

Matt (host): Welcome back to the Nimble Youth Podcast, the show that brings clarity, compassion, and expert insight to the challenges facing today's kids and teens. I'm your host, Matt Butterman. We just got back from the American Academy of Pediatrics Conference in Denver. And while we were there, something really meaningful happened to me personally. At the conference exhibit hall, I received a fifty year medal for living with type one diabetes from the type one diabetes charity, Children with Diabetes.

And that moment, standing there with that medal in my hand, sparked the idea for today's episode. Because today we're talking about teenagers living with type one diabetes, how they navigate the unique challenges of adolescence while managing a serious chronic condition, one that I know only too well. And I couldn't imagine having this conversation without my partner, Doctor. Gretchen Hoyle. She's a pediatrician with over twenty five years of experience, and she's walked with countless families through the ups and downs of type one.

Before we get into it, a quick reminder that the content of this podcast is intended for informational purposes only and should not be construed as medical advice. Always seek the advice of your doctor, therapist, or other qualified health provider with any medical or mental health concerns. So Doctor. Hoyle, before we dive in, what did it feel like for you as a pediatrician seeing that medal moment at the booth in Denver?

Dr. Hoyle: It was amazing. I mean, just to see that happen and it was completely unexpected. We were just headed over to talk with one of the-

Matt (host): It's kind of an afterthought really.

Dr. Hoyle: It was, yeah. And so we'd been talking to lots of the exhibitors there and wanted to see some folks about type one diabetes. And I kind of mentioned it off the cuff and their administrator there was pretty excited about being able to give out a fifty year medal. And it just really brought home to me that it's just, it is important to recognize these milestones for families and that this experience shows that there, it is, there's proof that there's, that you can thrive long term with type one diabetes and that there's lots of advances and lots of new hope out there for, newly diagnosed kids.

Matt (host): Absolutely. So I was right about the time of my fourth birthday when I was diagnosed, that was in 1974. Things were a lot different back then. But for today's teenagers, it's still a wild time of change, independence, and wanting to just sort of fit in. And when you have type one, it just makes everything more difficult.

It's not easy to carry type one throughout all of that change.

Dr. Hoyle: So then can you remember a time as a teenager when you just didn't want to deal with diabetes for a day?

Matt (host): Absolutely. I mean, that's the thing about diabetes and living with it day in and day out. It's like the sword of Damocles hanging over you, but, we'll call it the syringe of Damocles, I guess, a more appropriate metaphor. But it's the cloud hanging over you all the time. You can never escape from it.

So I think for teenagers, we often interpret not taking care of their diabetes occasionally during the teenage years as rebellion, where a lot of times it's just exhaustion. And there's always this temptation to just forget about it, right? Say, I need a day off. While mentally, I think that's okay, physically, you really, you can't have a day off because if you have a day off, then you run into problems.

Dr. Hoyle: Correct.

Matt (host): Immediately, it can be an immediate problem. And then obviously keeping a high A1C for an extended period of time really does lead to complications down the road. So you have to manage that very carefully. I don't think it's right to give up any of the normal milestones that you face as teenagers. You can certainly adapt to all that, but you can't also deny that you have diabetes.

Correct. And you can't just completely forget about it. So it's a tough thing to navigate. I will say that today's teenagers have it so much easier. I had to walk barefoot, through the snow in But, school, that sort of they have CGMs

Dr. Hoyle: Correct. Yeah.

Matt (host): Which allows you to monitor what's going on in the background. You don't have to stop your life. You just have to look at your phone app, every now and again, to see what's happening. If it's, if you have a pump, or better yet, like a closed loop system where, the CGM gives the pump information on where your blood sugar is, the trends that it's encountering, and then the pump will adjust the insulin based on that, which is fantastic. I've never worn a pump.

It's been around for a while. For whatever reason, perhaps I'm just something of a Luddite, but I don't want to carry around more tubing and so forth. Early on, I was very active. I was concerned about falling on it and damaging it. But, one of these days, maybe I'll finally get with the modern times.

And the closed loop systems really are pretty remarkable. And it's just a sea change from the technology that was available back in the 1980s when I was a teenager.

Dr. Hoyle: Right. And I would say it is remarkable how much progress we've made and it's organizations like children with diabetes that have helped move all that technology forward. And so it's when I was starting residency, in fact, my first patient, on the very first day of residency, 07/01/1997, I remember what my first admission was an 18 year old with a new diagnosis of type one diabetes. And so at that time, it was still lots of blood sugar checks, sticking finger

sticks, and then dosing with different short acting and long acting preparations. Over the course of my career, it has changed so much.

It's so much better for patients and families, but it is still a chronic condition and it is something that sometimes in adolescence can cause some bumps in the road because most of the time for adolescents, one of their core values is to be like everyone else. And so, when there's something, especially a chronic medical condition that interferes with that, then there are challenges that are inherent to that issue.

Matt (host): Yeah. Let's dig into some of the real world trouble spots.

Dr. Hoyle: Sure.

Matt (host): There's peer pressure. There's the social life aspect. And, some teens are embarrassed by having to sneak off to inject if they're doing MDIs, and multiple daily injections. And then, of course, if there's, like a sleepover, they'll have to deal with it then. Parties, late nights, and then even, risky behavior like, like alcohol.

So the teen life isn't steady like we, we want the diabetic lifestyle to be, right? You know, like, sort of steady state because that's what you want your blood sugar to be. Right. You want to be a flat line as much as possible, but life isn't like that. So from, from a clinical standpoint in your practice, where do you see the teens most likely to stumble?

Dr. Hoyle: Right, so teenagers in general, they often do, or at least want to feel invincible, which is a normal feeling at that age. And they also are enjoying to some extent some level of risk taking behavior. And just like we talked about becoming, as we're transitioning into adulthood, we want to have agency. We want to be able to make our own decisions. Sometimes for kids with diabetes and some other chronic conditions as well, having that additional level of risk can be problematic.

So for most parents, we're all aware that teenagers will sometimes engage in risk taking behavior. A lot of times we're worried about alcohol use or substance use. And then the stakes are higher, right? For kiddos with type one because if you're engaging in things that potentially could alter your state of consciousness, then there's running the risk that you can run low like on your blood sugar.

Matt (host): And not realize.

Dr. Hoyle: Correct, right. And so that was traditionally one of the biggest challenges that we had for kids who had type one or that they would just let those blood sugars really go up. And in fact, there was a period of time, like during my training and in the early 2000s, that one of the things that folks would do would be to sort of let their blood sugar run high. And it was a way to control their weight the way that they wanted to. And of course that is a big problem because ultimately

if your blood sugar is high like that, your A1C is going to be high, it's going to reflect all these other potential downstream things.

But of course teenagers tend to live in the moment and are not necessarily thinking about, Oh, I shouldn't do this because when I'm 50, then I'm gonna have eye problems or limb problems or other issues because they're thinking about what's happening in the moment. A lot of that has been alleviated by the CGMs or continuous glucose monitors. In fact, for most of these devices, parents who are also on the app can see their numbers. And as a parent and as a physician, we're like, oh, that's awesome. We'll be able to know what's going on and we'll get an alert if the child is low or what's happening.

But sometimes to teenagers, that feels a little invasive for their parents to have all that biometric data on them all the time. And so we're constantly, as each new technology becomes available, we have to sort of rethink what that relationship then looks like between the patient, the parent, and the condition so that we're maximizing it without losing the ability for the patient to develop agency like they need to during their teenage years.

Matt (host): Right. And so as we've talked about with our therapist friend, Martha Metzler, a couple of times, you have to be on the banks of the river and not control your child's navigation with diabetes, but you need to be at the same time helping them not get wildly off course. And we often talk about it as being the manager of diabetes when the child is really young to being more of a coach. It's not an easy shift, is it?

Dr. Hoyle: It is not. And so for parents who have had, especially I can only imagine for your parents to have a four year old so that by the time you're in your teens, they had been managing this for a long time. And they had done a great job and had known what all of the lab work was saying and they were getting pretty significant feedback. Like you'll get that A1C level, every few months and know kind of how things are going. And so for a lot of parents, that has been a source of reassurance that things are going well.

And so for parents to be able to start stepping back a little bit and not what we would consider to be micromanaging their kid's diabetes, which I would say for a really young child, micromanagement is completely appropriate. Exactly. So, this is one of those things where we do have to potentially figure out how to thread that needle between knowing that the child is probably like those, as we back off, those A1Cs may go up a little bit, which would indicate not as tight control. And then knowing kind of when to step in to say, okay, well, we need to get this back on track. I'm sure it was a very delicate conversation.

And that would be something that people who have kids with diabetes are probably constantly grappling with.

Matt (host): Absolutely. And this underscores the need for, we always talk about on this podcast, we talk about it takes a village to raise a child with diabetes. It absolutely takes a village. And that includes your physician, whether it's your pediatrician or your endocrinologist or both, and

your parents and your friends. And I think back on my teen years when, and childhood years, when, we didn't have all this technology.

And so there was a lot of just visceral, management of the disease. You had to go with how you felt, which is both good and bad. I mean, I think it's served me well in certain circumstances. I can kind of judge when things are going wrong. Right?

But at the same time, I was lucky and I had very intelligent and just wonderful parents who just found that right balance between absolutely taking care of it, but also when I got older, me to find my own course, to make some mistakes and to be there to make sure that things didn't get out of hand.

Dr. Hoyle: Right, right. And it also sounds like they encouraged you to be physically active, which of course is a huge benefit to folks.

Matt (host): It was a huge benefit for me. Would submit for really all type one diabetics, find something to do actively, sports wise. It really does assist with the control, For me, it was I wasn't a natural athlete in terms of coordination. I first tried playing soccer and wasn't particularly good at that. And then, baseball, I didn't have a successful little league career.

I think the coach put me out in left field hoping I'd get lost somewhere. And then, I tried basketball. I'm tall and I was tall as a kid. And just you'd think I'd be a natural for it, but really, I was not. So eventually, I got in like, there was a bikeathon event, through the local chapter, the JDRF, which my mom actually helped develop as she started, founded.

And so my dad was a recreational cyclist, and myself and my older brother went and did that, and I really enjoyed it. And I found that, of course, they had rest stops with all the food I'd need. So it was a great way to help control it. So initially, just got into doing rides. There were some bike paths where I grew up in the Washington, D.C. area that I was able to ride on and was relatively safe. So I got into doing that. And eventually, the desire to be a competitive cyclist bit me after seeing the nineteen eighty four Olympic road race on TV. And so I started racing in 1986.

And so at that point, I was riding a lot, riding every day, and eventually found, sort of, found my niche. I had an unceremonious first race. It got dropped fairly early on and limped across the line. But the second race I did, I got second place. So I found some immediate success that kind of hooked me into it.

And so through that, I found a way to help control the disease, the condition, and I also found friends. Eventually found a friend who was older, but he was a type one as well. And, so we rode together. He lived not far from me. And so we rode together frequently.

He was also just a really good role model. He had a couple of young kids, was an IT software engineer, and just was really doing well with his life. And so he was a real role model. And

obviously, did well with his diabetes management. And so both having the sport to become involved with and meeting with some success and then meeting other people who were dealing with it was for me just a real game changer.

And it helped me get through those really tough moments. Eventually, I became an elite level racer. And so when it came I couldn't necessarily just in terms of my performance, if I was racing a lot, I I couldn't go out and just get hammered at night, you know? Right. And so it was sort of a surrogate for my diabetes control.

Like I couldn't drink because I didn't, I wanted to do well in my events. And, it also helped with diabetes control. So, but again, this was before CGMs. And so there were some moments that were certainly challenging. I remember early on I had glucose tablets, which I would carry with me during longer, like road race events.

And eventually, people knew that I was diabetic in the Peloton, the racing Peloton. You build sort of friendships and even your rivals, there's sort of a chain there's a shared destiny. So people looked out for me. That's great. But I also looked out for them because, they knew I had these glucose tablets.

So occasionally, competitors would be themselves lagging. They weren't type ones, but it's an intense sport and sometimes you can run out of energy. And so they'd ask me for a glucose tablet and, I built some relationships that would come to my benefit down the road.

Dr. Hoyle: Right. I bet.

Matt (host): Absolutely. Would in turn do favors for me. So it was a game changer for me. I think for today's teens, it's the tech. The tech is a game changer.

These continuous glucose monitors, the pumps on all the apps. It's also, I think we've talked about how the online world can be a hindrance to mental health in many cases. But these days, you can find all these communities.

Dr. Hoyle: Correct.

Matt (host): All these sort of subcultures. There's actually a professional cycling team now for type one diabetics, team Novo Nordisk. And there are groups of type ones who ride together Yeah. And so for any sport, you can find that. And, there are also major sports figures who have made it known that they have type one.

Dr. Hoyle: Right.

Matt (host): In many cases, prior to acceptance or widespread acceptance of type one, these athletes had to sort of keep it on the downlow. It was a secret. They couldn't really be out with it. But thinking of Gary Hall Jr, the swimmer, who has type one and won all those accolades in

that sport. There was also a cyclist, during the 1980s, but when I was racing, I didn't really find out about him until a few years down the road, but his name is Dominique Garde, and he was a French professional who had type one.

And it's just an amazing story because he rode the Tour de France, I think, five times. The Tour de France, maybe the hardest competition in the world. And, he not only finished it all five times, he finished, I guess, highest twenty fifth overall, which is pretty amazing. And, he also won this major, multi day race in France called the Mide Libre, which goes through the Alps and was very difficult, it was sort of a warmup event for the Tour de France. And he won it overall with type one.

But he had to sort of, he couldn't be, wear it on his sleeve necessarily because he was facing discrimination. So getting the word out there to kids that they can live full lives with diabetes, I think is really important because managing diabetes is not just physical. It takes the mental toll, as I've talked about. And there's burnout and anxiety and things like depression. They're more common in teens with type one.

I certainly had my own struggles with it. I think a flux contributes to that, right?

Dr. Hoyle: Right.

Matt (host): And that's so let's discuss that a little bit. How do you, so how do you screen screen for support teens who are going through the emotional burden of

Dr. Hoyle: Yeah. Type And so there definitely are kids who will get frustrated with the situation. And of course that is improving as we get better at being able to manage it with technology. And so we do our typical evaluations for worries and sad feelings and that type of thing. But I will say that there is a bit of a, like there's kind of a balance to it in that you had sort of talked about that there is a community around type one and, and for some kids that having that community, it can be extremely helpful.

And so, when we think about the two big developmental tasks of this age group, building agency and building community, type one diabetes, kind of a little more emphasis on that for those kids. And so if you're, doing things, you're on a sports team with the, with, and you have friends on your sports team who know what your condition is, sometimes that can be really helpful in being able to kind of keep an eye out for you, like you were talking about from cycling and stuff. And so, while there, it does increase the risk of that sort of frustration, anxiety. Sometimes I'll have kids who will wonder why this happened for them. But it does feel like most kids are able to recognize it as a condition that's separate from them, but it's something that can at least to some degree give them the opportunity to work on both agency and community, maybe a little sooner or a little more intensely than their peers.

And a lot of times, having that experience makes them even better like friends to other kids, make them a little more socially fluid. It just depends on how that child is able to respond. And

so, and I also feel like that for kids who have had a chronic condition or dealing with a chronic condition or have a sibling with a chronic condition, a lot of times those kids to me seem a little wise beyond their years. And so that makes them just like a little more capable of putting things in perspective as far as anxiety, about like day to day things. And that also, I think just helps them function at a bit of a more mature level, which I think is really helpful. Become mature quicker because you have to.

Dr. Hoyle: Right. I would also choose that choice. Yeah, exactly. And I do think that like for folks who like, again, this is not necessarily a benefit of having this condition, but I do think that for most folks who do well with it, they have realized that some of the pitfalls of adolescence are really just higher stakes for them. And so they may be a little less likely to go down the path of getting involved with things like substance use and that type of thing, because they do need to be aware of their situation and surroundings, in case they have a crisis.

Matt (host): Yeah. Yep. And the support of parents and going back to that support team where we talked about, having a good physician is really important. I remember having one of my doctors, we were talking about how things were going. This was when I was in my 20s or 30s.

And, he just said, Listen, of course it sucks to have type one, but he's like, It may be a blessing in disguise in many ways. He's like, I think through just a healthy lifestyle, your chances of avoiding a lot of the things that catch up with people later in life, like a drinking problem, like a poor diet that can lead to a host of conditions. Correct. I think there's every reason to believe that having type one, can help you avoid some of those pitfalls. And that brings me to, bring me back to the moment, in the booth in Denver.

Receiving the fifty year medal was powerful and not just for me, but for the families who saw it and who see it. It's proof that you can live, thrive, not just survive, but thrive and achieve your dreams with type one diabetes. You always have to remember that because there are a host of reasons why the toll of living with it can really bring you down. But there's always hope and you can live a long life. And the gentleman who gave me the medal said, We hardly ever give out one of these.

Right. It strengthened my resolve to receive that seventy five year medal.

Dr. Hoyle: Right.

Matt (host): And that's my goal, absolutely. And these days, with all this technology, with all the advanced medical care and the support from not only parents, but friends and family who live with this disease. And that's something that the online community has really fostered, this sense of you're not alone. There are resources and there are people who are often going through this. So I think it's important to remember that a diagnosis of type one, and I hope that when parents hear this, that the diagnosis of type one doesn't define the rest of their child's life.



Matt (host): There are other factors that will define it, and there really are no limits, especially with this improved technology. I have a friend who, he's an extreme athlete, makes me look pedestrian by comparison. He bungee jumped a number of times. He's jumped out of airplanes, parachuted. He's done adventure racing, these ultra marathon sort of adventure races where they throw you in the middle of the forest, and you have to make it out alive.

And, you know, he's done this with, he uses pumps, but he has to take along spare pumps because he's not always sure that the pumps are gonna survive the rough journeys. But he does it, and he just never has said no. If there's a challenge, I wouldn't be surprised if he's one of the people who is gonna maybe maybe a type one with who who's gonna scale Everest someday.

Dr. Hoyle: Oh, wow.

Matt (host): That would be sort of the ultimate test, I suppose. But, really the only thing that you still can't do with type one is fly a commercial airliner, which is kind of a shame because that was the one thing that I kinda always wished that I would be able to like, I thought being a pilot would be a really cool job because I like I like air travel, but, I don't know. That might change.

Dr. Hoyle: Yeah. In the future, that may

Matt (host): be available. Technology and Mhmm. There's always redundancy in in-flight crews, and hopefully, they'll still stay the case. I mean, a single flight cruise is not a good idea for a number of so long as there's someone, if there is some sort of problem, someone can take over. But again, with this technology it used to be that people with type one couldn't do things like have a commercial driver's license.

Now they can, they have to go through routine sort of checkups. And then anything else. There are physicians, of course, with type ones, with any sort of job outside of really being a commercial airline pilot, you can do so type go for it. That's my advice. So we've covered a lot today from the adolescent transition to all the common pitfalls and to strategies for parents and teens and the vital importance of mental health through the struggle with type one.

And, we ended with what I hope is the biggest takeaway that with the right support with this community, teens with type one diabetes can live full and thriving lives.

Dr. Hoyle: That's right.

Matt (host): So thanks for listening today to Nimble Youth. Be sure to follow us on Facebook and Instagram, visit our website. We'll have special links for this episode for kids with type one, kids and teens with type one will have some links to resources that you can access. And there are many resources. You are not alone.

Please always remember that. And until next time, please take care of yourselves and your young ones.