
NON-FICTION | SPRING 2019

Diabetes Diary

By Jonathan Garfinkel

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Earlier this year I joined the Facebook group “Looped”. With the help of two mothers of diabetic children and a fifteen year old diabetic girl, I built a DIY app on my iPhone, following the meticulous instructions posted on Facebook. I have never programmed anything in my life. I’m lucky if I turn my computer on properly. But thanks to a bunch of software engineer nerds in California and Minnesota, I’m living on an app with a sophisticated algorithm that adjusts insulin levels on my pump in real time, responding to the Continuous Glucose Monitor affixed to my abdomen. This DIY, bio-hack system, called, the “Loop”, is as close to an artificial pancreas that exists in the world. It is not government sanctioned but it is also not illegal since nobody is selling anything – it’s all open source. It’s also changed my life.

It’s been a wild experiment – as life with any chronic illness is, especially Type One Diabetes. I just moved to a cold city in Northwestern Canada, in the first year of a PhD. I decided to keep a diary for a year of living on this renegade system. What follows are excerpts from my “Diabetes Diary”. These are daily reflections on life with a chronic illness in 2019, an age when a patient can take illness into their own hands in ways never imagined.

October 27, 2018

If I had been born 100 years earlier I’d be dead.

Sometimes I like to imagine the children. Their tiny bodies reduced to coma. After months of struggling. Confined to single beds. Lying half-awake and dazed. The smell of urine and sweat and the metallic. The room is dark and the curtains are drawn and the nurses function at a glacial pace. Parents cry at bedside, the curse of bad genes. These are the rhythms of caring for the nearly dead, a slow withering.

Then, one day, four doctors arrive with needles and vials. They draw back their instruments and plunge liquid into the skin of children. Slowly they make their way through the ward. Like Lazarus rising from the dead, the children awake from their comas, one by one by one.

How do you live when you know your life is on loan? Sometimes it’s gratitude. Other times, total anxiety. The double bind: I wouldn’t be alive if it weren’t for the technology I’ve been given. Which also means I’m tied to the technology. As a teenage diabetic I would fantasize running away from home. But it was a challenging thing to dream up. Inevitably I would become bogged down by logistics: how many syringes and vials of insulin could I pack with me as I headed off for the hills toward the land of Bob Dylan and the Bohemian Drifters? Do

Bohemian Drifters take insulin and have three regular sized meals a day? And what about snacks? How much food could I pack in my rucksack?

When I was twelve years old, three weeks before my bar mitzvah, I was pissing like crazy. I was thirsty as hell and most of my days were spent navigating the nearest bathroom. I once recorded: I drank fifteen litres of liquid in one day. I pissed thirty-five times. I was on a family trip with my parents and two little brothers in Paris. My memory of the Champs-Élysées was not architectural. I can tell you: there were six public toilets. I zig-zagged my way from one urinal to the next.

At the Royal Free Hospital, surrounded by a team of grim British doctors, a curtain was pulled around me. They spoke to my father in hushed tones. Later he took me into the hall. It must've been the hardest thing for a parent to give a child: his life sentence. When he told me I burst into tears. I didn't know what diabetes meant. I just knew it was forever. Something in my body was telling my t-cells to attack my beta cells. I had become a foreign and hostile environment to myself.

If you had shown me, in 1986, a video of myself 33 years later, I would've been perplexed. Who is this man with tubes and wires giving himself insulin through a phone? How is it possible to check one's blood sugar from a watch? What does this man become with all of this technology? Has he grown into it, or has the technology grown into him?

November 1, 2018

When Loop works it's a green circle in the left corner of my iPhone SE. It's a reassuring image: the artificial pancreas is working. Below the circle is an amber graph with my predicted glucose levels, an orange graph with my former glucose levels. A small rectangle marks the algorithm's calculations.

It's not a perfect system. A mini-Bluetooth computer, called the Riley Link, often craps out. My iPhone doesn't always cooperate. When Loop doesn't work, the circle turns red, a symbol of negative capability, a point of frustration. "I'm seeing red," the saying goes, which means my cyborg existence is on hold, which is also a reminder of the imperfections of our technology: this extension of myself can drive me bananas.

But not all problems in the life of the diabetic are related to Loop. Sometimes it's a simple act of forgetting.

Tonight at 12.30 am my legs start to feel funny. I feel like I've run 20 miles. Then they seize up. A general sense of atrophy. I know this isn't normal, so I check my blood sugar and notice it's quite high – 14.7. I think, that's odd. I just swam 2000 metres, the Loop circle is green, all is good. Then I see that my insulin pump tubing isn't connected to my body. I haven't been getting insulin for hours. I forgot to reconnect the tubing to the catheter in my stomach.

I could end up in a coma.

I calculate that I'd been disconnected for nearly five hours – normally they say one shouldn't be disconnected for longer than 90 minutes. This has NEVER happened.

I know I'm in for a night of havoc.

I consider calling the hospital.

I consider calling a friend.

Instead I reconnect, take some extra insulin and hope for the best.

Because my insulin is delivered through the pump and takes two hours to peak, when I'm disconnected it has a delayed affect. I know my blood sugar will rise over the next few hours. The Loop – thinking I've been connected this whole time – doesn't know this. If I'm not careful I can go into ketoacidosis and possibly end up in a coma. Living alone in a city I don't know many people in, I feel vulnerable. I make some herbal tea.

I go to bed and set an alarm for 5. Topaz the Cat sits on my chest and purrs. Oddly enough my German translator Frank has left a message on Whatsapp saying we should talk, he wants to know when the novel will be done, the German publisher is asking. I'm months away from completion.

I think about the strangeness of having a translator in Germany, also a type one diabetic, calling me on Whatsapp and leaving a phone message in the middle of the night (his day), a night when I feel closer to death than I have in some time. I care about Frank; he knows me intimately through my writing. I think about the time he had a low blood sugar at his country house because Hinrich had mis-timed the pasta and Frank, the orderly German that he is, had injected himself for the precise moment he thought dinner would be ready so his Novorapid would peak in time for his carbs. But Hinrich was twenty minutes late, Frank went low, and I could see the shame in his face. He didn't want anyone to worry about him, but he also wanted everyone to worry, because he needed to eat or else die. Hinrich apologized, brought him bread and jam, and like a hungry dog Frank went after it, after which he had to go to the couch and lie down. Dinner was ruined, as we say, though Hinrich and I did enjoy a very nice Barolo along with the pasta.

It was strange to watch Frank experience a low blood sugar, something I've experienced countless times. I felt like I was looking into a mirror. There is something desperate and animal-like about the low blood sugar, something uncanny, I thought, yourself but not yourself, a stranger in your body. Then I thought of Freud's essay, which I happened to be reading at the time, and Heidegger, who took the uncanny from the place of psychoanalysis into the realm of ontology, and then I wondered, which one is right? Then I started to wonder if I was having a low myself, if Frank's low from several months ago was somehow passing over to me, from German to Jew, across continents and oceans via Whatsapp, and then I thought, shut up, go to sleep, this is nonsense.

When I awake I check the numbers on my phone: 7.0. By 10 AM I am at 5.5. The green circle glows in the corner of my phone. The Loop says, “Everything is normal.” And it is, as though nothing happened.

Jonathan Garfinkel is a writer whose work has been translated into twelve languages. He is the author of the book of poems *Glass Psalms* (Turnstone Press, 2005) and the chapbook *Bociany (Storks)* (KFB, 2017). He has written numerous plays including *The Trials of John Demjanjuk: A Holocaust Cabaret* (2004), the Governor-General shortlisted *House of Many Tongues* (2009) and *Cockroach* (2015); they have been produced throughout Canada, Germany, Russia and Ukraine. His memoir *Ambivalence: Crossing the Israel/Palestine Divide* (2008) was published in five countries to critical acclaim. He is also an award-winning non-fiction writer and has been anthologized in *Cabin Fever: The Best New Canadian Non-Fiction*. His first novel *The Altruist* is forthcoming from House of Anansi (2020). Named by the Toronto Star as “one to watch,” Garfinkel is currently doing a PhD in Cultural Studies in the field of Medical Humanities at University of Alberta. Find more of his work at jonathan-garfinkel.com

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