

Hugging the Cactus

T1D is like a prickly cactus (literally and figuratively), but I've learned to embrace it, thorns and all.

COLLEGE DIABETES NETWORK / DIABETES ADVOCACY / YOUNG ADULTS

CDN Creates Guide for Newly Diagnosed Young Adults

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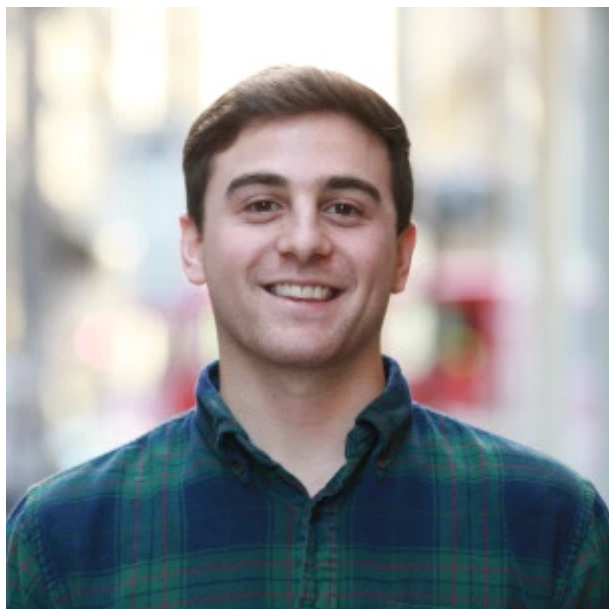
I often tell others that I feel lucky to have received my diabetes diagnosis at a young age. Why? One major reason is that it didn't really interrupt my life – I was so little that I barely remember it, so it wasn't necessarily a traumatic event (at least, not for me – my parents probably strongly disagree with that).

But I've heard many different diagnosis stories from fellow T1Ds over the years, and not everyone was as fortunate as me. In fact, I met a few students at the last couple of CDN annual retreats (<https://www.youtube.com/watch?v=ysGbIkNbek4&feature=youtu.be>) who received diagnoses just as they were starting their college careers. Diabetes was still pretty new to some of them, which made me realize that growing up with diabetes is *probably* a bit easier than developing it during one of the most formative and chaotic periods in life: young adulthood. Add college and the “real world” into the mix and you've got a recipe for a mass quantity of stress.

This is why I think it's wonderful that the College Diabetes Network recently created a specialized guide for newly diagnosed young adults: *You've Got This: A Guide for Young Adults Diagnosed with Type 1 Diabetes*. The guide offers tips and tricks on how to adapt to life with diabetes, and covers areas like relating to peers and navigating school and work.

Two students who helped bring this guide to life, Andy and Deja, were kind enough to take time out of their busy schedules to answer some questions I had about the guide.

□



Andy



Deja

Tell me about yourself. Where are you from and what do you do for a living? What are you studying in

school?

Andy: Thank you for this opportunity to talk about CDN's new guide and my T1D experience! My name is Andy Zeiger and I'm from Danville, California near Oakland. I recently graduated from the University of Washington (UW) with a degree in molecular biology and I'm currently part of the Asthma Collaboratory at UC San Francisco researching population genetics. I love reading history and biographies. After graduation I went on a two-month cross country drive (on my own!) to learn more about our country's cities and big thinkers. I also enjoy taking my dog Rose on walks and talking to her about my problems.

Deja: My name is Deja Gipson; I am from Atlanta, GA. I am currently in my sophomore year, studying Electrical Engineering at the University of Alabama. I am 20 years old.

You were diagnosed with diabetes as a young adult. What was your diagnosis like and how did you react?

A: My diagnosis happened during winter break of my junior year of college because my dad observed that I went to the bathroom three times during the new Star Wars movie. Within 48 hours of hearing I had type 1 diabetes, I had picked the brain of an endocrinologist, learned how to count carbs with a diabetes educator, and discussed dietary strategies with a nutritionist. These resources primed how I viewed my diabetes in those early days: I was given the tools and resources to do this. So that's how I reacted, I just jumped headfirst into living with diabetes. Apart from crying in a restaurant bathroom my first day with diabetes because I didn't know if I could eat a Philly cheesesteak (I can and do), I worked hard early on to not let myself get too negative about the diabetes. In the almost two years since my diagnosis I have learned that the WAY in which I was diagnosed – by being provided with lots of positive support and great resources – is a key reason why I have achieved tight diabetes management and a positive outlook. This is the reason why I believe strongly in CDN and their guide for newly diagnosed young adults. When individuals with T1D have access to the strong social support networks of CDN, and the insightful and useful information in this guide, they will be better equipped to thrive with diabetes.

D: My diagnosis went a lot smoother than most, compared to the diagnosis stories I've heard from others in the diabetes community. I was diagnosed at 17, which was my senior year in high school. I was actually admitted into the hospital the week of my senior prom. If I would have stayed in the hospital any longer than I did, I would've missed it! So as a senior in high school, that was a big deal for me. Fortunately, I was able to attend, my dress just fit a little bigger than it did when I first tried it on due to the weight I had lost.

When and how did you become involved with the College Diabetes Network?

A: I returned to school after winter break newly minted with T1D and ready to take on a heavy course-load as well as my research position on campus. For the subsequent few months, I put my head down and worked hard, figuring that successfully incorporating T1D into my life meant shouldering the burden on my own. I would soon find that the best way to successfully integrate T1D into my life was actually to allow people to help me and, in letting them help me, I could find ways to in return, help them. I began volunteering with the Pacific Northwest Chapter of JDRF where I was lucky to meet Kassidey Short, a UW student who had been living with T1D almost her entire life. We founded a CDN Chapter on our campus and began working with the Seattle University CDN chapter to build a support system for T1D students in Seattle. We anchored our CDN Chapter to the local JDRF infrastructure and built connections with various organizations at UW including the disability services office, residential life and local clinics. We utilized CDN's many resources to put on two educational panel events for high school seniors and college freshmen. During my senior year we were recognized for our work in building a support system for T1D students when I was awarded a Mary Gates scholarship and our group was featured in the UW student newspaper. CDN sent out applications to attend a workshop in Boston to create this guide, and I could not pass up the opportunity to learn about the diabetes experiences of my peers and become a better advocate for T1D in the broader community.

D: I became involved with CDN once I got to college. I was informed by my endocrinologist that my school most likely had a Chapter and that I would feel comfortable knowing and interacting with other students my age with Type 1. He was very correct! I have made bonds through CDN that will last a lifetime!

CDN is launching a guide for newly diagnosed young adults on November 13th. What kind of information does this guide contain?

D: The guide that we've created for newly diagnosed young adults contains the "real" things you need to know about having diabetes at this age. The information in the guide was collected from a group of young adults, so I believe that the contents are truly authentic and will help anyone become more aware of the things you really need to know about "dia-beet-us"!

How did you contribute to the guide?

A: In the spring of 2017, CDN hosted newly diagnosed adults from CDN Chapters across the nation at a workshop in Boston. We received a packet of information to review which would serve as the framework for this guide and were asked to come prepared with comments about the guide and reflections on our experiences with T1D. As with every member of the workshop, I deconstructed my own diagnosis experience for the most valuable insights and shared them with the group. We had sessions moderated by the founder and CEO of CDN, Christina Roth, and we had guest researchers prime us with questions based on their own experiences with diabetes from a clinical and biomedical research perspective. Personally, I sought to contribute to the guide by relaying positive reflections on a living with type one. My experience with diabetes has forced me to become more efficient and deliberate

with my daily activities. It has taught me incredible insights about my body and I have seen massive benefits in taking care of my mental and physical health every day. While T1D is a chronic illness with its unique challenges, individuals with T1D can relate to the daily struggles and adversities felt by anybody living with a chronic illness. Empathy and compassion are born out of a concerted effort to appreciate the struggles and pressures befalling our neighbors, and T1D has created a platform for me to do that. Furthermore, Insulin was first used in human clinical trials in 1922! If I had been diagnosed with T1D as a 20-year old prior to 1922, the standard of care would have been a miserable starvation regiment and I would have lived for approximately two to four years. We are living at a time when the gap in life expectancy between people living with type 1 and the general population is closing and we can live a relatively normal life with the disease. That is the miracle of science that I wished to convey!

Is there a part of the guide that you think is particularly helpful to newly diagnosed young adults? Which part, and why?

A: The first section of the mental health chapter of the guide discusses positive approaches to “diabetes control”. I wish I had been able to read this chapter the day I was diagnosed. My care team and family prepared me with great resources and support, but all too often I felt like I was riding in the passenger seat, living at the whim of my disease. This part of the guide reminds us that our diabetes is our own, we will make adjustments throughout our life and will never perfectly have it under control, but that’s okay. It’s better to strive for the tightest control possible than to feel guilty or defeated in pursuit of unattainable perfection.

D: I believe that the Family portion of the guide is the most important. Your family are the ones who care about you the most, and sometimes their “caring” can come off as rude, which can get to be annoying and overbearing. I believe that it is important to let them know how they can help you so that way they can still feel a part of your life and can help you the correct way.

What advice would you give to a young adult newly diagnosed with diabetes?

A: Every day I check my blood around five or six times and give myself five shots of insulin. Nobody does this for me, which means I am completely reliant on myself to count carbs and dose my insulin and make sure that I have tight control of my diabetes. However, it is nearsighted to think that I alone affect my health; in fact, we are all stakeholders of each other’s health. As Benjamin Franklin related in his *Appeal for the Hospital*, “We are in this world mutual Hosts to each other... the Good, particular Men may do separately, in relieving the Sick, is small, compared with what they may do collectively.” Essentially, if you were just diagnosed with diabetes, you should know that you gain strength from the help of others. You may not yet know anybody who has diabetes and you may think that people without it can’t understand what you are going through, but carrying the burden of the struggle by yourself is painstakingly difficult. I know because I have tried. Type 1 diabetes is a silent struggle but depression, chronic pain and obesity are silent struggles too. These struggles may not involve blood gymnastics, but more people than you can imagine do understand what it is like to grapple with their health every day, and they want to help. My advice would be that you are promoting your health and the health of those around you when you acknowledge the gravity of your community’s struggles and actively seek ways to help. Being supportive to others is a great way to turn your diabetes into a positive.

D: Know that you’re not alone in this! You can live a prosperous life and show diabetes that you’re [□] the boss!!!

Thank you for answering my questions, Andy and Deja! “You’ve Got This: A Guide for Young Adults Diagnosed with Type 1 Diabetes” is available digitally on the CDN website (<https://collegediabetesnetwork.org/newdx>) on November 13th, along with videos featuring CDN students talking about their experiences and what they have learned. Here’s a sneak peek! (<https://www.youtube.com/watch?v=PKUTf6IQygE&feature=youtu.be>).

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