with diabetes. It was considered a weakness that no one in your family wanted to admit to.

So, it was easy to ignore. That being said, I want you to know that you are forgiven. For the late nights, the extra bag of potato chips, the neglect of yourself and most of all for the lack of self-love.

Forgiven, because what you have done or what you have not done has made you the person you are today.

And, Charles, the amazing thing about this devastating experience is that it will produce an epiphany. You do matter. Your thoughts and experiences have value.

When you get home there will be a phone call from one of your nurse practitioners who will help you get referred to a complex care centre, which will support not only your physical health, but your financial and emotional well-being as well.

As you try to learn everything you can about diabetes, vindicate yourself. Try to put yourself first on occasion and, if you can, ignore your family’s negative attitude about diabetes.

As you try to learn everything you can about diabetes, vindicate yourself. Try to put yourself first on occasion and, if you can, ignore your family’s negative attitude about diabetes. It is their problem. Be strong. Be positive. Diabetes is not a character flaw. You will speak openly to your physician about night-time hypoglycemia and learn how to effectively manage it by modifying your treatment plan.

In fact, from this moment will come a brand new, unexpected opportunity to speak – and to be heard. You will help the complex care centre, and other people with diabetes, by giving inspiring speeches. Your self-esteem, which has been squashed by so many setbacks, will start to grow and bloom.

And from that moment, later in your life, you will understand your true purpose. You will start a whole new life chapter. Remember, be strong. Be true to yourself. Diabetes is not who you are, but merely an expression of your life.

You are worthy,

Charlene

“As you try to learn everything you can about diabetes, vindicate yourself. Try to put yourself first on occasion and, if you can, ignore your family’s negative attitude about diabetes”
The hardest thing Cindy, an energetic 52-year-old woman from Milton, Ontario, has ever done is come back from a deep depression. There were plenty of difficulties before that; in fact, those troubles were most likely the reason she finally tipped into depression when she was in her early 40s. Both parents were alcoholics, which contributed to a “hellish childhood,” she says. She became a very meek person who didn’t stand up for herself. “I let people tell me how I should feel and how I should do things. I felt like a doormat,” she recalls.

Fifteen years ago, Cindy faced some serious family struggles which involved multiple interactions with law enforcement, which were beyond her control. This resulted in her and her family moving from Mississauga, ON, to Milton, ON for personal reasons. But the accumulated stresses of parenting began to catch up with her. Though she had been a successful public relations executive for a number of years, she found herself unable to get out of bed. She was in her early 40s and knew she needed to get help. She stopped working for almost a year while receiving psychiatric counselling and participating in a short-term program for people with a spectrum of mental health issues. Finally, she began to recover and resumed work.

A year later, having finally achieved a measure of emotional balance and stability, Cindy was shocked by the news that she had developed type 2 diabetes. It felt terribly threatening in a couple of ways. Her mother had been diagnosed in her 40s with the disease, but had not managed her blood sugar levels very well – a path that Cindy feared that she would follow. She also was frightened that the diagnosis might pull her back into the “that dark place” – in other words, back into a depression. “I remember that first finger prick,” she recalls.

I was sitting at the table and thinking, “Haven’t I faced enough difficulties in my life?”

Cindy is writing to her younger self at this moment.
Dear Cindy

Well, the moment has arrived. You thought you were going to escape this terrible disease and be different from Mom, but you did not. Why did this happen?

The first pinprick… You hate this already! You feel sad about where the disease will lead. You worry you might slip back into depression. You’ve gone through so much with your son… Isn’t that enough? Is this disease more punishment for being a terrible mother? You are perpetually challenged with negative experiences and often feel you have no joy in your life. Diabetes feels like more evidence that a dark cloud is forever following you.

Cindy, take charge of your life! You are going to find this hard to believe, but managing diabetes will empower you. You will determine your destiny. You will lose 38 pounds, hit the gym almost every day and feel better than you did in your 40s. You will become a truly different, authentically confident person. Goodbye doormat!

I’m not saying this path will be without bumps. But you have the self-reflective tools you learned in managing depression. You list your thoughts and feelings, and the cascade of concerns that they trigger. Then you question the accuracy of those associations. For example, just because your blood sugar level is not where it is supposed to be, and you feel defeated, that does not mean that you are a poor performer or a failure.

This form of self-therapy will help you overcome a tendency to catastrophize your experiences and uncover the strength and determination that prevailed during your recovery from depression. This is the life-changing event you have needed to live a healthier way of life. Forget about your family members: you are different.

You’ve always had a negative impression of yourself. I see the true reality of the person who you have become; full of strength, courage and determination. Shed all of the baggage you have been carrying around with you for so many years.

I’ll close with saying how proud I am of you. You have overcome unimaginable circumstances throughout your life. You will learn to live with diabetes. You will look better and feel energized, your passion and zest for life will return.

Congratulations Cindy… you did it.

Cindy

“I see the true reality of the person who you have become; full of strength, courage and determination. Shed all of the baggage you have been carrying around with you for so many years”
Fatima grew up in Brazil and from a young age enjoyed being in the kitchen, cooking and baking. That love of domestic arts grew to include sewing, embroidery and gardening as she entered adulthood and became a teacher. Her father died at the age of 43, which led to the relocation of the entire family. Fatima emigrated to Canada when she was 23, and eventually everyone else joined her. Fatima married and all was well until she lost a baby when she was 28. A year later, she got pregnant again and was diagnosed with gestational diabetes. Although she was told that the condition would disappear after she had her baby, it did not. Fatima was filled with despair. “I blamed myself for the first year after I was diagnosed,” she remembers. “I didn’t talk to anybody. I wouldn’t answer the phone. I would sew all day long.” Her life was empty. This year of self-imposed isolation and intense guilt ended when her vision became blurry and her body began to hurt. Her doctor referred Fatima to an endocrinologist, who in turn recommended that she attend a week-long seminar on diabetes. For eight hours a day, Fatima was submerged in information about diet, exercise, medication and the effects of diabetes on the body. At the seminar she also learned how to use insulin. It was a huge turning point. “The more I learned, the more I started to better manage my diabetes on a day-to-day basis,” she says. Now 59 years old, Fatima is writing to herself at 29, during her lonely year after being diagnosed.
Dear Fatima

You are spending all day, every day, scolding yourself. You’re overweight. You should stop cooking and baking so much. You don’t deserve to be here. You don’t deserve anything.

But, Fatima, heaping blame on yourself won’t change anything – and it certainly won’t make your condition better. Here’s what will: opening your mind. You will have the chance to attend a seminar that will help. You’ll look around at the other “students,” who will be people your age, but also older people, babies and children, too. You will realize: Diabetes can happen to anyone.

After soaking up all the information in the seminar you will start going to the library to understand your condition even better. Being diabetic will teach you how to eat healthy food and to exercise more. Insulin will help to improve your blood sugar levels. And over the years, there will be advances in medication that will continue to alter your life for the better.

But the best thing that you can do – that will cause all of this to happen – is to look at your diabetes in a positive way. Decide to have a great relationship with it. Your diabetes and you will have your “ups and downs,” just like any other relationship. Some days will be easy and other days not.

However, with optimism and faith in yourself, you will become content and develop a positive way of living.

Empty no more,

Fatima

“Being diabetic will teach you how to eat healthy food and to exercise more. Insulin will help to improve your blood sugar levels”
Mario

If there is one thing that has defined Mario for most of his life, it is his dedication to working in the competitive insurance industry. Fiercely athletic in his younger years, playing football, hockey, soccer, rugby and competing in triathlons, sports activities gradually faded from Mario’s life as his family grew and career demands intensified.

That environment partly explains why he pretty much ignored a diagnosis of prediabetes at age 46. “I chose to put other things first because I was fearful to admit to having a chronic illness within a corporate environment. I thought there was a stigma attached to having diabetes,” explains Mario, now 55. But also, having experienced no serious symptoms, the condition was easy to ignore. He just did not believe it was worth worrying about.

Four years after his diagnosis of prediabetes, Mario went back to the doctor and discovered that he had full-blown diabetes, as well as high blood pressure. This time he made an effort to exercise more, limit sweets and take his medication, which were pills. But his efforts fluctuated.

It wasn’t until he was 52, nine years after first being told he was at risk of developing diabetes, that Mario truly grasped the dangers he faced. The first event was his doctor telling him that Mario’s kidney function, which had already begun to be impacted by diabetes, had dropped significantly further. Mario felt shock and fear upon realizing how serious his situation was. His elderly mother, who was now seriously ill, had been experiencing compromised kidney function and here he was, much younger, facing the same situation.

Whilst waiting for a nephrologist appointment, Mario woke up in the middle of one night and noticed that something was wrong. His hearing felt distant and the sweat was still pouring from him. “The first thing I thought was that I was having a heart attack,” recalls Mario.

Mario went into the kitchen, thinking he would take some aspirin and call 911 in there. His testing kit happened to be on the kitchen counter, so he decided to check his blood sugar. It was hovering close to three. So he opened the refrigerator and ate part of a piece of cake. In the next few minutes he tested himself four times and watched his blood sugar rise. “It was quite a scary condition. Slipping into that state, which I now realize was hypoglycemia, was traumatizing,” says Mario.

These two developments also made him feel terribly guilty. Disregarding his condition for so long, he acknowledged to himself, was selfish when his family and ailing parents all depended on him.

Mario chose to write to himself at age 43, when he was first told he was at high risk of developing diabetes.
Hey, Mario

When your doctor tells you that you’re at risk of diabetes, listen to those words carefully. When you attend the Diabetes Education seminar – listen and heed those words. This is something you can’t ignore!

You think you can. After all, you don’t feel any different. And being at risk of diabetes is not exactly something you are willing to talk about. You live in a corporate culture where admitting a weakness just isn’t done. But here’s the problem, Mario. It’s like smoking and damaging your lungs. By the time you quit, the damage is done. If you don’t manage your blood sugar, the damage is being done, silently. Once you discover the extent of the damage, it’s too late.

So, do not try to change everything at once – take small steps, incremental steps, to work up to your health goal. When you feel disappointed with your test scores, don’t stop measuring sugar levels. You used to enjoy playing sports. Go back to this. Don’t worry if you are not the athlete you once were. Find and commit the time to health and balance.

Fear of talking about the disease, so that you are not labelled, will not work so well for you. You need help – you actually need to talk to someone who has gone through this or knows the disease intimately. Find a coach who will keep you inspired, keep you active.

And don’t forget to recruit your family to the cause. Empower them to help and support you. You will eventually learn that asking for help and support is a sign of strength and character. You have tried to control too much.

If you’re recommended to take insulin, do it. Don’t fear the needle and avoid it for such a long time. By the way, the night you wake up in a cold sweat with soaked clothes, check your blood sugar levels right away and avoid the panic attack – it’s just hypoglycemia. Hypoglycemia will haunt you every time you work out, change your diet, feel stress or have an infection. But like everything else, it’s your new normal. Testing and managing your sugar levels better will help to curb those extreme lows.

Once you begin to take this disease seriously, you will be able to relinquish your stubbornness about doing what you want to do rather than what the doctors and your wife are telling you to do. It will be hard, and there will be many small failures in managing the condition along the way. But small failures are nothing if they bring you the benefit of living healthily and living life to the full overall.

Don’t wallow in self-pity. Get over it. Your life depends on it!

Mario
One summer day when Nadege was 37 years old, she woke up and found herself in a semi-private room in a hospital in Calgary, AB. Gathered around her were her parents and other family members, who all lived some distance away. Her mother shrieked, “My daughter, my daughter! You are alive!”

“What happened?” Nadege asked, full of confusion. “Why are you all here?” She had been in a coma for a week. The last thing she remembered was going to the hospital with a relentless migraine following an overnight shift at work on Sunday night. The hospital doctors put her on an IV with pain killer, and the rest was a blank. Apparently, though, she had been released from the hospital and gone home. When she didn’t show up on Monday evening for her night job, her manager asked the police to check on her. She was found unconscious in her apartment and rushed to the hospital, where she remained in a coma for seven days.

“What caused it? To this day they are unsure,” says Nadege. “It could have been a stroke, a seizure or acidosis.” The doctors suspect it was related to Nadege’s type 2 diabetes, which she had had difficulty managing from the time she was diagnosed at age 28, nine years earlier. At the time, she was young, her career was on the right path and she had been feeling invincible. “The diagnosis felt like a death sentence,” she remembers.

Since being diagnosed, one of the most challenging things that Nadege has had to deal with is hypoglycemia, which she has experienced countless times. She would shake, start feeling cold inside and sense all her systems shutting down, like a computer closing down its programs. She began to get migraines, during which she experienced blinding flashes in her right eye. With a doctor’s advice, she would try different medications and eat according to the instructions she’d been given, but nothing seemed to help. She hated the incessant finger-poking. And she simply could not understand why diabetes had happened to her, despite her responsible lifestyle. She prayed to be healed.

“I thought I was probably a freak of some kind. People who knew about my condition pitied me. I hated it!” Nadege exclaims. “Since my prayers were not answered, I decided to ignore the disease and go on with my life.” This went on for nine years: starting a new regimen, hating it and then giving up. But emerging from the coma marked a true turning point. Nadege, now 38, describes herself as a new person, “always laughing and taking things slowly.” Here, she is writing to herself on that day, a year earlier, after she woke up in the hospital room.
Hi, Beautiful

How are you doing? I know, you feel overwhelmed. Take a deep breath. Don’t panic, stop worrying. No, you are not cursed. No, God did not forsake you. No, it’s not your fault. It was probably going to happen, one way or another. Especially since none of your relatives told you that diabetes runs in the family and that you should watch for it.

I understand; it’s so discouraging. But you know what? You are not alone. You can outsmart the disease. The changes it requires are truly not as complicated or hard as you might think! You can do it, baby girl. You are a fighter!

There will be a key person to help you – a certified diabetes educator and a pharmacist. She will explain how the disease actually operates in your body and how your body reacts to food and your medication. Everyone’s body is different and it appears that everything you were doing before was completely wrong.

You will begin reading food labels and learn to avoid the foods that are bad for you. You will become more active, and focus on being healthy rather than the disease. Staying in touch with the pharmacist, even outside of your appointments, will be an enormous help.

All of this will show you that you can live without headaches, without feeling nauseated, without hypoglycemia. You will have to go through several regimen adjustments before you find out how to avoid hypoglycemia. But eventually it will not be an issue. Also, there are people working very hard to develop new technologies and better medication to help you control the ups and downs.

You can start working again. You are almost there. You just need to keep pushing a little bit further. You could have died, but God did not allow it, so you should not fear anymore. Take control of your life, as you can once again be on top of the world!

You can do it, Princess!

I love you.

Me

“You can start working again. You are almost there. You just need to keep pushing a little bit further”
Renira

Renira, a composed, thoughtful 32-year-old, was born in South Africa, grew up in Winnipeg, Canada, and currently lives and works in downtown Toronto, Canada. The daughter of a physician and physiotherapist, she was encouraged to go to medical school. Instead, she has achieved three Master’s degrees in journalism, occupational therapy and public health.

“They all sort of happened naturally,” explains Renira. “No one plans three Master’s degrees.”

However, that unlikely trio of scholastic achievements has brought her to a position that uniquely draws on all three disciplines. She is a “knowledge translator” for an academic hospital, which means that she helps move scientific discoveries into widespread practice in medicine and elsewhere. And Renira doesn’t stop there; she works on her own projects and uses spoken-word poetry, storytelling and public speaking to further her reach.

This degree of self-actualization seemed improbable ten years ago, when Renira’s own health changed dramatically. Her father died very suddenly in a freak accident when she was 20. Two years later, feeling that she had already lived through the worst part of her life, she began losing weight rapidly. Her stomach started churning in unfamiliar ways after each meal. She had just started the occupational therapy program at Western University in London, Ontario, Canada. At her friends’ urging, she consulted a doctor, who diagnosed her with type 1 diabetes.

It didn’t feel particularly life-changing. She learned how to count carbohydrates and take insulin, and started doing it while continuing with her studies. The diagnosis and insulin seemed to help, but, almost as if life was spiteful towards her positive attitude, things took a dramatic and unexpected turn for the worse. She began to experience strange sensations. Neuropathic pain made it impossible to sleep; she would pace her apartment all night. Her resting heart rate was above any level she knew was normal. And then her stomach started acting up. She didn’t feel like eating anything. It became too difficult to go to lectures, participate in labs and study for exams. In December, Renira asked to take a year off from school to go back Winnipeg, where her family lived. She had no idea what was going to happen. She writes back to her younger self at this time.
Dear Renira

You think you are dying. There is not much more your 80 pound body can take. The doctor told you as much, but you can see it for yourself in the way your paper-thin skin wraps itself tightly around your clavicles. In the way hollows have dug themselves around sockets that used to house determined eyes. In the way your mom rushed home when you didn’t have the energy to pick up the phone. She thinks you might die, too.

You want to give your stomach sustenance, but you haven’t eaten in months. You’re not sure how you ever could again. The acid-and-bile mix that comes up persuades you it is dangerous to try.

You think you are dying, and you’re not sure what to do. You have never been in so much pain, never truly known what it is to be helpless. There is no joy in lying on the couch all day and watching movies you are not even paying attention to.

You compare this pain to the pain your dad must have felt. He was always so composed, articulate, and jovial. You were all these things, too, and you know how quickly this can change. It is your biggest fear not to be who you are.

When people ask you how you got better, it will be okay that you can’t really explain. Doctors couldn’t give you a definite answer, either. You will say that your body probably needed time to adjust, that all the sensations you felt were probably related to those adjustments and to blood sugar levels and stress. But you will never know for sure. Just be glad that you got better!

You will have days where you forget what you went through. I want that for you. But be careful with your carb loads and remember that insulin is not a cure that lets you eat whatever you want. You will have that cheesecake once in a while, but please don’t make it a weekly habit and load up on insulin to compensate—you could develop a pattern of high and low blood sugars, and create future damage for which there will be no compensation.

Think of insulin not as a burden but as a backseat passenger in the vehicle you will use to drive through this life. Get to know it. Understand what makes it cooperate with you and what makes it go rogue. Learn to work together and do it soon. The road will never be even, but you have so many places to go.

Let’s keep driving,

Renira

“Think of insulin not as a burden, but as a backseat passenger in the vehicle you will use to drive through this life”
When Rishma moved from Tanzania to Toronto at age 12, she had no idea that a huge chunk of her young adult life would be spent serving as a caretaker to her father, who has type 2 diabetes, as well as a number of other health challenges. Not surprisingly, being on the cusp of adolescence, she was most concerned about trying to make friends and fit in to her new country, so she wasn’t really paying attention to her father’s first battle with cancer, which happened when she was 13.

But she was 22 during the second bout, and it made an indelible mark on her. Midway through his treatment he landed in the ICU with pneumonia. His organs were failing, and his family had said their goodbyes and were trying to arrange his funeral. After 27 days in the ICU, a last review of her father’s bloodwork before turning off the breathing machine showed great improvement. He turned the corner and survived. That day happened to be Rishma’s birthday.

“That is when I realized how important my dad was to me, and I honestly still think God heard all our prayers and gave me a special gift,” she says.

That day also was the beginning of Rishma’s role as a caregiver, alongside her mother. A year later, her father was diagnosed with type 2 diabetes and bronchiectasis, which is a chronic lung condition unrelated to his diabetes. Today Rishma is 40 years old and writing to herself at 23, after learning that her father had these two new health problems.
Dear Rishma

You think that your life has already been deeply affected by watching your father narrowly escape death. But now, with his two newly diagnosed conditions – type 2 diabetes and bronchiectasis – your life is going to be very tough for quite a while. Your caretaking role will intensify. And that’s not all. Because your mother has been traumatized by what your father has gone through, she often feels depressed. When your father suffers any health emergency, small or large, you are going to be the first line of defence.

In one sense, this is fine. It’s part of your culture to take care of your parents. But Rishma, unravelling your father’s health issues will be like untangling a bird’s nest.

One of the most difficult aspects of caring for your father will be his temper. His outlook will grow very dark. He will become quick to anger and refuse to talk to you. Or he’ll fight with you and be very dramatic. This hurts your feelings. His mood swings will be so intense that you will wonder if he is bipolar.

What I suggest? Educate yourself now about all of his conditions, particularly diabetes. I know that navigating the healthcare system is difficult and you won’t always find timely support. But if you keep researching, and talking to doctors and pharmacists, you’ll find more information.

Use your own power of observation, too. You will realize that your father’s mood swings are as a result of low blood sugar. He is very frightened about his health conditions, but tries to act tough. He can get angry if he doesn’t notice drops in his blood sugar levels, causing him to become mean and say hurtful things. These hypoglycemic episodes could be avoided if he tested his blood sugar more frequently, but he can be stubborn and unwilling. If you bring the testing kit over to him, he will do it. Then you can give him his tablets or fruit, and 20 minutes later he’ll be happier. Your father could choose other medication options for his diabetes, but he’s willful, worried about the cost and wants to stick with tablets. Still, keep trying.

And Rishma, you have a life to lead as well. Don’t be afraid to find your independence, move out of your parents’ home and have a boyfriend. You can still be very involved and helpful by taking your mother and father to their appointments. Being in a constant state of vigilance is wearing. It will do you a world of good to be able to confide in someone else.

With respect,

Rishma

“Educate yourself now about all of his conditions, particularly diabetes”
Sometimes the most exhilarating changes in life coincide with the most daunting developments. That’s how it was for Warren just two years ago, when he was 31. Change number one: he was promoted into a new area – quality assurance – with a new boss at the bank where he worked. A second, even more thrilling milestone was his upcoming marriage to Jessica, a young woman he had met at a previous job. Just three months before that important ceremony was to occur, a third, life-altering event landed with a thud. After a routine physical, he learned he had type 2 diabetes.

A new role, a new boss, a new marriage and, suddenly, a new struggle: diabetes. Having grown up in an active, healthy family, and having participated in competitive cheerleading from high school up to the age of 26, Warren was shocked and embarrassed by the diagnosis. How could he possibly tell everyone, he wondered? How could he have let himself get to this point? He confided in his fiancé, and she supported him. But he couldn’t bear to tell the rest of his family.

Warren is writing to himself after the diagnosis.
Dear Warren

Congrats on the upcoming wedding! It’s going to be everything you wanted, and more. Your family, being big and very loud, will hijack a few moments. But honestly, when do they not? You are so concerned with making sure everyone else is being taken care of that you might forget about yourself. Please, please, please make sure to focus on you too, because the doctor has given you news you should absolutely not ignore. You’ve got type 2 diabetes. You need to make some changes to get it under control.

I know how you feel. You’re ashamed. YOU have let this happen. You have messed up. You are at fault. You have let everyone down.

You are pretty sure you know what will happen if you tell your family. There will be shock and concern, but most of all, disappointment. They’ll have questions: where did you go wrong? Are you watching your diet? Are you exercising often enough? And they’ll have answers, too: you should probably just lose some weight and everything will be okay. The list of reactions could go on and on, but the only thing you know for sure is that you feel like you have failed. You’re experiencing overwhelming guilt and anxiety. You need to look at these feelings and realize they do not define you. They are not the rest of your life. You can deal with this, and thrive, but you’re going to need help.

Jessica will be your rock. Trust her. Confide in her. She will give you more hope than you can possibly muster on your own. Don’t be afraid to tell people about your diabetes. Most of them will be curious and want to talk about it. Every time you talk to someone new, you’ll feel a little bit better and more positive. Seek out opportunities to speak to others with type 2 diabetes. You will find comfort, knowing that they will not judge you.

You’re going to learn a ton, use the new knowledge, then ignore it, struggle a bit and then get back on the right path. In fact, accepting the changes you need to make won’t be all that difficult. The bigger challenge will be telling your family, which you and I still have not done, two years later. Why? You’ve always felt that you aren’t a perfect fit with the rest of your family. You are large and dark. They are blond and thin. If they learn you have diabetes, it seems as though it will make you even more the odd one out.

Muster the courage to share your condition. It would lift a huge weight from your mind. Secrets can be even harder to bear than health setbacks. Enjoy the wedding and dance the night away. Cheers,

Warren
There are plenty of occupations that can make it hard to eat properly, exercise and comply with a medical protocol. But it’s difficult to imagine a job and lifestyle that will make this harder than working in a carnival. Yet that’s exactly what Wayne was doing for years, crisscrossing the U.S., after he was diagnosed with diabetes at age 31.

“I didn’t exercise and I ate what I wanted,” he recalls. “I thought things were okay and I never paid much attention to my health.” At first Wayne took pills for his condition. At age 39 he added insulin to his treatment plan, but he continued to be casual about his health, rarely checking his blood sugar and eating in an undisciplined way. He was warned about the long-term complications that could come with diabetes, but dismissed them. He says: “When I was younger, I thought, ‘Yeah, yeah. I’ve heard those stories, but I never really thought it could happen to me.’”

Now 57 and living back in Canada, his native country, Wayne has grappled with a cascade of long-term complications that affect his vision. He didn’t heed the first warning; at age 44, when he was driving away from the carnival in the evening, he hit a telephone pole, putting a significant dent in his truck. Though unhurt, he was perplexed because he had always been a good driver. A year later, he discovered the cause – he had a cataract in his right eye.

The cataract was surgically removed. He didn’t realize that it was a result of his diabetes until four years later when he had a medical exam, which was required in order to obtain a special driver’s licence for work. At that point he also discovered his HbA1c was 11.

Worse, his vision problems continued. He developed a cataract in his other eye and had it removed. He began getting monthly or bi-monthly injections in his left eye and occasionally in his right. He also had a retinal peel on his left eye. Not surprisingly, he became very fearful of going blind.

In recent years, Wayne has finally become more proactive about his health. However, his shift work at a shelter has wreaked havoc with eating well-timed meals. So he has worked with his healthcare professional to find an insulin treatment regimen that best suits his job and lifestyle, and also gotten a continuous glucose monitor that helps him understand the patterns of his blood sugar levels.

“I can always do better at eating regular and healthy meals and managing my diabetes. At the same time, I’m doing quite a lot compared to earlier in my life, because I now know how vital it is to look after my health,” he says. He’s currently completing a Master’s in social work, aiming to become a trauma therapist who works with marginalized people. Wayne chose to write to his younger self at age 44, when he was driving away from the carnival, headed into bright sunlight, and suddenly crashed into a telephone pole.
Dear Wayne

What? You hit something with your truck – something you didn’t even see? Impossible. You are such a good driver, but you’ve just gotten out of the truck and seen a big dent in it.

It would be easy to put this incident behind you and never think of it again. But Wayne, I want this to wake you up! Your health is vitally important. That accident was due to a cataract, a complication related to your diabetes.

I know that no one in your family ever stressed the importance of keeping fit – just the importance of a good education. I know that it’s easy to put off fitness and eating right as something to worry about tomorrow. I hate to have to tell you this, but someone has to: those long-term “complications” they told you about regarding diabetes are real. And some of them are headed right your way.

Frankly, they will be frightening. As a visual person who has a near-photographic memory, the idea of losing your vision is particularly terrifying. You’ve always loved learning new things, so reading, of course, is critical to you. You will also fear having strokes, like your father did. He didn’t have diabetes, but you worry that you have inherited a predisposition for a stroke, which can also be a result of uncontrolled diabetes.

So, don’t just go with the flow. If you just do a little bit more each day to remain active, you can maintain your fitness levels. Eat better with simple choices. Monitor your diabetes. It’s hard but you are worth it. I know you can do it!

Goodbye for now,

Wayne

“As a visual person who has a near-photographic memory, the idea of losing your vision is particularly terrifying”
As a young doctor, I conducted my first ever diabetes clinic in July 1977 and from that point on I was “hooked” by the specialty! Over the next 40 years I saw not only an unfortunate increase in the number of people with type 2 diabetes but also many beneficial changes in the overall treatment approach. Over that time, there have been huge advances in clinical research and consequently a much greater focus on preventing long-term complications, which can result in morbidity and mortality. Individualized care (a truly patient-centred approach) is now accepted as the key to effective diabetes management and achieving better outcomes in people with type 2 diabetes.

From a blood glucose (blood sugar) control perspective, there has been a dramatic increase in the range and quality of therapies available, both oral and injectable, and improved technology has enabled better delivery devices and monitoring systems. These advances have resulted in therapies which not only help to successfully manage blood glucose, but are better tolerated, with lower risks of hypoglycemia (low blood glucose/sugar) and weight gain compared with traditional therapies. Some have been shown to reduce cardiovascular events and mortality in people with type 2 diabetes at high risk of cardiovascular disease. Indeed, we have come a very long way; and in 2021 we will celebrate 100 years since insulin was first produced. However, there is still much work to be done! Currently, only a small percentage of people with type 2 diabetes achieve all their treatment targets and live a life free from diabetes-related complications.

One of the biggest challenges I face as a physician is the concerns that people with type 2 diabetes often have about starting insulin. This is largely due to the anticipation of negative side effects (e.g. hypoglycemia, weight gain) and the feeling that a need for insulin is an indication of “failure”, and that starting it will further adversely affect their quality of life leading to negative implications for family and work relationships. These concerns can lead to long delays in starting insulin, prolonged poor control and therefore increased risk of complications (e.g. eye disease, nerve damage, kidney failure and cardiovascular disease). The key to improving this situation must include better and earlier education for people with type 2 diabetes.

If I could write back to my younger self, I would particularly reinforce the importance of having open conversations (including soon after diagnosis) with my patients about starting insulin. I would highlight that given the progressive nature of type 2 diabetes, insulin therapy will be required in most cases in order to maintain good blood glucose control in combination with a healthy diet and exercise. I would emphasize that starting insulin is not an indication of failure, and that it can be an important step in the treatment pathway with the potential for clear health benefits. If the individual and their healthcare professional work together and demonstrate commitment to managing type 2 diabetes, starting and progressing insulin treatment does not need to be difficult.
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