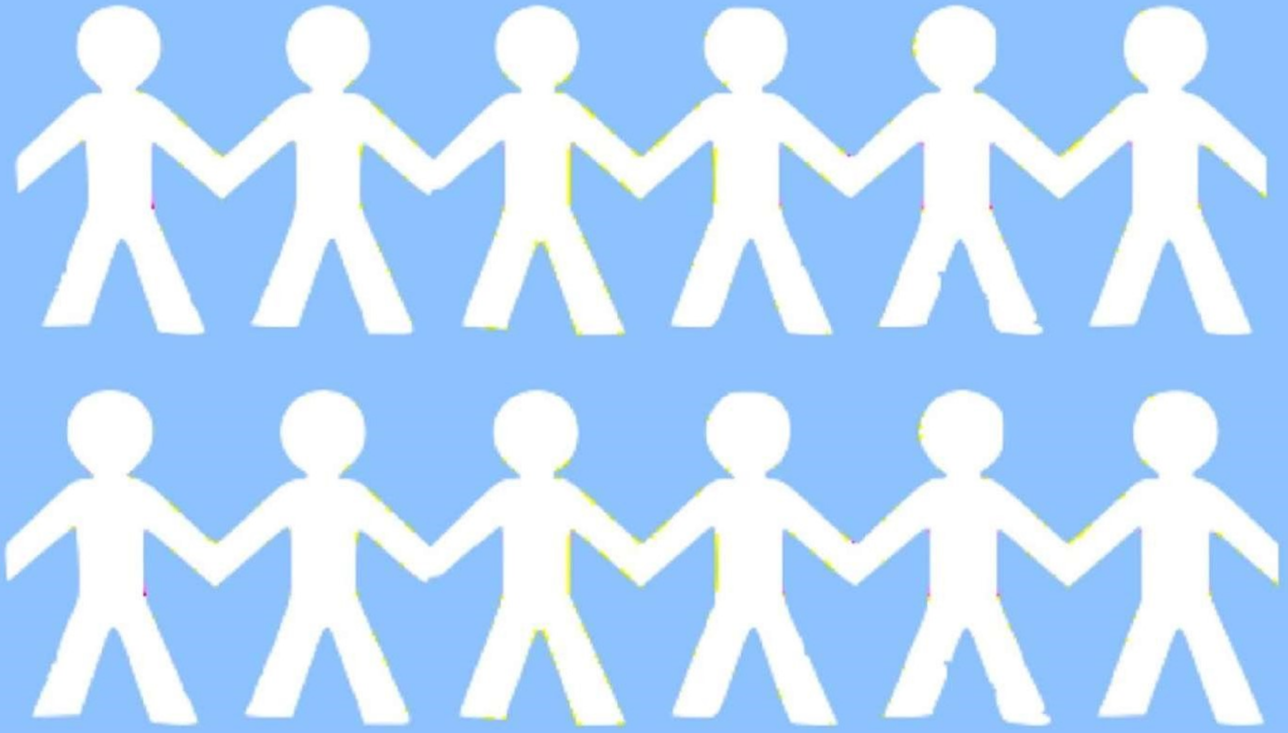


You Are Not Alone

Advice for living with type 1 diabetes by teens for teens

By Oliver Shane

Mental Health Awareness Pamphlet

Please note: These surveys are the personal experiences of People with T1D. This pamphlet Does NOT contain medical advice and is not to be construed as medical advice. Also, it is not an endorsement of any Mentioned product or technology.

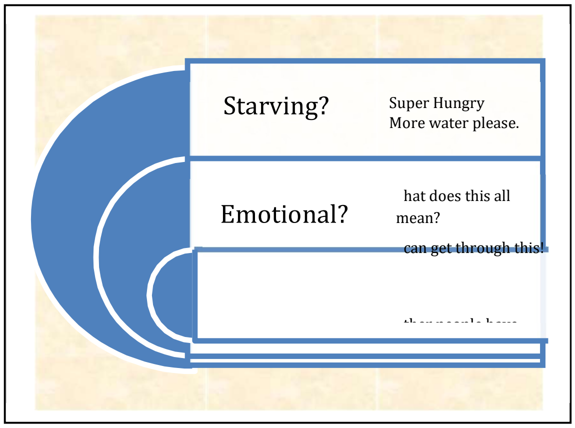
We are All in This Together

Hello, my name is Oliver Shane, and I'm a type one diabetic; odds are, if you're reading this, you are too.

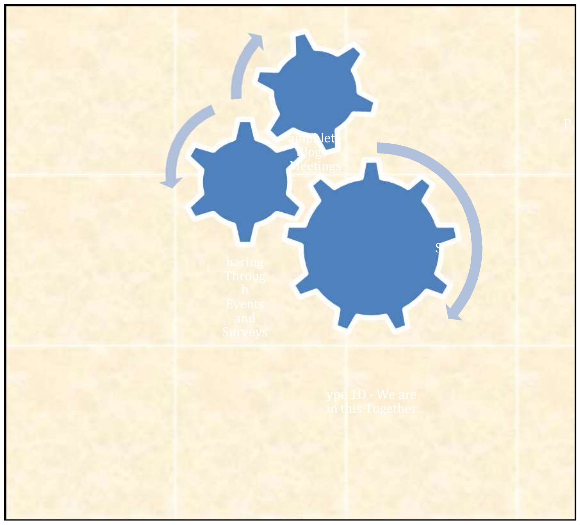
Living with type 1 diabetes is a daily challenge that requires constant management of blood sugar levels, insulin injections, and careful monitoring of one's overall health. It is not just a physical condition but also a mental illness that can significantly impact an individual's well-being. Unfortunately, the mental burden associated with this chronic illness, particularly among teenagers, often goes unnoticed. The fact that it's a constant job with no downtime, and which causes regular physical exhaustion form lows and highs make it incredibly tricky to manage. **That's a lot of pressure for a sixteen-year-old.**

In this pamphlet, I aim to shed light on the importance of mental health for individuals with type 1 diabetes, particularly focusing on the experiences of diabetic teens like myself. Through interviews and personal stories, I hope to provide valuable insights and coping strategies to help others navigate the complexities of their journey.

The inspiration for this project stemmed from a noticeable gap in available resources. While numerous materials exist from health specialists about managing mental health and diabetes, **there seemed to be a lack of firsthand accounts from actual diabetics, especially teenagers.** It became apparent that the voices of those who truly understand the challenges and triumphs of living with type 1 diabetes were missing from the conversation. Hence, I embarked on this endeavor to bring together a collection of interviews from other diabetic teens who shared their personal experiences, coping mechanisms, and insights into the mental aspects of living with this illness.



To conduct the survey, I reached out to a diverse group of type 1 diabetics, primarily through email and personal connections. One instrumental figure in my endeavor was **Adriana Richard from T1D to the Third,** who played a vital role in distributing the survey to a significant number of participants. Their support and outreach helped ensure a wide range of perspectives were included in this project!



Upon analyzing the survey responses, I discovered **a wealth of helpful insights and coping strategies** that participants shared. One striking finding was the incredible breadth of difference in styles of coping with diabetes. It became evident that there is no one-size-fits-all approach to managing the mental toll of this illness. Some participants found solace in **artistic expression, using photography** as a means to document their diabetic journey and explore their emotions. For others, connecting with fellow diabetics and **finding a support group proved invaluable** in alleviating feelings of isolation and loneliness. The diversity of coping mechanisms highlighted the importance of individualized approaches and emphasized that each person's experience with type 1 diabetes is intrinsically unique.

In this pamphlet, I aim to showcase these various coping strategies and provide a platform for diabetic teens to share their stories and insights. By amplifying their voices, I hope to foster understanding, resilience, and a sense of community among individuals navigating the challenging terrain of type 1 diabetes. Whether you are a teenager with diabetes seeking solace and inspiration, or a concerned parent, sibling, or friend looking to support your loved one, I believe the experiences shared within these pages will offer invaluable guidance and hope.

Join us as we explore the complex interplay between mental health and type 1 diabetes through the eyes of those who face these challenges every day.

Let their stories and advice serve as a source of inspiration, empowerment, and unity as we navigate the path towards better mental well-being for all those affected by this chronic illness.

Together, we can break the silence surrounding the mental burden of type 1 diabetes and foster a more compassionate and supportive environment for everyone!

SURVEYS

Preferred pronouns: He/Him

Length of diagnosis: I have had diabetes for three years.

Diagnosis: My symptoms [illegible] my body weight and peeing it all out only moments later. There was something seriously medically wrong, and it just kept getting worse. My parents at first assumed my symptoms were a sign of a tapeworm. They gave me an antibiotic that would help me fight one, but that didn't help much. With no other options, we had to go test my blood glucose. I was afraid of the fingerstick, because I was afraid of officially knowing I had diabetes.

When I was diagnosed with diabetes in the Urgent Care, it was a massive shock. Not one person in my family (that I knew about) had any sort of autoimmune disorder. The lady at the Urgent Care recommended that I go to the hospital immediately, as I was bordering on ketoacidosis. I was taken to Saint Mary's Hospital in West Palm Beach, where they quite quickly suited me up with a heart rate monitor, IV tube drip feeding me insulin and nutrients, and a couple of other goodies.

That night, that one horrible night, was, and still is, the worst night of my life. I was moved into the ICU, where I would spend a majority of the next two days situated in. Every hour, they would come in and stick my finger. Of course, even putting aside the fingerpicks, I still had to have my blood drawn every four hours. I was confused and scared and felt alone, not knowing exactly what would become of my life. And I was starving. I hadn't eaten nor drank anything in almost sixteen hours, and I would have to wait even longer before I could see the endocrinologist and be able to finally eat. I'm thankful that part of my life is over, and I'm thankful that I managed to overcome it, and learned to deal with my diabetes.

Diabetes management: I manage my diabetes by using an omnipod dash, dexcom g7, and tidepool loop algorithm. The tidepool loop algorithm, the biggest innovation in diabetes management since my diagnosis, uses artificial intelligence to control my corrective bolusing, as well as automatically shutting off my insulin when needed, saving me both time and stress while managing both highs and lows automatically.

Effect on mental health: Since my diagnosis, I've found that my mental health was initially a lot worse. I felt constantly burdened and stressed by this illness. As I learned to manage it, and grew a better understanding of my circumstances and their side effects, my mental health started to improve. I think it's important to note that I also started going to an actual school and the covid-19 lockdown ended at around the same time as my one-year "diaversary", which might have had some correlation with my improving mental health.

Coping mechanisms: For my diabetic coping mechanisms, I try to rationalize my illness. I consider that it's livable, and that I have a strong enough grasp on my diabetic management that I won't be affected greatly by the potential side effects (as long as I do what I need to). I've found this incredibly helpful for me, as it allows me to keep focused and motivated on taking care of my diabetes. That being said, this is a bit of a high-stress coping mechanism, and likely wouldn't work well for everyone.

Advice for new diabetics: It might sound cheesy, but it's true. My younger self was terrified by this illness. When I was lying in the hospital bed, right after diagnosis, there was so much I was hearing (plenty of which just wasn't true) which frightened me. I was scared of losing a limb, or being hospitalized yearly, or even just going into a coma at any moment. In the end, none of that, none of those scary prognoses, would be true. **I wasted so much time being scared for nothing.**

Hopes for the future: I'm really hopeful that someday we'll find a way to treat Type 1 diabetes using stem cell replacement. If we're able to replace the damaged cells killing with healthy ones, it could change everything. We could say goodbye to daily injections and have better control over our blood sugar levels.

Even if stem cell treatment isn't in the close future, there's still plenty to look forward to. Technology like Dexcom, pods, and other devices will hopefully continue to make the diabetic quality of life better and better. Even within the past ten years, we've gotten continuous glucose monitors that give us real-time data on our blood sugar levels, and closed-loop treatment systems, make it easier to stay in range through artificial enhancement.

Living with Type 1 diabetes may never be perfect, but with these improvements, we can have a better quality of life and more freedom.

Age:19
Preferred pronouns: She/Her
Length of diagnosis: 12 years

Diagnosis: I was diagnosed at the age of five. I don't remember anything from my diagnosis since I was so young. My best piece of advice is to get involved right away. I wasn't, and I got stuck in a dark place because I felt alone.

Diabetes management: I use the t:slim X2 with Control IQ technology. This works with the Dexcom G6. I use NovoLog for insulin. When I was first diagnosed, I was on insulin pens. Then I was on the Animas Ping, then the old Medtronic, then back on shots, then I got my Dexcom and joined the Tandem pump. It has gotten much easier as life goes on.

Effect on mental health: The correlation between mental health and diabetes is *not* talked about enough. T1Ds are 3x more likely to develop a mental health disorder or an eating disorder. Many people have called me lazy or over dramatic because of how sad diabetes makes me sometimes. It definitely had a hold on me in my middle school years when I continuously hid the fact I had diabetes, but it does not now. I live freely.

Coping mechanisms: Diabetes camp, JDRF events, starting my own organization, and *talking* about it publicly! These have literally saved my life.

Advice for new diabetics: It gets better. It may not seem that way, but it will.

Hopes for the future: Obviously a cure but for now affordable insulin and continued new pumps would be great. And the stigma of T1D to be demolished.

WE ARE IN THIS TOGETHER

Age: 15 years
Preferred pronouns: She/Her –
Length of diagnosis: 12 years

Diagnosis: I was three, and it was the day after Christmas, and I was afraid not knowing what was going on. As I got older, I got friends who were dealing with the same things, and it helped.

Christmas, and I was afraid not knowing what was going on. As I got older, I got friends who were dealing with the same things, and it helped.

Diabetes management: It gets easier at times, but there's also hard times. I manage by using Dexcom to watch my sugars.

Effect on mental health: A lot of my family and friends are afraid to take me with them because they don't want me to die, and that's had a hard impact on my mental health because it feels like rejection.

Coping mechanisms: My friends and I cope by listening to music or writing in a journal to help with all the emotions of it.

Advice for new diabetics: You're gonna be okay. You got this.

Hopes for the future: I hope that one day I won't feel like I have to bind to take insulin or check my sugar or be self-conscious about where I put my site because I'm afraid of what people are gonna say.

Age: 14 years
Preferred pronouns: She/Her
Length of diagnosis: 1 year
Diagnosis: I was diagnosed April 8th, 2021. I was with my dad and had been peeing and drinking a lot and my vision was terrible. I threw up around 11:30 p.m. and we drove to the children's hospital in Pittsburgh, Pennsylvania. I was 450. That's not as terrible as I've heard, but it was an experience.

Diabetes management: Diabetes management has gotten easier. I manage it very well and keep track of my food.

Effect on mental health: It has made me a little more sensitive. When my sugar gets high, I just want to explode.
Coping mechanisms: I just think to myself, "If you get mad, it will get worse. Just relax, and you can fix this."
Advice for new diabetics: You're going to be ok. It's not as bad as you think. You are not alone.
Hopes for the future: A cure!

Preferred pronouns: She/Her 19 years
Length of diagnosis: 10 years

Diagnosis: I was diagnosed through routine blood work. I felt fine. It felt like I was just going through a growth spurt being constantly thirsty and gaining weight even though I was extremely active. My neighbor (who was Type 2) recognized that I was showing signs of Type 1, so my doctor ordered routine blood work. I was never hospitalized at diagnosis!

Diabetes management: I use an insulin pump, the t:slim X2 with the Dexcom G6. I have been on a pump since 2013 exactly one year into my diagnosis. It has gotten both easier and harder since I've been diagnosed. ***Easier*** in the way of knowing how to carb count and manage it. ***Harder*** in the way of mental health and eating.
Effect on mental health: I would say that diabetes has put a damper on my abilities, but I feel that it has given me things that I would have never achieved without diabetes. **For example, Type 1 gave me my best friend.**

Coping mechanisms: I take pump breaks whenever I feel the need to. A pump break, to me, is going back to injections for a few weeks. I feel they've been very effective. It gives me a new state of mind to where I can refocus.

Advice for new diabetics: You're not alone. Your diagnosis *does not* define you, and you have a community full of support behind you.

Hopes for the future: I hope that diabetes can eventually be reversed or a cure. To me, that looks like cell transfusions or another form of cell replacement.

"I think I probably drank close to a literal gallon of water a day. Despite all of this, I was still losing a lot of weight." Age 15 -

Age: 18 years
Preferred pronouns: She/Her
Length of diagnosis: 11 years

Diagnosis: When I was seven, I did not feel well for a while, so I went to get a glucosamine test, and it came back that my blood sugar was 201. I was in the honeymoon stage for about a year. This surprises people a lot because it is such a low number compared to a lot of other people. I felt scared and isolated because I am the only one who is diabetic in my family, so I didn't know what to do. I would not allow anyone else to do my shots unless I was asleep.

Diabetes management: I currently do shots and have a CGM. CGMs weren't a thing when I was diagnosed, and it has made management easier. However, management has gotten more difficult because of growing up.

Advice for new diabetics: I newly diagnosed children should be able to talk to a "veteran" diabetic because they should be able to know and understand **that they are not alone**.

Effect on mental health: I feel it has contributed to me feeling more anxious because I really want control and diabetes does not always let that happen.

Coping mechanisms: Talk to other people who are diabetic. It usually makes me more calm and reminds me that I am not alone.

Hopes for the future: A CURE!

Age: 20 years
Preferred pronouns: She/Her
Length of diagnosis: 11 years

Diagnosis: I was diagnosed when I was nine years old because my mom noticed **I was drinking a lot, tired all the time, and losing weight even though I was eating a lot of food.** It was very scary as a kid because nobody explained the situation to me, and I was just pushed through the process at the hospital without truly knowing what was going on.

Diabetes management: I use a Tandem t:Slim X2 and a Dexcom with ControlIQ. This technology has made diabetes management so much easier for me because it gives me peace of mind and helps me see trends and catch lows and highs before they happen.

Effect on mental health: I suffer from health related anxiety– especially surrounding low blood sugar and my future with diabetes complications. Diabetes doesn't stop me from doing the things I want, but it does certainly put parameters in place while I'm doing those things.

Coping mechanisms: –

Advice for new diabetics: Lows and highs do not define your worth as a person.

Hopes for the future: I know everyone hopes they will find a cure, and I would love that, but truthfully in my lifetime I would love to see advancements in closed loop technology and to see the pharmaceutical monopoly on insulin be dismantled.

Age: 15 years
Preferred pronouns: She/Her
Length of diagnosis: 11 years

Diagnosis: I was just over four years old and right around Thanksgiving weekend started wetting the bed multiple times a night out of nowhere. My parents couldn't keep up with doing the laundry! Eventually, they took me to my pediatrician who immediately recognized it for what it was and sent me right away to my current endo in NYC (I didn't need to go to the ER thankfully!).

Effect on mental health: Diabetes has definitely had a major impact on my mental health. It is so demoralizing to think about both how it is never going to go away until there's a cure and how different it makes me from everyone else. It can be very hard to prevent diabetes from limiting you, and putting in all of the effort to do normal things makes it not worth it at times. Additionally, it has given me a lot of issues with control. Since I have no control over such a major aspect of my life, it makes me crave that control in other areas.

Coping mechanisms: I don't have a lot of coping mechanisms which probably isn't good. **The best thing I would recommend to new T1Ds is to talk to another diabetic kid who has had it for a little longer.** I didn't know anyone who had T1D until I was 12, and it made me feel really alone and like no one else in the world understood my struggle.

Diabetes management: I'm 100% self-sufficient with managing my diabetes. I wear a CGM and insulin pump (and am switching to a closed loop system with the two in the near future). It's gotten both easier and harder as time has gone on. I'm doing much better than my parents (who were the primary ones responsible for years since I was diagnosed so young) because obviously I know my body best, but with that comes a lot of burnout that makes it very hard.

Advice for new diabetics: One day it will be manageable. **I've got a pretty good handle on it right now and am completely in charge of it for myself which I never thought would've happened.**

Hopes for the future:I really really really hope that there is a cure in the near future. I'm sure everyone is going to say this, but there really is *nothing else* that could be more influential than this.

Age: 19 years
Length of diagnosis: 11 years

Diagnosis: I was drinking a lot of water, peeing a lot, and lost a good amount of weight in a small period of time. I also had a yeast infection that didn't go away with antibiotics.

Diabetes management: I use an insulin pump with a CGM. My management is pretty good.
Living with diabetes is hard as I have my moments, but it only makes me stronger

Effect on mental health: I do not think diabetes has limited me in any way.

Coping mechanisms: Take things day by day as your body is always changing.

Advice for new diabetics: Don't feel so stressed. Everything works out.

Hopes for the future: To find a cure.

Age: 17 years
Preferredpronouns: She/Her
Length of diagnosis: 14 years

Diagnosis: I was diagnosed with T1D when I was three years old. My dad was deployed to the Middle-East, my sister was three months old, and we decided to visit family in a different state for the 4th of July. What was supposed to be a fun vacation with family turned into an emergency hospital stay. Being three years old, I didn't understand what was going on. All I knew was I was sick, and they were going to make me better. The mantra that kept playing in my family's head was, "It is what it is." Eventually we all learned to live with it, and I live a normal life or as normal as someone with diabetes can live.

Diabetes management: I currently use the Omnipod Dash and Dexcom G6 systems. However, I started off with the Medtronic pump and CGM. Since I was diagnosed, I have seen waterproof, touch screen, and tube-less pumps. Now we are looking towards the closed loop system. With the improvements in technology, living with diabetes has definitely gotten easier. I have been able to sail in regattas, go ziplining, and perform in school shows.

Advice for new diabetics: This is just one set back. It will make you stronger. You will become outspoken, a leader, and an advocate. You just need to take it and make the most of it.

Hopes for the future: As all diabetics, **I hope that one day there will be a cure. But more short-term, I hope that the price of insulin without insurance is lowered as well as the education of people on diabetes increased.** Only about 10% of all diabetics are type 1, so most people don't know much about it. This includes medical personnel which is very dangerous.

Age: 17 years
Preferred pronouns: She/Her
Length of diagnosis: 15 years

Diagnosis: I was very young, so I personally do not remember a single thing from my diagnosis story. But my parents have told me that it was the typical diagnosis story: peeing a lot, drinking a lot, mood swings, and always being hungry.

Diabetes management: I have a Dexcom G6 that monitors my BG 24/7. I use the t:slim X2 control IQ that also helps to manage my diabetes. I do not eat any differently than others because as diabetics we can still eat whatever we would like even though it's seen as otherwise to the world around us. Managing diabetes since I was diagnosed has become harder because growing up and becoming a teenager really messes with your management of the disease.

Effect on mental health: Diabetes has made my depression and anxiety significantly worse. It makes it very hard to go out–especially with Covid. I'm afraid I'll get it and the risks of getting it as a T1D are scary. I feel like it honestly has limited me. I feel scared to go out in public sometimes because any type of sickness hits us as diabetics a lot harder.

Coping mechanisms: Coping mechanisms can differ for every person, but I make sure I have a solid support group at all times that know all the ups and downs of diabetes, so I never feel alone. I think that any new or experienced T1d should always have a solid support group.

Advice for new diabetics: Live your life no matter how others see you because of this disease. They don't know what it's like, and nobody will truly understand your story.

Hopes for the future: **For there to be a cure to T1D.**

Age: 16 years
Length of diagnosis: 15 years

Diagnosis: I was 17 months old. I lost weight super fast, was peeing a lot, and drinking a ton. **Diabetes management:** It's gotten way easier with all the technology. I manage with an insulin pump and Dexcom.

Effect on mental health: Diabetes has had a *big* impact on my mental health, wanting to fit in and feel normal and not have to constantly worry. It causes a lot of anxiety.

Coping mechanisms: Diabetes camps and having a support system has helped greatly.

Advice for new diabetics: It will all be okay.

Hopes for the future: **I hope one day everyone will find a cure whether they choose to get it or not!**

Age: 18 years
Preferred pronouns: She/Her
Length of diagnosis: 16 years

Diagnosis: I can't really remember since I was very little, but what I do remember is going to the doctor's three times in the same week and was told that it was just the flu. Finally my mom said something had to be wrong because I had no improvement. They did bloodwork and found out I was diabetic.

Diabetes management: I make sure to be on top of everything and always cover my sugar every three hours.

Effect on mental health: I do not think diabetes has limited me, but it has had an impact on my mental health. It made me feel as if I were different and not worthy of a normal life, that I couldn't be like other everyday people.

Reach out !

You are not alone

Coping mechanisms: I just reach out to my community and tell them how I am feeling. **What I think everyone should know is that they aren't alone.**

Advice for new diabetics: Live your life. Don't think your diabetes limits you. Hopes for the future: **A cure to be found.**

Age:15 years
Preferred pronouns: She/Her
Length of diagnosis: 6 years

Diagnosis: I went to my pediatrician where she told me the emergency room was expecting me. I don't remember much but I was fairly calm.

Diabetes management: I use a DIY loop insulin pump. I haven't always used a closed loop pump. It has gotten easier in some aspects.

Effect on mental health: It has caused a lot of stress and other issues. Diabetes limits me by making me nervous to do most things because of my blood sugar, and a lot of times I can't/won't eat because of my blood sugar.

Coping mechanisms: I don't have any good ones :(. I think diabetics should definitely find a support system!

Advice for new diabetics: Get a Dexcom when you can, **and try your hardest but *give grace.***

Hopes for the future: **A cure! A cure with no harsh immune suppressants :)**

Name and age: 18 years
Preferred pronouns: They/Them
Length of diagnosis: 6 years

Diagnosis: I was diagnosed in 2016 two days before Valentine's Day! My family and I went sledding and my mom noticed my symptoms and had me test my blood twice! We rushed to the hospital and because two people in our house had diabetes we were allowed to go home that same night. Within the first week, I was taking care of it mostly on my own because I don't like not being in control. I just needed help with all the math.

Diabetes management: I have a Dexcom to help monitor my blood sugars and I've gotten much better at feeling whether my sugars are high or low. Pumps help, and I'm going back on one but pens and syringes also work fine. You just need to figure out what works best for you

Effect on mental health: Diabetes isn't easy and there have been times I didn't take care of myself because I didn't want to be different. Don't let that happen to you! The people who matter will want to learn and help or at least try to understand, and those who judge won't matter in the long run.

Coping mechanisms:

Find yourself a support group. That's the best way to go about dealing with your diabetes! I struggle on my own, **but when there are people backing me up, it's so much easier.**

Advice for new diabetics: Just breathe. You really won't mess up as bad as you're worrying about.

Hopes for the future: A cure, and until then, more and more products that make life easier.

Name and age: 17 years
Preferred pronouns: She/Her
Length of diagnosis: 7 years

Diagnosis: I was only 46 pounds, skin and bones, and going to the bathroom very often. My doctors thought I just had the flu. My mom knew something else was wrong. One day I stayed home from school because I was very sick. I was barely able to breathe and was vomiting and ended up going to the hospital where eventually I got my blood sugar and ketones checked. I remember being so cold. I got to ride in a panda bus, and I almost died. My blood sugar was 1,159 which is crazy high. I remember being so scared that I was going to have to ride in a helicopter to be transported to the other hospital for some reason, but my mom always told me that those extra moments could be lifesaving.

Diabetes management: I manage my diabetes with my Omnipod and Dexcom G6. I am very independent. It has gotten easier as time has gone on as I have learned and matured more.

Effect on mental health: Diabetes plays a big role in mental health. Sometimes I get very anxious when I am high that I could get in trouble. I don't think diabetes limits me in any way shape or form.

Coping mechanisms: My coping mechanisms are my friends and family. I think they have been very helpful to calm me down when I feel anxious, worried, or anything like that.

Advice for new diabetics: You are not alone. You are stronger than you know. You will get through this, and the other people you meet with diabetes will be some of the best people in your life.

Hopes for the future: A federal price cap on insulin.

Name and age: 17
Preferred pronouns: She/Her
Length of diagnosis: 9 years

Diagnosis: When I was eight years old, I was diagnosed with T1D. My blood sugar was around 650mg/dl and I was going in and out of consciousness. I was transferred to two different hospitals but finally got the care that I needed. I had all the normal symptoms, but no one was able to diagnose me until it was almost too late. I have been dealing with diabetic burnout on and off for years because it really is a full time job. I always hated the term "the new normal" but it really is true. My entire life changed in the blink of an eye. Suddenly the seemingly healthy child that I once was became a scared child that would never recover. Something my doctor tells me is to separate myself from the numbers. A number on a screen can't tell what one is feeling or the struggles going on in life. The number is just a way to let me know what the next move needs to be.

Diabetes management: I started out on injections for about a year and then got a pump. In the past few years I have also started using a CGM which really is a lifesaver. Being a teenager where hormones are constantly changing, diabetes is harder to control and track.

Effect on mental health: I am no stranger to mental illness. I became so anxious that I completely isolated myself and wouldn't leave my house. My endocrinologist thought that I should see a therapist, and I have been with him ever since. The stress of being chronically ill is incredibly high, and it is a full-time job. Even if you have had it for a while, it doesn't always get easier. I fell into a pretty bad depression and even thought that the world would be a better place without me in it. I have struggled to crawl out of that dark place, but I am slowly getting better. I would like to say that diabetes hasn't ever stopped me, but that would be a lie. I've had to sit out during sports and activities more than I would like to admit. I've missed school quite a bit and had a difficult time getting work done with blood sugars acting up. I do think that I am stronger and more persistent than the disease, but it definitely comes with trials and tribulations.

Coping mechanisms: I have had so many coping mechanisms throughout the years. I tried log books and apps that never seemed to work. I do think that if one can attend therapy, it would do wonders. I also think that it is important to take some mental health days because it is such a full-time condition and sometimes it is easier to take something off of one's plate for a little bit. Right now I am taking everything one week at a time and reviewing numbers and graphs at the end of each week, so I know what I can improve on.

Advice for new diabetics: It is okay to struggle. I don't think the hospital really tells people how difficult and draining the disease really is. I have spent countless nights crying because I would never be "normal" or because things seemed too hard. Allowing oneself to struggle and having hard times is so important. Being able to sit in an uncomfortable situation and acknowledging what is happening and not focusing on changing it is such an important skill to have.

Hopes for the future: I don't think that we are as close to a cure as what is being shared by the public. I hope that people will be more aware of what the disease is and how to help without being too involved. Really I just wish people were more aware of the struggles and didn't set such cruel stereotypes.

Age: 17 years
Preferred pronouns: She/Her
Length of diagnosis: 9 years

Diagnosis: On June 27th, 2013, I went to the hospital in my town. They told me I had a 24-hour bug and would be fine. On July 1, 2013, I went to my pediatrician where I was told I had Type 1 diabetes and was sent to a children's hospital. I was there for seven days. I was taught my “new lifestyle” and learned how to give myself insulin and carb count.

Diabetes management: I have a tandem t:slim X2 and Dexcom 6G which help so so much. I also have plenty of diabetic friends including my boyfriend who also helps a lot. It has definitely gotten easier since I was diagnosed.

Effect on mental health: It has not played a good role. I have depression, anxiety, and an eating disorder. I got all after I was diagnosed.

Coping mechanisms: –

Advice for new diabetics: It gets easier. Don’t give up.

Hopes for the future: I hope for a cure for us all.

Age: 21 years
Preferred pronouns: She/Her
Length of diagnosis: 9 years

Diabetes management: I manage my diabetes with a pump and a Dexcom. These have helped my life so much. My diabetes management has gotten easier over the years since I learned what makes my sugars spike more than others, and I also learned roughly how long it will take for my sugars to drop and rise!

Effect on mental health: As soon as I got diabetes, my mental health declined, and I was diagnosed with major depressive disorder. This means I will be on medication for the rest of my life. Although this has happened, I learned compassion and developed strong empathy for other people.

Coping mechanisms: My coping mechanism for diabetes is definitely camp. Being around other diabetics definitely helps me feel less alone in my fight.

Advice for new diabetics: It will get better. You’ll develop amazing friends with the same illness. Don’t be scared. You will be more than okay. Don’t worry about your future Getting diagnosed with diabetes led me to being a camp counselor and being a camp counselor led me to wanting to be a kindergarten teacher and work with kids!

Hopes for the future: My future expectations for diabetes is free insulin for all.

Name and age: 13 years
Length of diagnosis: 7 years

Diagnosis: My parents took me to South Dakota one time when I was six, and we had to stop like every 30 minutes for me to go to the bathroom or get water, so my mom knew something was up. We continued with our trip, and I had multiple meltdowns that my mom believes were from my high blood sugar. When we got back to town, my mom took me straight to the hospital to get blood drawn. The nurses told her she was crazy, and that I didn't have diabetes. After my blood was drawn, my grandma got me McDonald's which wasn't the best idea. Later we got a call. “Oh yeah, she has diabetes,” so we went back to the hospital to learn what I had to do. My dad and I had no idea what was going on because no one told us, but my mom and grandma knew exactly what was happening.

Diabetes management: I manage it by changing my pump and sensor and moderating my blood sugars and taking care of them. It has gotten easier because I now have a pump and a sensor and have learned what to do with high and low blood sugar.

Effect on mental health: I cry a lot easier when my blood sugar is high or low, and it only limits it when I'm sick because of blood sugars.
Coping mechanisms: –
Advice for new diabetics: Just do it.
Hopes for the future: A cure.

Name and age: 25 years
Preferred pronouns: She/Her
Length of diagnosis: One month.

Diagnosis: A little over a month ago, I got very sick. Back in January, 2022 I was diagnosed with depression, anxiety, and an eating disorder. For the longest time I thought I was having eating disorder flare-ups. That was until I ended up having all the symptoms of diabetic ketoacidosis (DKA). I lost 13lbs within about three weeks. When I went into the hospital, I was immediately taken to the ICU after being in severe DKA. My organs were failing and the doctors told me I was lucky I got there when I did. I spent three days in the ICU until I was stable enough to go home.

Diabetes management: I wouldn't say I am the best at being diabetic, but I am only one month in. Physically I've never felt better. I see my muscle coming back with the weight that I am gaining. Mentally is where I struggle. The “Why me?” question hits me hard most days. I'm tired of being the sick girl after 24 years of being healthy.

Effect on mental health: Diabetes has changed me as a person altogether. I am very grateful for a lot more– especially the good days because I don't get many of them. I just struggle a lot when I try to be out and about but my sugar drops and everyone feels that they need to take care of me. I feel like a burden most days.

Coping mechanisms: I like to take pictures. I think documenting my journey will help me later in life, so when the days get hard, I can look back on the days when it was worse and remind myself how far I've come.

Advice for new diabetics: Your life is not over. A healthy one has just begun.

Hopes for the future: To find some sort of cure or ways to have a one-and-done surgery for permanent insulin.

Name and age: 28 years
Preferred pronouns: She/Her
Length of diagnosis: 14 years

Diagnosis: I was uneducated and scared. I never would have thought this would happen to me or that Type 1 even existed. I played three sports year round and lived a healthy lifestyle, so when I finally was diagnosed I was shocked. This diagnosis changed every aspect of my life.

Diabetes management: I manage my diabetes using my CGM Dexcom and on average six shots of insulin daily. I have used the t:slim pump in the past which did make managing my diabetes easier, but much like life there are a lot of highs and lows (literally). Overall advancements made because of research have made my life easier, but diabetes is never easy. You just learn to embrace it.

Effect on mental health: Diabetes is just hard; it can take a toll on your mental and physical health. No one truly understands what a T1D goes through on a daily basis unless you also live with T1D. In the beginning of this journey, it also affected my self esteem, and I felt alone because none of my peers had the same struggles. I think it's important to find support groups of people who are also living with T1D. I found some through JDRF and became an active volunteer. This gave me a sense of purpose and made me empowered instead of limited because I always wanted to define diabetes not let diabetes define me.

Coping mechanisms: My most helpful coping mechanism for diabetes is managing it by living an active lifestyle. I try to go to the gym five times a week, and when I'm not at the gym I'm outside being active walking, running, hiking, swimming, and more. Staying active helps manage my diabetes and my mental health. I think newly diagnosed kids would also benefit from doing the same. When I was first diagnosed, I played three sports year around. This helped me stay fit and healthy and was an outlet to release any of my frustrations. When I was diagnosed at 14, I felt embarrassed that I was different from my peers. Now that I am older, I realize that my diagnosis has made me a stronger, more resilient individual. I do not see my diagnosis as an obstacle but more as a badge of courage, one that I wear proudly.

Advice for new diabetics: It's important to manage your diabetes. Being a teenager is hard enough and then being diagnosed with T1D during your adolescent years is very challenging. Life gets in the way, but it is most important to prioritize your health over anything else. Embrace your diabetes..

Hopes for the future: I hope in my lifetime I can say that I used to have Type 1 diabetes. Until there is a cure for T1D, I will continue to be an advocate and raise funds for research for a cure. Since my diagnosis there have been many impactful findings and technologies created to help make my life and others who live with T1D more manageable.

Age: 25 years
Preferred pronouns: He/Him
Length of diagnosis: 22 years

Diagnosis: I was diagnosed with Type 1 diabetes at the age of three, and there hasn't been a single memory of living a normal life. I know that I will have to live with needles and injections for the rest of my life. I know slowly overtime I will become self-managed in taking care of my diabetes. There were good times with it and times where I just wanted to give up. Over time I built confidence that diabetes will not ever stop me.

Diabetes management: I use a Tandem and Dexcom now. I'm always checking on my blood sugars daily and giving corrections if needed to keep it between 100-150 blood sugar range. Since I was diagnosed, it was finger pricking and needle injections daily. Overtime, I used fewer needles thanks to advances in technology to prevent me from having to finger prick again. I would say it has gotten easier in the last 23 years, but it's always a priority for me to constantly look out for my diabetes. However, I know that one day I can forget to have diabetes in the future with the awesome technology that is being created. =-)

Effect on mental health: I would say diabetes does definitely play a huge role in my mental health. If I do feel highs or lows, it definitely impacts my daily routine and my athletics that I'm heavily involved in. Early on, I thought my life was over when I thought that diabetes limited me in every aspect. My college football coach inspired me that with the bad hand that I was dealt, I can be limitless in anything that I do in life. He unfortunately passed away in 2020 from pancreatic cancer. He inspired me to know that diabetes will not ever defeat me, giving me a tough mindset that I can do all things–especially now running marathons and overcoming impossible athletic challenges.

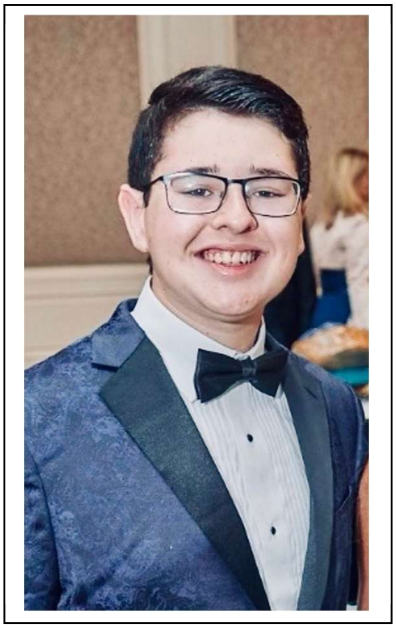
Coping mechanisms: I really don't have a coping mechanism for diabetes since I’ve had it my entire life.

Advice for new diabetics: Your life is not over. It's the beginning of something great for you within: the human spirit of overcoming obstacles. For the rest of your life, you just need to work a little extra hard one step at a time to overcome anything. The victories in life will fall into place if you start with a winning attitude. There is never "I can't." It's always "I can." Never be broken and never surrender. You also have loved ones and a whole family of T1Ds that will support whatever you choose to set your mind to. Never be limited. Everything in life is earned and not given to anybody. You will have to work extra hard to win the victories in life. Strive each day, ignore the critics, and be yourself. Life will be different, but your hunger for greatness lies within you.

Hello again! Congratulations on finishing this pamphlet! After almost twenty pages worth of interviews and advice from other diabetics, I really hope you found something that helped you.

I want to thank everyone who participated in this project, my scoutmaster Joanne Palchak for helping me format everything, Adriana Richard for helping me organize several interviews, as well as you kind folks for reading it!

Diabetes is always going to be a difficult illness, but one sentiment I hope we all can share is hope; hope for better technologies, hope for a cure, hope for the future! Every day, this illness gets easier to manage, and that'll hopefully lighten the awful mental load associated with it.



In the meanwhile, this project was a wonderful learning experience for me, and I really hope you managed to get something out of it! Odds are, I might do a second wave of interviews for the next release. If you're a teen or young adult with diabetes, and you're interested in participating on another one of these surveys, feel free to email me at Oliver@shane.com, and I'll be more than happy to share the form with you!

Till then, thank you so much for your time, you're doing great!

RESOURCES and HELPFUL LINKS:

- **Help A Diabetic Child (HADC) - www.helpadiabeticchild.org**