

Beyond Type One

Lisa Hanimov

At first glance individuals may not consider living with Type One diabetes (T1D) to include a whole range of literacies, however in this article, Hanimov explains how T1D is innately and naturally a form of literacy. She shares how her *diabetes literacies* emerged overtime encapsulating new relationships, medical tools, and becoming self-aware to help support her health.

When I look at food, I don't mindlessly admire it and haphazardly get to shove it in my mouth. I see sugar, in the form of carbohydrates, plotted on a multidimensional graph with proteins and fat and serving sizes and sickness and exercise and needles piercing into my triceps. I didn't always do this. Before I received the diagnosis that I had Type 1 diabetes (T1D), I saw food as food and ate it as such—simply, casually, with no real thought attached. The spring of my third-grade year, during my first Florida comprehensive assessment text (FCAT), I began to drink an excess amount of water—not because I was nervous about testing, but to fill my quench for thirst that was never satisfied. The mass consumption of water lead to my bladder always being full, which meant I became familiar with using the restroom. The deciding factor was when I no longer could contain my bladder and woke multiple times throughout the night to urinate. Thirsty, hungry, and tired, I began to put on weight which was unusual since I was eating well balanced meals along with getting regular amounts of exercise. On March 9th, 2010, it was decided that I would be admitted into the hospital, and since that day, I would have to forever execute formulas, memorize where to

Literate Activity

In his article, “Unraveling “Writing”:
Interweaving Maverick Literacies
Throughout a Literate Life,” in
the spring 2021 issue (11.2) in the
Grassroots Writing Research Journal,
Kevin Roozen explains that Paul
Prior developed the term “literate
activity” (1998, p. 138) to describe all
of the many ways that texts are part
of people’s lived experiences in the
world. It extends beyond our typical
ideas about “reading” and “writing”
to include the broad range of
practices and processes we employ in
the creation and use of a wide array
of texts.

give myself injections, and grasp the function of machinery to give myself the ability to live a considerably normal life.

For readers of the *Grassroots Writing Research Journal*, an article about living as a diabetic might not seem, at first glance, to be very connected to studying literate activity. But the fact is that to live with Type 1 diabetes is to become aware of, and involved in a whole range of new literacies. In the remainder of this article, I’d like to share a description of how my *diabetes literacies* have emerged over time. These literacies include awareness of my symptoms, reading and understanding information about my condition, and using a range of medical tools to help support my health.

To live with Type 1 diabetes, I have to be constantly aware of my insulin, a hormone produced in the pancreas that unlocks your cells so they can use the energy in your food, which circulates in your blood as glucose. A healthy person’s pancreas pumps out insulin in exact, perfect doses, masterfully managing the level of available glucose so that it never rises too high, which could lead to many complications, or too low, which could kill you on the spot. My pancreas, however, doesn’t make insulin. It can’t. For reasons no one can fully explain, my own immune system killed off the Beta 2 cells that produce it. That’s what Type 1 diabetes is—an autoimmune disease in which your body turns against itself. It’s frequently confused with the more prevalent form of diabetes, known as Type 2, but the diseases are not the same. Unlike Type 2, Type 1 diabetes can’t be prevented or managed with diet, exercise or oral medications. Instead, it requires artificial insulin, through injections, not pills, to stay alive. Before insulin was discovered in 1922, Type 1 diabetes was a terminal disease. Today, artificial insulin means that a Type 1 diagnosis is not a death sentence. But living with diabetes takes much more than simply giving yourself shots. It requires constant, unwavering attention to your meals, lifestyle, and medications. Even the most conscientious person with diabetes will never achieve the balance that a healthy pancreas effortlessly maintains. If I take too much insulin, my blood sugar will drop too low; my body will sweat and tremble; I will become anxious, irritable, and confused. If I don’t quickly eat something to give my body the glucose it needs—or, worse, if it’s the middle of the night and I am too deeply asleep to notice the warnings I could lapse into seizures, become

unconscious, and never wake up. I am fortunate to have grown up in an era where diabetes has become easier to manage. With our society becoming more aware and with advancements in technology, my mother can now sleep less anxiously. I have evolved from where I first started twelve years ago, but I still rely on the traditional formulas and calculations to help fight for my life.

Another literate activity that I've had to become familiar with, is correctly using the medical tools I use to keep my diabetes under control. To function properly, diabetics inject insulin through the bloodstream. But before you implant the needle, you have to make sure you prime the syringe, pump the plunger, fill up the barrel with the appropriate amount of insulin, tap out all the air bubbles, have a person nearby to double check your calculations, and then the needle is ready to be instilled into the desired disinfected area. To begin my transition from never owning my own needles to becoming educated on how to inject myself, my doctors gave me a "Bag of Hope." This bag embodied useful resources that helped me navigate the challenging period of adjusting to a life with T1D. Along with educational materials, a special friend—Rufus, the Bear with Diabetes—was also a part of this assemblage. Although Rufus is a lifeless stuffed animal, he was the first tangible element that showed me I was not alone while learning to take shots and test for blood sugars. Rufus is a teddy bear of the classic design, but he sports a diabetic alert bracelet and has red patches on his paws to show where the finger pricks should be done. Other colored patches on his body indicate where he should take his shots (Figure 1).



Figure 1: Rufus, the bear with Type One Diabetes.

Rufus was the first concept I had to master, even before the formulas. The doctors gave me **saline**—a solution that consist of salt and water—and extra syringes so I could practice giving shots to Rufus before executing them on myself. I learned the proper regions where shots should be injected and the benefits of rotating my insertions to allow my raw tissue to have a break. It amazes me that a stuffed, muted bear was an instrumental force in my life that offered me strength and support. Rufus foreshadowed the training, education, discipline, and life altering experiences I would later encounter.

No insulin dose comes without a calculation. What and how much I consume has to be established before I eat. There are four different types of injections to learn about: carbohydrate coverage at a meal, high blood sugar correction dose, total meal dose, and total daily insulin requirement (Lantus). First, you have to understand that no two diabetics will be entirely similar. A diabetic's correction ratio, carb ratio, and target ratio is determined with an endocrinologist, a doctor who deals with all biochemical processes that make your body work. These doctors make calculations based on the patient's weight, height, fitness level, and an individual's true habit of diabetic maintenance. There is no guarantee that what your doctor assigns will work perfectly, so with trial and error the patient is able to see what works best for them and their lifestyle. In my beginning stages, these formulas were foreign to my knowledge, and I heavily relied on my mother until I was fully capable of taking responsibility for myself. With my life constantly being on the line, it was mandatory that I followed my mother's instructions. At home the task of staying alive was much simpler and less uneasy; however, when I began to attend school again this mission made me nervous.

Fortunately, we were informed to request a 504 plan from my school administration so together we could develop formal plans to give me the proper support I needed. By law, I was given accommodations to drink juice in class, use the bathroom as desired, take injections at lunch and have a personal nurse. Even with the presence of a nurse around me, my mother handwrote lunch notes that corresponded to what I was eating. The notes always included the total carbohydrates, as well as how much insulin to inject for the meal (Figures 2 and 3).

These daily notes cushioned my shift back into school; the full weight of T1D was not yet fully on my shoulders. Over my elementary and middle school years, I developed habits to nourish my body while learning to accept this new lifestyle. This process of adapting meant that not only did I have to learn a whole new range of literacies, as did my mother, but we used additional kinds of new literacies to make adults at my school aware of the situation.



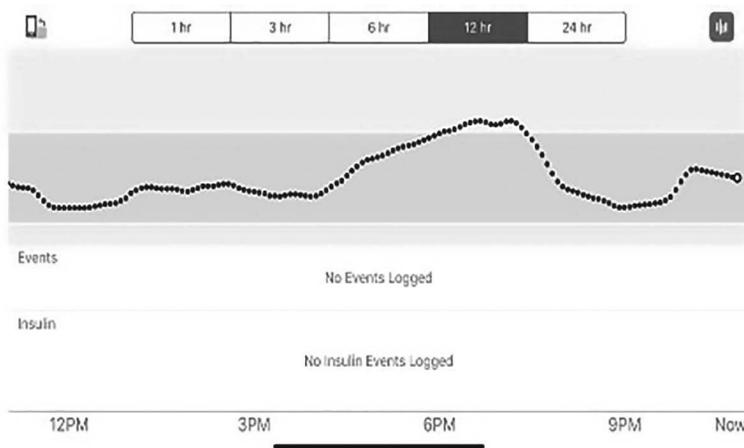
Figures 2 and 3: Examples of the daily lunch notes my mother would write.

In addition, my mother and I together developed literacies that helped us both feel safer. Up until I went back to school, my mother and I were inseparable. The fear of death lingering over our shoulders made it more impossible to detach from one another, which is why these lunch notes were so important. My mother was able to keep an eye on me through the nurse knowing I was injecting properly. This helped me to become more self-reliant.

At age 11 I was introduced to a new approach in caring for my diabetes and was coached on how to use an artificial pancreas. From the beginning of the changeover, I immediately saw a decrease in my **A1C**—a test that measures what percentage of your hemoglobin, a protein in red blood cells that carries oxygen, is coated with sugar (glycated). The higher your A1C level, the poorer your blood sugar control is and the risk for complications intensifies. This godly machine executes all the formulas for me, has insulin storage, personalized settings, alarms and requires a new insertion roughly every three days. Now I can have flexibility and adaptability in my life to perform the activities I enjoy and my favorable tendency for spontaneity are now more acceptable. When I moved to insulin pump therapy with Animus Ping in 2012, which uses Dexcom Graphs, though I would still continue to monitor, it was so liberating to be free of guessing and hoping the insulin delivered by my needles would work as I expected. The pump gave me freedom to be the most metabolically normal I had felt in years.

As technology progressed my pump had advanced and is now integrated with my **Dexcom CGM**. CGMs are continuous glucose monitors which constantly tracks blood sugars to my phone or pump (Figures 4 and 5).

A sensor gets plunged through the first layer of skin, reaching blood vessels and situates there for about ten days. Connecting to the sensor is a transmitter that records blood glucose levels via Bluetooth to detect patterns and falls in blood sugar, alerting when my levels are on the rise, or when it's heading low. The Dexcom was a challenge to become familiar with in the



Figures 4: Example of my Dexcom CGM blood sugar readings.

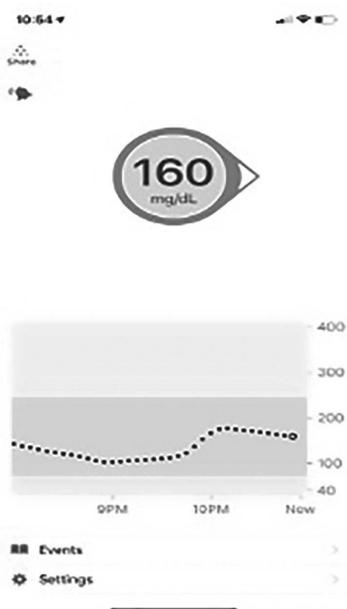


Figure 5: Example of my Dexcom CGM blood sugar readings.

beginning. A new blood sugar would be plotted onto the graph every five minutes, with arrows displaying what direction my glucose was heading in.

All of these texts can be considered literary inscriptions, which Latour and Woolgar (1979) describe in their book *Laboratory Life*, as more than just the traditional things people might think of as texts. Lucas Weber (2018), in an unpublished classroom paper, discussed the concept of inscriptions, and he was able to conclude that literacy is everywhere. Weber continues to say that he believes that the charts and handwritten inscriptions evident in aviation are a prime example of an extension of literacy, which I can advocate for. Latour and Woolgar (1978) discuss the complicated literacies that take place in laboratories, including the kinds of reading of machinery that are involved in my diabetic literacies. Although the graphs that I am reading are electronic and no handwriting is required from me, learning to read charts and understand them should definitely be considered a literate activity. There is so much to grasp and determine from glancing at my Dexcom graph. I remember getting my first pump when I was in elementary school, and thinking “Wow, my life literally runs on batteries now.” That being said, I am always unsettled by the fact that these devices can fail, and I would be in trouble. Having a backup plan in mind is not unusual with the circumstances I live with, so I am grateful to have my roots of computing all the formulas by hand.

Type One diabetes has taught me that diabetes, in and of itself, is a form of literacy. I had to learn how to read my body and then act upon what I was feeling. To this day, I have pump complications and have to resort to using my syringes until the problem is resolved. Technology has made living with T1D less of a burden for both me and my loved ones. However, I am grateful to have spent a few years without the technology to really acquire an appreciation for the advancements and become more in tune with my diabetes.

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Lisa Hanimov is currently finishing her Bachelor of health sciences at the University of Central Florida and hopes to pursue a career focusing on the physical and holistic outlook on health. Lisa enjoys meeting new people, painting with friends, exploring different sceneries, and challenging herself mentally, and lately has acquired an interest in ceramics.