

Fried Chicken, an Airport Ride, and Why Diabetes Is So Hard

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About a year ago, I had one of those moments that stops you in your tracks. I still haven't forgotten it.

I was on a ride to the airport when the driver, a man I'll call Sam, asked me what I did for a living.

"I write about diabetes," I said.

There was a long pause, and then Sam admitted he had diabetes. I immediately began asking questions to learn more about his story. It was heartbreaking to hear, and even though I live with diabetes myself, Sam reminded me why managing it can be so hard. I have not been able to get his story out of my head, which is why I'm sharing it now.

Sam's journey highlights six diabetes challenges, all of which are frustratingly common: lack of blood sugar data, low motivation, judgment/failure, lack of support from loved ones, a challenging food environment, and uncoordinated care. Using some of the tips proposed below, I hope we can start to address these challenges as a community.

Sam's Story: What's So Hard About Diabetes?

Sam was diagnosed with diabetes 16 years ago. He took pills for years and resisted going on insulin for a long time. When we spoke, he was taking NPH and fast-acting insulin twice daily, using a sliding scale to determine the dose; it didn't matter what he had eaten.

Sam only checked his blood glucose twice daily. He said his A1C

"once got down to 8%," but he recently had several weeks of blood sugars "way off the range." He later clarified that he meant "over 300 mg/dL" for weeks straight (roughly equating to an A1C of ~12%). Sam had already developed some kidney problems and, more recently, issues with his feet. He's only in his 40s.

"I love fried chicken and eat it every single day," Sam told me. He later added that he frequently drinks regular soda, snacks on chips, and eats too many sweets. Sam also said he likes salads and knows he should eat them more often.

Exercise is also difficult; Sam is overweight and drives a cab for 10–14 hours per day, leaving little time for movement. Sometimes, he works late nights and sleeps most of the day. He loves basketball and used to play a lot, but now he says it's too painful to run down the court.

Sam's insurance is through the Kaiser Permanente managed care organization, and he does see his primary care doctor regularly. A pharmacist mostly helps him with his diabetes and insulin doses, often by phone. At a recent appointment, Sam's primary care doctor didn't even realize he was on insulin—and he had been taking insulin for 2 years!

"Diabetes can be depressing," Sam told me. "To feel like you have done everything right and still get a 225 mg/dL on the meter." He said he "never" talks about diabetes with his wife, even though he believes she wants to be supportive and helpful.

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Sam said his son “gets all over him” about his lack of exercise, which only makes him shut down. “I can’t deal with it,” he told me.

I asked Sam one of my favorite questions: to identify his Bright Spots. “When things go well with your diabetes, what do you do?” He didn’t hesitate: “I cut back on my eating and stay away from the soda and sweets. That’s when my blood sugar is in the 70-, 80-, 90-mg/dL range.” The hard part, he admitted, is actually doing those things consistently.

I sat in the backseat racking my brain for tips that would be realistic, actionable, and not too paternalistic. Because I live with diabetes myself and write about it full-time, I felt a duty to share *something* useful. But I knew I had to deliver any advice gracefully—a tough balance.

Then I ran out of time.

We got to the airport, Sam thanked me profusely for sharing the ride, and I got his business card to stay in touch. I brainstormed tips for him all weekend and then sent him an email with the three most important things I could think of:

1. Find ways to drink less soda. I gave him a bunch of ideas, like not having it in the house, pouring out half the can before drinking it, or buying sparkling water and adding a lime instead.
2. Figure out why caring for your diabetes matters to you TODAY. For example, more energy to play basketball with his son or a better mood when talking to his wife.
3. Check your blood sugar 2–3 hours after meals to learn how different foods affect you.

I received no response.

I sent a follow-up email a week later, checking in and asking if he had received the note. “How can I be helpful?”

No response.

I sent another follow-up email a month later. Dead silence.

This bothered me greatly because I believe people can change if only they

are given the right information and experiments to try. But perhaps Sam’s response isn’t surprising; during our ride, he was hesitant to even admit he had diabetes, perhaps because he’s ashamed of it.

I think there are a lot of lessons from this story, and there are things we as a community can try to help in such cases. What follows are some recommended tips, coming from my perspective as someone living with diabetes.

What Can We Learn from This Story?

Challenge 1: “Avoid long-term complications” is not a motivator for Sam—or for many other people with diabetes. Why should Sam care about his diabetes and do something about it?

Diabetes has a time perspective problem; it requires sacrificing short-term pleasure (e.g., tasty food) for long-term gains (e.g., good health). Some people are good at making this tradeoff—what psychologists Phillip Zimbardo and John Boyd call “future-oriented” individuals (1). People who have this time perspective find it easy to save money, exercise, or go through the daily diabetes hassles to avoid long-term complications. But not everyone is like that. Those who tend to be more “present-oriented” may not see “avoid long-term complications” as a good motivator. Instead, they often prioritize the present moment, which can lead to counterproductive health decisions (e.g., eating junk food or smoking). I suspect Sam is more present-oriented, which means he needs a different motivation approach that focuses on the now.

• **Tip 1: Appeal to today and now.** When Sam makes unhelpful food choices and has high blood sugars, he might notice something: he has less energy, doesn’t think as well, may have mood swings, and probably has to go to the bathroom more often. How does he act or feel when his blood sugar is out of

range? I’ve found that taking care of my diabetes *today* makes me a better person *today*; that’s something even present-oriented people can get behind. For care providers, ask your patients, “How does an in-range blood sugar benefit you *today*?” Ask patients to pair how they feel and act with what their blood sugar actually is. What patterns emerge?

- **Tip 2: Appeal to emotion.** Instead of offering an intellectual reason to care for diabetes (“to avoid long-term complications”), how about a deep emotional one? Why should Sam take care of himself? Does he want to be able to play basketball with his son, take long walks with his wife, or go on that adventure vacation he’s always dreamed of? These heartfelt reasons to prioritize diabetes are easier to remember and may be more compelling than the typical “long-term” motivators.

Challenge 2: Diabetes is an invisible disease, and checking blood glucose twice per day doesn’t give nearly enough feedback.

Sam has no idea what is happening to his blood sugar after different meals or during the middle of the day. That means his mealtime insulin doses are a shot in the dark, and he receives little feedback on his diabetes decisions. It’s like driving a car with a blacked-out windshield.

- **Tip 1: Check blood glucose more often to make diabetes more visible, especially after meals.** For example, Sam could check his blood sugar before and after breakfast for a week, then before and after lunch for a week, and then before and after dinner for a week. Better yet, his health care provider (HCP) could lend him a real-time continuous glucose monitoring (CGM) device, which would provide even more and better information.

Sam needs to see how different meals and insulin doses are affecting

his blood glucose; twice-daily checks won't teach him nearly enough and, arguably, won't teach him anything at all. One of the biggest advantages of blood sugar data is learning to pair cause and effect: "When I drink soda, my blood sugar goes high. When I drink water, my blood sugar stays on target." As a person with diabetes, my own data can be very motivating and instructive. However, I needed to be taught *when* and *how often* to capture that data. For someone on insulin, it should certainly be more than twice per day.

- **Tip 2: Teach people with diabetes why the numbers matter, what the numbers should be, and what to do with their data.** Often, people with diabetes aren't told what a high number means or what to do about it. Even worse, many diaTribe readers email me asking what their blood sugar should be; they've never been told their target range! (Many professional associations recommend 70–180 mg/dL; I tend to aim for a slightly tighter 70–140 mg/dL because I have CGM to help guide me.) When Sam gets a high blood sugar reading, he needs to understand that there is a menu of options to bring it back into range (e.g., take additional insulin to correct it, go for a walk, or eat fewer carbohydrates at the upcoming meal). If we agree that glucose data are valuable for people with diabetes, we must also give them *specific* guidance on what to do with those numbers.
- **Tip 3: Use professional (retrospective) CGM if real-time CGM is not an option.** Sam could wear a professional CGM system (e.g., Abbott FreeStyle Libre Pro, Dexcom G4, or Medtronic iPro2) for a short period of time, allowing his HCP to collect 1–2 weeks of glucose data passively. Once data are collected, Sam and his HCP could review the data *together* (and without judgment!) to uncover patterns during the day and over-

night. When is glucose going high or low, and why might that be? HCPs often report that data collected via professional CGM and displayed graphically (by time of day) is an amazing teaching tool.

Challenge 3: When blood sugars are out of range, people with diabetes are made to feel like failures. Blood sugar data are neutral pieces of information used to make a decision, not a "grade" or "test" or judgment on performance.

When Sam said, "Diabetes can be depressing," he was sharing what many of us with diabetes feel—like we are a failure when the number on the meter isn't what we expect. I've done some work in diaTribe showing that more than 22 factors influence blood sugar, many of which are impossible to track and adjust for (2). As a diabetes community, we have to get over attaching blame and judgments to glucose data. To make this point, I often use the analogy of flying a plane. No pilot in the world views a plane's GPS and speed readings as a value judgment: "You are a bad pilot." The plane's current location and speed is neutral *information* to drive an action: change the way the plane is flying. Let's use blood sugar data in the same way.

- **Tip 1: Use "check" instead of "test." Frame glucose data as a helpful diabetes partner.** HCPs must emphasize that more glucose data means more information to make decisions and learn. When people with diabetes feel that each glucose check is a test, and the grade is an F, they may check less often, which is counterproductive. The more we can remove judgment and blame, the better off we'll be.
- **Tip 2: Do not simplify diabetes to "food, exercise, and medication." It downplays the complexity of the many factors that influence blood sugar.** Reassure your patients that "not every single high or low blood

sugar is your fault or even possible to understand." Share my article, "How Many Factors Actually Affect Blood Glucose?" (available from www.diaTribe.org/factors and summarized here in Figure 1) with patients as a starting point for understanding the complexity of diabetes and blood sugars.

Challenge 4: Many people with diabetes feel too embarrassed or ashamed to seek support from loved ones.

Some of this relates to stigma, shame, and blame. Sam may feel like he caused his own diabetes, so he should be the one to fix it. For those of us living with diabetes, we might also worry about burdening our loved ones with our issues; this leads us to try to take on diabetes alone.

- **Tip 1: Family members can be an amazing source of support, guidance, and diabetes help. However, they may not know what to say or how to be helpful.** Candid communication is key, and it only takes a simple question and a bit of vulnerability: "I notice that sometimes diabetes is a hassle for you, and I'd love to be helpful, but I'm not sure what to do. How can I make diabetes easier for you? What should I say or do when your blood sugar is high or low? What do I do that is unhelpful?" Notice the neutrality here and the use of questions, which allows the person with diabetes to set the terms of engagement. Personally, I also find it useful when there is a specific plan in place with a loved one (e.g., we go for a walk after dinner when my blood sugar is high).
- **Tip 2: The person with diabetes should feel empowered to enlist loved ones for help.** Living with diabetes, I want to feel strong and independent ("I got this! I don't need your help!"), but obstinacy carries no badge of honor. It's amazing what can happen when loved ones are even slightly

FOOD	BIOLOGICAL
↑↑ 1. Carbohydrates	↑ 11. Dawn phenomenon
↑ 2. Fat	↑ 12. Infusion set issues
→↑ 3. Protein	↑ 13. Scar tissue and lipodystrophy
→↑ 4. Caffeine	↑ 14. Insufficient sleep
↓↑ 5. Alcohol	↑ 15. Stress and illness
MEDICATION	↑ 16. Allergies
→↓ 6. Medication dose	↑ 17. A higher glucose level
↓↑ 7. Medication timing	↓↑ 18. Periods (menstruation)
↓↑ 8. Medication interactions	↑ 19. Smoking
ACTIVITY	ENVIRONMENTAL
→↓ 9. Light exercise	↑ 20. Expired insulin
↓↑ 10. High-intensity and moderate exercise	↑ 21. Inaccurate BG reading
	? 22. Altitude

■ **FIGURE 1.** Based on personal experience, conversations with experts, and a literature review, this is a partial list of factors that can affect blood glucose. They are separated into five areas: food, medication, activity, biological, and environmental factors. In most cases, the arrows show the general effect these factors have on my own blood glucose (a sideways arrow indicates a neutral effect), but not every individual will respond in the same way (and even within the same person, things may be different from day-to-day or over time). Certain factors may also apply more to type 1 than to type 2 diabetes (or vice versa). Factors with up and down arrows are, of course, the most challenging; they sometimes increase blood glucose and sometimes decrease it. The best way to see how a factor affects your patients is through their real-world experience of checking their blood glucose more often or wearing a CGM device. What patterns emerge in the collected glucose data, and what factors could be driving those patterns? Explanations behind each factor can be found at www.diaTribe.org/factors. BG, blood glucose.

involved in my diabetes—lifting my spirits when the meter number is unexpected, substituting green vegetables for higher-carbohydrate side dishes, buying less junk food, and taking walks with me when I'm frustrated. This quote from Dr. Brené Brown's *The Gifts of Imperfection* (3) summarizes things beautifully: "Somehow, we've come to equate success with not needing anyone. Many of us are willing to extend a helping hand, but we're very reluctant to reach out for help when we need it ourselves. It's as if we've divided the world into 'those who offer help' and 'those who need help.' The truth is that we are both."

Challenge 5: Food environment + human biology hardwired to love junk food + sedentary lifestyle = super challenging to make optimal food choices and be active.

It's easy to blame people like Sam for their "lack of willpower," but he has to overcome built-in cravings for junk food, sugar's addictive call, an environment that encourages truly unhelpful choices, and a society that has designed itself to avoid activity.

• **Tip 1: Encourage patients to make changes to their environment; these are often easier than summoning willpower.** Decades of psychological research have proven that we are all influenced

by subtle cues in our environment that can work both for and against diabetes management. For someone like Sam, it could mean having a case of water bottles in his car, so his default option is not soda. It also might mean having plenty of seeds, nuts, berries, vegetables, and other low-carbohydrate snacks readily available in his car, so he is less likely to stop and purchase junk food. Even using smaller cups and plates counts as an environment change. In essence, this is about making better choices the automatic, default option and making undesired choices more difficult.

- **Tip 2: "Moderation" doesn't work for some people. "Black & white" rules are sometimes far easier to follow, particularly with unhelpful foods.** There is a tendency to tell people to "moderate" what they eat and to "cut back" on sugar or desserts. Animal research suggests that sugar is as addictive as many hard drugs (4). If that is true in humans, and some believe it is, isn't moderation an absurd concept? We wouldn't tell smokers to moderate their cigarette consumption or drug addicts to moderate their use of cocaine; we would tell them to quit. With this in mind, maybe we should stop over-prescribing moderation and focus on what Chip and Dan Heath call "black & white" rules such as "I don't eat cake," "I don't eat chips," or "I don't drink regular soda" (5). For me, it's easier to have a "no" policy than to have a "yes, but in moderation" policy. If I have one "hit" of junk food, I'll often eat the whole package and then wallow in shame and frustration.
- **Tip 3: Ask about sleep.** The research on sleep is staggering. Studies repeatedly show too little sleep is associated with higher A1C and blood glucose levels; greater insulin resistance; more hunger, calorie consumption, and

carbohydrate cravings; weight gain; higher levels of depression; lower quality of life; and more. A slew of biological changes occurs with too little sleep, including higher levels of cortisol (indicating stress), increased inflammation, and changes in hunger hormones, which can all contribute to greater insulin resistance and higher blood glucose (6). When I make bad food decisions and am tempted to overeat, it's often because I didn't get at least 7 hours of sleep the night before. I didn't ask Sam about sleep, but boosting his hours in bed might also help reduce sugar cravings, improve his insulin sensitivity, and even increase his willpower.

Challenge 6: Many patients still receive uncoordinated care from providers with few financial incentives to keep people healthy over time.

What is interesting in Sam's case is that his care provider (Kaiser Permanente) should have been providing the right incentives because it serves as both his provider and his insurer. I can only assume that the insurer 1) thinks Sam is doing fine, 2) has no idea Sam needs help, or 3) isn't supporting Sam with actionable lifestyle advice, the right therapies, and a feedback loop that responds to what he needs.

- **Tip 1: Embrace digital technology to make data collection easy, tighten feedback loops, and provide ongoing remote support.** The days of connecting glucose meters to cables, manually downloading them, and trying to make sense of the data should be over. Many Bluetooth- and cellular-enabled meters and CGM devices are now available, and these should be demanded by HCPs and patients, integrated into clinical practice, and fit into a more continuous care framework with remote monitoring. When Sam had several weeks of blood

sugars in the 300-mg/dL range, his care team should have been alerted, and he could have received a phone call, text, or video chat. (No, not a fax!) Meanwhile, Sam could be using an insulin dose titration application ("app") on his phone that would update his doses based on his pattern of high glucose levels. At least three basal-only titration apps have received clearance from the U.S. Food and Drug Administration: Voluntas' Insulia, Sanofi's My Dose Coach, and Amalgam Rx's iSage Rx. Basal-bolus titration apps are also in development from several companies. Managing diabetes at a population level—leveraging connected devices, algorithms, apps, and Cloud-based software—is possible and should be moving far faster. HCPs can embrace these tools, provide input on them, and test them in real-world practice.

- **Tip 2: Don't give up on people with diabetes. Is the conventional advice we're sharing actually effective?** Some might say that Sam is beyond help, but I think he is simply lacking tools, knowledge, and support. I've heard more than a few HCPs at conferences express fatigue and frustration with "difficult" and "nonadherent" or "noncompliant" people with diabetes. For those of us living with diabetes, this is hard to hear; we're often trying hard, but the tools, data, and support aren't meeting our needs or fitting into our life. Yes, we're absolutely personally responsible for doing better, but at the same time, a lot of the conventional advice we receive may need rethinking. When I was diagnosed with diabetes in 2001, I was told I could "eat whatever I wanted, as long as I took insulin for it." In my view, this is the *worst* advice to give to someone with diabetes because it's a blank check to continue eating the types of food that drive blood

sugar wildly out of range. For me, eating a low-fat (and therefore high-carbohydrate) American diet with diabetes was like pouring gasoline on a fire. It wasn't until I switched to a low-carbohydrate, higher-fat approach to eating that my blood sugars and diabetes burden radically improved (6). What's striking is how different the conventional advice was from what actually worked for me. Perhaps we should be reexamining a lot of our accepted wisdom, given how many people like Sam are still struggling.

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Duality of Interest

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