



Selected transcriptions from
the award-winning podcast.

Diabetes Connections

with Stacey Simms

diabetes-connections.com

Diabetes Connections EXTRA

Stacey Simms

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Introduction

When I started Diabetes Connections in 2015, the idea was to provide a new resource: a weekly podcast about diabetes from a professional journalist. I wanted to use my 20 years of broadcasting experience to provide T1D news and information, along with great stories, shared experiences, and inspiration. I'm very proud of the show and after more than 320 episodes, a wonderful loyal audience and several awards, it's fair to say we've hit the mark.

There has been one thing missing, though. Since episode one, listeners have asked for transcripts. I've been reluctant to provide a written version of any episodes, until now. Part of what held me back is the changing nature of the subjects I cover. Interesting in the moment or even the month, does an interview about a diabetes company now out of business or technology now obsolete hold up years later? Transcripts are also expensive and time-consuming.

Here's what changed my mind. I'm in dozens of closed Facebook groups that focus on diabetes. I speak at conferences all over the country. Time and again I see newer diagnosed people and families asking the same questions. I see long-time D-parents and adults in our community with misconceptions and common worries. I decided that there was a place for the podcast to help.

Starting January of 2019, I would focus on a basic issue of diabetes management once a month. We'd do a deep dive with a healthcare professional and create a longer, more in-depth episode that could be shared for a longer time, perhaps years. I realized this was the perfect type of show to transcribe. I looked back through the show archives to see what other "evergreen" types of episodes would make sense to include.

What follows here is what I'm calling "transcription-plus." We don't write as we speak and we don't read in the same way we listen. To help "translate" I've cleaned up the text a bit. No meanings have been changed; if you listen to the episode while you read, it will be very, very close. But it's not exact. Please also keep in mind that these are not formally written and edited essays or articles. They are conversations.

Some of the conversations that include specific technology or brand names may be dated. Check the "date aired" at the start of each chapter and check back to Diabetes Connections for updates. There's a search box on the homepage, so it's easy to find out if there's more information on a topic that grabs your interest. Enjoy, share and learn!

Thank you for listening and for reading!

Stacey Simms

HOST, DIABETES CONNECTIONS



LISTEN AT WWW.DIABETES-CONNECTIONS.COM OR ON ANY PODCAST APP.

Guilt Free Food Advice

with Melissa Joy Dobbins

[EPISODE ORIGINALLY AIRED 10/24/2017]

Melissa Joy Dobbins is an award winning, nationally recognized food and nutrition expert, certified diabetes educator, registered dietician nutritionist, spokesperson, speaker, blogger and podcaster with more than 20 years experience and a proven track record of providing real solutions for real people so they can enjoy their food with health in mind.

Stacey: Melissa thanks for joining me. I think this is going to be a lot of fun. I'm glad to talk to you.

Melissa: Oh Stacey, thank you so much for having me on your show. I can't wait.

When we talk about food and nutrition there are so many different topics and directions we could go but let's just start with you. Why was this interesting enough to you to make it your career?

I remember being in high school and watching infomercials with people selling pills and powders and books and products and wondering what it was all about.

I grew up studying ballet. I am from a very artistic family. My father was an actor, director and playwright. My mom is the visual artist, graphic artist. My brothers were musicians. And so I was a ballerina and I wasn't even going to go to college. I went to a performing arts high school where I saw all kinds of crazy nutrition diet stuff. I remember thinking to myself, there should be somebody here to talk to us about food; there should be somebody here to talk to us about the emotional stuff that goes along with food. I didn't know what a dietitian or a counselor was.

I like to say I survived that performing arts high school. I went back to regular high school for my senior year and had an excellent chemistry teacher. I'll never forget, Mr. Rudolph. He kind of looked like Kris Kringle, which was kind of funny is it was Mr. Rudolph. He was just the best teacher and he made me love chemistry.

I had moved around a lot growing up. I had gone to three different high schools and all of a sudden it was

like bam. I'm going to college. I was never going to go to college and everything kind of happened really fast. So I said "Well, I'm good at science and I have to make a decision." So I went into college as a pharmacy major because that's what all my chemistry classmates were doing. I barely survived, about three semesters of organic chemistry and biochemistry before I realized this is going to be the death of me.

I went to my college counselor and I said, 'Okay, I'm good at science, but I want to work with people. I don't want to be in a lab somewhere. This is just really abstract. I just don't get it.' And he said, 'Well, you should look into dietetics.' And I said isn't that a book by L Ron Hubbard? I'm serious. I thought I'm like dietetics, right? So for those who don't know that's "Dianetics" and so he's like no, no, no, check this out. I enrolled in a few classes and then I made the mistake of volunteering at the local hospital where they put me on the tray line. And I thought gosh, you have to have a college degree to plate up food. I'm so confused, you know. Long story short, as soon as I took some nutrition classes and most of all saw the campus dietitian in action. She was helping a group of sorority girls talk about like body image. I was like, that's what I want to do. I want to help people sift through all this nonsense and craziness and you know, take care of themselves in a way that's healthy.

I'm fascinated by the ballerina experience and I want to go back to that because you must have seen many difficult eating situations firsthand. But do you have a personal connection to type 1 diabetes? Or any diabetes?

My grandfather was diagnosed with type 2 when he was 80. Which was probably right around the time that I got out of grad school and started working as a clinical dietitian. I worked as a clinical dietitian for a couple of years and then had my dream job as an outpatient dietitian. A short time into that job, I covered for a colleague in our Joslin Center for diabetes. That's when I realized I love working with people with diabetes. I was getting kind of burnt out on eating disorders and weight loss and I just was like wow, this is so interesting and I can really help people. I can really empower them. It was so rewarding and that's when I became a Certified Diabetes Educator, back in 1997. I'm happy to say I have maintained that credential for 20 years, which is not easy.

Aside from my grandfather who got diagnosed with type 2 at the age of 80, my father who since passed away, was diagnosed with type 2 in his early to mid 60's. But my niece was diagnosed with type 1 when she was 14. Now my father and my niece didn't happen until I had been a CDE for over 15 years. So yeah, it was it really wasn't because of any direct personal experience. It was really that that work experience and just seeing what a huge difference I could help, I could make in people's lives that they could have a more fulfilling positive life, quality of life.

Did your niece's experience change your perspective on working with people with type 1 at all?

Not really. Most of my work with diabetes is type 2. I have done a little bit with type 1 but as you know, the majority of people with diabetes have type 2. So I was in, even though I worked initially at the Joslin Center for Diabetes, I was really based in a more general setting. If somebody had type 1 they were going to go to our Joslin Center, they were going to go see a specialist. I was seeing more of the typical type 2s until about 2011 when I

worked in a high-risk OB clinic and a lot of that was gestational diabetes. There were some type 1s on pumps who got pregnant and some multiples and things like that, but the majority of my experience has been type 2. So when my niece was diagnosed with type 1, I was just at a loss. I was like, I don't even know where to begin to help you. I did an interview on my podcast with my niece and my sister-in-law to delve into their story and kind of how that all unraveled. Well, not unraveled, I mean unfolded.

There's a lot of unraveling.

Yes! It was a really hard interview for me to do because it, it was a very emotional situation and I felt helpless. Even as a CDE, I felt helpless and I remember calling a friend of mine whose son had been diagnosed around the age of nine or ten. I said to her, 'What do I do? How do I support my niece and my sister-in-law and my brother and my other niece?' I was thinking about sending a care package. And she said, 'Great, idea, make sure it has nothing to do with diabetes.'

Exactly.

That was the best advice I ever got because I realized, I just need to show her my love, my support, and that there's more to her than this. My daughter and I went to Walgreens and we got magazines and nail polish and blankets and fuzzy slippers and things like that.

That is such a great bit of advice. Because you know, you want to be reminded that life goes, on it's going to be okay and that you as the aunt, you're still seeing them as people, not the diabetes people. In 20 years as a CDE, is there any advice that you give people that has changed significantly since you started?

Yes, a couple of things. The biggest thing I've seen in my 25-year career is the emergence or the detection of vitamin D deficiency and the changes in the recommended daily amounts. The recommendations are higher than they used to be but they probably still need to be higher. A large portion of the American population is Vitamin D deficient. The only way you know for sure is to go to your doctor and have your levels checked. I'm in Chicago, I don't get a lot of vitamin D from the sun and that's our primary source. So especially if you're in a Northern part of the US, we're not getting enough vitamin D from the sun. Also because we use sunscreen, we cover our bodies, so that we don't get skin cancer or things like that.

The other problem is because the primary sources the sun, it's really not found much naturally in foods. And then you know, some foods are fortified like cow's milk vitamin D is added to that. But it's almost impossible to get the amount that we need from food alone. So, if you do have a deficiency, you do need to supplement and in my field we try to say food first; try to have a balanced diet. But no one has the perfect diet – I'm a dietician and I don't – so if there are some deficiencies here and you might need supplementation. Case in point, about 15 years ago, I was diagnosed with a B12 deficiency and I'm not a vegan or vegetarian and B12 comes from animal foods. It's important to work with your health care provider and see what your levels are

Is Vitamin D deficiency particularly troublesome in people with diabetes?

There is research looking into the connection. In fact, I just did an interview for Everyday Health on calcium and diabetes and when I was looking into the research on that, it's not just calcium, it's calcium and vitamin D together, decreasing the risk for developing type 2. Now type 1, as you know, it's a completely different disease. So there is some research looking into the connection between vitamin D deficiency and the incidence of type 1 diabetes. But vitamin D deficiency is hard to detect and the symptoms are kind of vague. It may be closely related to cancer and MS and other diseases, so it's really important that people know if they're vitamin D deficient or not. And the one thing that's really important is if you do go to your doctor to get your levels checked, and you are deficient, you need a prescription level dose to get you back up into the normal range, and then you need to go on a maintenance dose. People say, "Oh, well, I'm deficient, I'm just going to take an over-the-counter supplement." That might not be enough to get you back up. So that's something people can talk to their doctor about.

What else has changed?

I first became a dietitian back in 1993, when I started my hospital job. Shortly after I started is when carbohydrate counting came about. So I was learning how to do, you know, it's clinical so mostly tube feedings or the ADA diet the American Diabetes Association diet. I remember clearly when that changed, another dietitian trying to explain to me that a carbohydrate is a carbohydrate and I was just like what? Wait, there's sugar and there's simple carbs and complex carbs. What do you mean a carb is a carb? But once I kind of wrapped my brain around it, I realized this is good. Previously, the exchange diet, which most people are probably familiar with, gives you a certain number of roots, a certain number of vegetables, certain number of grains, certain number or certain amount of protein. But nobody eats this way every day. Even as a dietitian, it's challenging. But carbohydrate counting gives people a flexibility on how they want to spend their carbohydrate allotment per meal and per snack. And I just feel like it was a complete game changer.

We came into diabetes in 2006 when it was still kind of mixed. I knew, I knew people who were still doing a little bit of exchange. I knew people using older insulins who really had to "eat to the insulin" with set meal times and amounts. Whereas we jumped right into carb counting and I can't imagine doing it any other way for a two-year-old. It was so much easier than I think it could have been. Although in the beginning we counted every single carb. We measured ketchup and counted out peas. Until I went back to my doctor month later. He laughed and say, Stacey, you're doing great, but simmer down.

Well, of course. It's scary!

What about the lower carb trend? What you think of super low carb? I think there are a few different ways to

look at this. We in America all probably eat too many carbs to begin with. But I'm talking about a low-carb high-fat plan where people are trying to get in fewer than 30 carbs a day. Where do you come down on that as a dietitian?

First of all, I completely agree, as a nation, most of us are eating way too many carbs; whether you think they're good carbs bad carbs, whatever, we eat way too many carbs. What I recommend for people with diabetes is what I recommend for everybody: just have a little bit more balance in the diet. Maybe you need a little bit more protein. Maybe you don't, but when it comes to specific diets or types of diets, like low carb, paleo, vegetarian, that sort of thing. The first thing I would ask an individual is what's your preference? If you really like a vegetarian lifestyle diet, I need you to know that you're probably going to have more carbohydrate in your diet than somebody else so it might be a little bit more challenging for you to control your blood sugars. If you tend to like more of a Paleo, that's different too. Of course, I'm talking the extremes.

Sure

With a Paleo diet you will have fewer carbs and it might be easier for you to control your blood sugars. So, I like to start with you know, what what's your tendency? What's your preference? Where are you at? Because if you're trying to do something that is completely different than what you tend to like, it's going to be hard to to sustain. At the end of the day, research shows kind of all diets work and no diets work. In other words, the only diet that works is one that you can live with. That's why it's so individualized.

I encourage people to kind of experiment a little bit; maybe try to cut down on some of your carbs. Try moving towards that and see if that works for you. As a starting point, think about half of your calories from carbohydrates and spread them throughout the day. See what that looks like. If it's too much carb for you, go ahead and cut back. My concern with the really low carb like 30 grams a day is, not only do I see anything extreme as almost impossible to stick with, our brains need glucose and our bodies need carbs for energy. So if we don't give our body that then it has to break it down from our protein and fat stores. I don't know that there's a lot of research that shows this is not the healthiest way to provide energy for your body. But if you eat this way and you like it and you feel good, who am I to judge? Everybody is the master of their own body and their own preferences.

I will say to make sure you're not fooling yourself into thinking that this is what you have to do in order to be healthy. There's a lot of different ways to eat and be healthy.

What I hear a lot with those really strict carb diets is that you're going to reverse diabetes or cure diabetes. That's when I just like lose my you-know-what. Because I don't want to give people false hope. With diabetes, yes, you need to do the best you can with diet and exercise and taking the medications that you're prescribed in the proper amounts and as prescribed. But this whole concept of well if I just do this, I can get off insulin or get off these pills - I just like to take a step back.

Let's say, you have high blood pressure, and it wasn't a salt related high blood pressure, it's genetic, it runs in your family. You have high blood pressure. Would you be saying, 'If I just do XYZ and I'll get off the blood pressure medication or other medication?' We don't see that. Sure, people are concerned about side

effects. Absolutely. We don't just want to load up on a bunch of pills, of course not, but we see this reluctance especially in diabetes. There are medications for a reason. There are different kinds of medications that work in different ways. And that's a tool in the toolbox that I want people to feel good about using and not feel as though the whole goal is to get off of that medication.

Exactly. You don't fail if you need it. If you're trying and you've changed your lifestyle and you realize that nobody's perfect. There is this shame, I think, that's in diabetes. That's not around high cholesterol. That's not around high blood pressure. It's amazing to me.

Yes.

Melissa, one of the things I really enjoyed seeing was that you were talking at some of these conferences that we all go to, to health care providers about social media. How difficult is it to get some of these doctors, health care providers to be okay with even little logging on to Twitter? It must be such an interesting discussion.

Oh, it is and it's something that I'm very passionate about. Several years ago. I was asked by Today's Dietitian magazine to write a 4,000-word article on diabetes and social media. I was thrilled and I cranked out a draft and you'll understand, there's a difference between social media and mobile health. Social media we're talking like Twitter, Instagram, Facebook. Mobile health means things like software and apps and things that have data you can share with your healthcare provider.

So I wrote my outline and that was approved and I clarified that I can talk about social media and that mobile health is not my arena. But later, my draft was rejected because they decided they wanted to go more in the mobile health range. But the beauty of this, and this is really how I live my life, things happen for a reason. One thing leads to another we may not see what it is at the time but be open to the journey, right?

So I was like, wow, you know that was a lot of work, but when I was writing that 4,000 word article, I interviewed people like Hope Warshaw, Joe Weisenberger, Toby Smith's son, other colleagues of mine, Manny Hernandez, who have diabetes or are diabetes educators who work in that space. Doing that told certain people in that arena that I'm really passionate about this topic and that led me to speak at AADE in New Orleans, which was three years ago.

I did a presentation on social media and diabetes and then I did a workshop with Hope Warshaw who's written many, many books about diabetes. She's the RD CDE guru and we had over a hundred people in the room, and we had tables of 10, and we had a leader at each table, to kind of help people log into Twitter and learn why they should do this. To learn the importance of meeting people with diabetes where they're at. We need to make sure that to be plugged in and in that space. And it was so well received that right after that session, they said let's do this again next year in San Diego. So I did it again in San Diego and that's when I realized we needed a different way. With a table of 10 there's still 10 different experiences. One person doesn't want to do Twitter. They want to do Pinterest. Or someone's been on Twitter, but they forgot their login. Or someone's got an Apple.

Somebody's got Android. I said we need a booth at the expo hall with a techie guy and a CDE and we need to walk people through this one-by-one.

Because diabetes educators oh my God, they are the salt of the earth. They will do whatever they can to help their patients and clients, but a lot of them don't get the social media thing. Who does, until you dive in and do it? You learn by doing. And that flies a little bit in the face of science health educators, because we are not trained that you learn by doing. We are trained here's the science. Here's how you do it. You practice, practice, practice, and then they release you to into the wild. It's just a whole different mindset. It's not as rewarding as working with somebody with diabetes, but it's almost as rewarding to work with a diabetes educator and say, okay, let's think about this differently. Here's how we can approach this; it doesn't have to be a time suck. You can make it work for you. Where are your patients? What are your passions? And just see them go, 'Oh, wow. I'm so excited. Now. I know how to help my patients.'

That's fantastic. Melissa, before I let you go, one more question for you. Did I read that you are taking ballet again?

Yes, after a 25-year hiatus, a couple of years ago. I went back to ballet. It started off as a midlife experiment of running, which I hate and that led to a triathlon which is a really strange way that that that came about. I'm the last person you would think to do something like that. And when I did that which I will say two things. Doing a triathlon is a little crazy, but also well, I did a sprint triathlon. So it's a very short one. But it's still like a 5K run and a 20K bike I think, and at least 15 minutes of swimming. I mean, it's a little crazy. But at the same time, having done it, I firmly believe anybody can do one if you train for it.

And as a side note, I heard Jay Hewitt speak several years ago; he's a triathlete, and he has type 1 diabetes. He was so inspirational and I just sat in the audience going, 'Oh my God, I'm so lame.' This guy is ripping off his wet suit and making sure his insulin pump doesn't come out and you know, he's crashing, like literally not crashing his bike but crashing his blood sugars and has it go to the medical. And he finishes and it's so inspiring. He planted a seed. It was years before I acted on it. But that seed was growing in me for a long time going, 'this guy's amazing. I need to, I need to run because I can.' After I did this triathlon I thought, "Oh my God if I can do that, I can go back to ballet." And so I did and I have been loving it. So amazing.

I love it. Melissa, thank you for joining me.

Oh, my pleasure. It's been so great talking with you.

More from Melissa at: www.soundbitesrd.com

Get Diabetes Organized

with Susan Weiner

[EPISODE ORIGINALLY AIRED 01/02/2018]

Susan Weiner is an award winning registered dietitian-nutritionist and certified diabetes educator. She is the 2015 AADE Diabetes Educator of the Year and the recipient of the 2016 Dare to Dream Award from the Diabetes Research Institute Foundation. Susan is the author of *The Complete Diabetes Organizer*. She is a highly sought-after national and international speaker and has authored dozens of articles on diabetes, wellness and nutrition.

Stacey: Susan, thanks so much for joining me and Happy New Year.

Susan: Thank you Stacey. I'm so excited to be here and happy and healthy New Year to you and your listeners as well.

Thank you so much. You know, it's funny. I was so excited to talk to you because after 11 years now of type 1 in my house and my husband has type 2. We have stuff everywhere. You know, we try to stay organized and I have my cabinet and then we have a bag in another bag and then but there's stuff everywhere. And then it's the routine and the doctor's appointments. So I know you're going to fix me and everything's going to be good today. How do you start? It seems overwhelming when you have to do as much as you have to do for diabetes.

Oh, you hit the nail on the head. I start off my presentations by telling participants that we don't do diabetes perfect and we don't do organizing perfect. So start with one small piece that can help your day and your diabetes day go a little bit more smoothly. Maybe that has to do with the supplies that you need when you leave the house in the morning. Maybe it has to do with preparing what you need for the next day the night before. We can talk about a few of those little things throughout our discussion today, but just start very small. Any one little thing that you want to do is going to go a long way.

When you're starting out, how do you even know what to pick? How do we start?

I like starting in the kitchen. Maybe that's my registered dietitian hat speaking. We ask people to prepare healthy meals and they have the education in so many circumstances. They know how to carb count. They know more about portion control, what's healthy and what's not. So why aren't they doing it? Could it be that they can't see their countertops? Or that everything is so jumbled up in the refrigerator or pantry?

Start by stepping out of your kitchen for a moment and looking in. See what you want to tackle first. Choose one small space; maybe it's the countertops. Let's start there. If it's overly cluttered with newspapers and maybe bills that you have to pay or doodads that you put on throughout the day and people just left around. Start by decluttering there. Decluttering gives you such a fantastic sense of accomplishment. You can find what you need when you declutter. The second piece in the kitchen, which is so helpful, is move things out that you're not using day-to-day. If you still have your Christmas china out in the kitchen, and it's already January, it's time to reassign that to a different place in your home. So you can get to your usual pots and pans and wares that you need for day-to-day meal preparation to make it that much easier for you. So start with decluttering one small area of your home and the kitchen, as the hub of the home, is usually the best place to start.

That's a great point about the kitchen because my husband and I did that a couple years ago. He loves the kitchen and he likes stuff – he likes the mixer and the coffee stuff that he has. We had to figure out what really needs to stay out and what we can move so we can see the countertop.

Absolutely true. I use the acronym SPACE. Space starts with S for sorting. Sort what different things in the kitchen what you're using every day. If you have two coffee makers, you want to use one and get rid of one right? To make more space start by sorting. P is for purge. Donate, get rid of the stuff that's chipped or broken or that you're not using. A is for assign. Move things to where you need them to be in the kitchen or into another place in the home. C is for containerize. Put things into clear containers because "clear is king." You can see through them and know what you have. And then E is just for continuing the efforts of maintaining whatever strategy you're using. So these little acronyms help us realize how to organize and really how to stay with it. How to equalize the system.

That Purge one is really hard for me. I sometimes need to call my sister or my husband. To just confirm that it's okay to donate or throw something out. Sometimes I know it's junk! Why do we hang onto stuff?

If you haven't used an appliance in about a year, that's the gold standard that I use, get rid of it. It's the same thing with clothing that you're holding onto forever. And, Stacey, so many people are in need. If you want to donate to a Goodwill store or your church or a synagogue, people can definitely use what you're not using. But tossing it and that feeling of openness that's going to help you feel more accomplished and less cluttered is going to help you stay organized, stay focused and really stay motivated.

When I thought about diabetes organization, my first thought is the cabinet with the supplies. I'm a cluttered person. I don't mind piles and things like that. It's kind of embarrassing to say I'm not the neatest person in the world. But, whenever we get a new shipment, I try to go through the "the cabinet" and get rid of old stuff or organize. How can we tackle that diabetes cabinet or even create a space because a lot of people don't have a whole cabinet to dedicate to it.

I ask people to think like a library. And for people who haven't been in a library in a while, a library is that place with the big hard books that you get to read that you don't have to read on a different type of technology or device. In a library things are put together that are alike. So cookbooks might be in one section, and children's books will be in another section, and romance novels in another section. So you can find what you're looking for easier.

Diabetes supplies can be grouped together so that you can find what you need more easily. If you don't have an entire shelf or shelf space for it, you can get a clear plastic container or even a couple of stackable containers. You want to use vertical space not horizontal space. Horizontal space spreads out but vertical space that stacks up helps you find what you need in a jiffy. And on the top put a little label, it could be with a piece of masking tape that you write on so, you know exactly what's in there and what the expiration dates are. And, Stacey, if you're finding that things are a little bit cluttered, maybe in your extra storage supplies, extra batteries, or things of that nature, go through it. Slim it down keep what you need toss what you don't or we use the word before, purge. Purge what you don't need. It will help streamline what you need so you can find it easier.

There's just so much stuff especially with pumping. I've seen a lot of people use an over-the-door shoe organizers. It's clear and I think that's great. But I don't like to take everything out of the boxes. I feel like it's better to keep it in the box. Do you have a stance on that?

I think it depends on what it is. When I do diabetes organizing talks, I bring the clear plastic shoe bag with me to show people what it looks like. That's one of my props, because I like to show that you can put into the shoe bag either individual supplies or even carb counted snacks. Kids who are trying to help to get more involved in their diabetes management, so they can feel empowered, can re-put things in the clear plastic slots so that you can see it. I think that that's really a good idea.

But again, every tool, tip, and strategy has to work for the individual. If you like to keep things in the box, the only issue that I have with that, is do you know when the box is empty? It's great, if you're traveling to keep the box because it has the, might have the prescription on it, may help help you get through traveling easier, shows the expiration date. But if you use the last supply from that box and the box is empty when you reach for it, then that's an issue. So when you take something out of the box or it's becoming emptier mark on it, say one left, two left, whatever's in there so that you can see it from the outside. Remember that "clear is king." So in a clear plastic container, you can see what's in it. But if the box is not clear, mark what's in it on the outside so you can see what's inside.

There's nothing worse than opening that box of insets and there's nothing in it! When you have teenagers, they do that with food all the time. They put back the potato chips with nothing in the bag or the milk has a drop left in it.

Exactly, teenagers or significant others or spouses that seems happen across the board. Absolutely true.

One of the points you make about organization is about health records and doctor appointments. I wasn't thinking of it that way. Can you talk a little bit about why that's important?

It's so overwhelming, diabetes overwhelms, which was a term coined by the late great, Dr. Richard Rubin. And diabetes overwhelms encompasses all that we need to do, all day long, without a day off without a moment off, when you have diabetes. That includes keeping up with provider or clinician appointments and everything that has to do around your health records. Even though you can have electronic health records and everything is now sent through portals, your medical paperwork is not always carried through and there are errors and mistakes. So, I always ask people to write down their questions either pen to paper or to put it on an electronic device, whatever works best for you. That helps to take the remembering out of remembering. When you write something down, it takes the remembering out of remembering.

Then I like to ask, what is one date that we all have to observe in this country? It might not be a holiday that we like but one date that we all observe in this country is April 15th - tax day. So, I use that as a point of reference for your medical paperwork or bills or unpaid bills or unpaid insurance claims or issues. Use last year's April 15 as a reference point and as a current point after April 15th of this year. And everything that's reference that can be old insurance policies flex spending plans, maybe old lab work, whatever it is, old logs, you can keep that in reference. The previous year of reference, a lot of people like to keep in a binder because they still like to touch it. They like to look at the paper. Then after, you can scanned that into your computer. The current documents can be kept, again scanned in, but also in a current binder so that you can bring it with you to medical appointments and actually show it or reference it while you're with the physician, while you're with your healthcare provider. So I really like that. It helps to keep you organized but it also reduces that diabetes overwhelms feeling that you may have when there's so much you have to do. Finances are truly a big issue.

Yes. There is so much to do. Even, as you said, with electronic records, a lot of us do like the paper. I like a printout even with just account numbers and passwords. Stereotypical here, but many moms run the household or wives run the household for banking, and doctors' appointments, and all that stuff. I have four people in this house, three of whom have a chronic condition, everyone with different multiple doctors and keeping up is difficult.

It's very overwhelming and anything we can do to reduce that stress will help. That stress will absolutely affect your diabetes, and your chronic condition, and your ability to cope. So everything that, when we get rid of some of the

things that take up our precious minutes, then we have more time for want-tos. Want-tos which may have nothing to do with diabetes or any chronic health condition. So by streamlining these things and giving us peace of mind, I have everything in my hand when I go to the doctor's appointment and sure you have it on scan, you have it on back up. But you look also more serious when you go into that clinician appointment with everything lined up. You're better prepared on the phone when you finally get in touch with a representative if it's in front of you on paper. You can take notes and thumb through it. It's very important for follow up that way.

We talked about the kitchen and I want to go back to this. We talked about countertops and organizing supplies, but we never talked about the actual food. Do you do you organize your food?

It's a great idea to organize your food shopping and your food the way that you need it to be organized so that it works for you. Everybody has different levels of organization, but if you keep a shopping list, whether it's pen to paper or you use an app or you do it on the notes section of your phone, you're more likely to buy the supplies you need to prepare your healthy meals. You also don't double purchase which can really break your budget. When you're preparing a healthy recipe and you're looking for one of those ingredients and you can't find it, that's an issue if you don't buy what you need to have.

When you come home and unpack your groceries, ask yourself if you're unpacking for fit or for use? Think about if you've ever taken out a can of beans or a can of tuna fish or some veggies that you're buying and you shove them in. Either to the refrigerator or you fit them in to the black hole in the back of the pantry. If that happens, you're never going to find it and you're going to wind up duplicate purchasing it. It makes a lot more sense to buy a few, or to set up your pantry, so you can find things. Maybe you need a lazy Susan in your refrigerator or your pantry so you can find things. Or taking all your seasonings and spices and putting them on a tiered rack, so you can see what you have. It makes sense to explore more vertical space. Stacking things together in clear containers that are labeled so you can see what you have.

Also, look at tossing what might be expired, tossing things that are duplicate purchases that you don't need, take an inventory, and see what you do need. We also tend to purchase things that are in our prime real estate, which is the area between our shoulders and our knees. That's what you reach for a first that's prime market space in the supermarket. By the way, Stacey, there are 45,000 different items in a typical supermarket. So, we want to go in with a list and get what we need. But even in your pantry keeping things that you need most often right in front of you in that space between your shoulders and your knees is so great because you could find what you need really quickly. And keep the things that you want to eat less often, maybe the less healthy items that are sometimes foods, on a high shelf where you can't get to them as often. All these little practical tricks will help make things so much easier for diabetes management.

How did you get into all of this? Were you organizing your pantry as a little kid?

No, no (laughs). I've been a registered dietitian and certified diabetes educator for 28 years, and I'm very

clinically and classically trained. I was looking at the people that I work with who have diabetes and other chronic conditions and people who were trying to maintain and lose weight and I was really listening. I'm a very good listener and trying to see where they are in their journey, there was still something missing. Then one night my very dear friend Leslie Josel who is an organizing guru and a very famous professional organizer, called me and said, 'You know tonight I'm going to be on the TV show as the organizer "Hoarding Buried Alive." So I tuned in. It's a great show and I tuned in and I'm watching her take this man, he happened to have been an Elvis impersonator in Brooklyn, and I'm watching this man who also had chronic health conditions who was feeling completely overwhelmed in his existence. And by Leslie taking very small steps, very small tools, tips, and strategies that worked for him one small step at a time. So he felt accomplished in what he was doing. A light bulb went off in my head and I said, why can't we take these strategies and make them specific for lifestyle change for people with diabetes. Because 99% of diabetes management is self-management.

Really is, it's unbelievable. So an episode of Hoarders is what led us to this, huh?

Susan: So I'm going to make you laugh. It's called, "Hoarding Buried Alive" because we don't say someone is a hoarder the same way that we stay away from calling somebody a diabetic, rather than a person with diabetes. That's personal preference, but I was schooled on that as well.

Well, I appreciate that. Words are important.

Yes, as a matter of fact, there is a new paper that's just come out between AADA and ADA on language and diabetes and it doesn't apply to everyone but it does address the sensitivity that some people have for language. For example a person may not want to be referred to as a diabetic but a person with diabetes. Not to test your blood sugar, but to check your blood glucose. Not to use the words control and compliance but rather influence. So language is very, very important and helpful in education.

I agree 100% and I actually try very hard to use the words the way you just laid them out. It's really been quite an education. I don't really mind if someone says, oh your son's a diabetic. But it just doesn't sound right to me. It's more like, he's got diabetes. He's a person with diabetes, but it's not offensive to me. When you start talking about this from a healthcare perspective, though, the wording is so important. So I'm glad you brought that up.

We're speaking in January and this time of year we're all a little overwhelmed. We've made these resolutions. Maybe we've bitten off more than we can chew. You were talking about starting small with the man who was a hoarder. Can you bring some of that advice to us?

Take a step back and look at what your goals are. Not your healthcare provider goals, not your spouse's or

significant others goals. Your goals and what you want to do. Pick one goal and be smart about it. And then break it down into a step. What doesn't work is when you speak to your provider and they say lose weight or exercise more. That vague goal is so overwhelming and when someone says eat healthy, I don't even know what that means. It has to be a lot more specific.

If one of your goals is, for example to exercise more that that is an umbrella goal. Break it down into a small accomplishable step. So take out your schedule for the week and say, you know, I can probably fit in 20 minutes of walking with my neighbor who loves to walk at 6:30 in the morning before work. If you're not a morning walker I could fit in at six o'clock in the night after work or during lunch with a co-worker. And then circle it in, put it in your phone as an appointment. Really as an appointment. Set yourself up for success by the night before because morning minutes are completely precious, especially when you have diabetes. And I have a lot of organizing tips for that as well for the mornings. Lay out your clothes the night before, your sneakers, your socks, your hat, your sunscreen, whatever you need so that you just accomplished one or two times a week walking. And that will be something checked off your calendar that you did.

The gym is certainly not for everybody. The treadmill is certainly not for everybody. It could be dance. It can be walking, but schedule it in as a small appointment and that's really where you start. And as a certified diabetes educator, I work very diligently to listen to the people I see in my office, to hear where they are on their journey, when we set up these goals. So that they don't feel overwhelmed and they don't look in the rearview mirror to see what they didn't accomplish. We work on what they can do, what they can accomplish with the limitations of time, and maybe physicality. There may be certain things that they can or cannot do. But I really suggest only taking on one goal at a time.

You mentioned mornings and people with diabetes. Can you give us a couple of tips?

Of course! I love to set things to music. So whether it's a child, a teenager, adult, or an older adult find three songs three to four songs, and put them on a playlist that you wake up to in the morning. Songs that you love, not that a parent loves or a spouse loves. Songs that you know that you love in the morning. When the first song comes on as your wake up song, that's the time that you're waking up and you're checking your CGM or your blood sugar. You know, you're enjoying the song, you know when the songs going to end. You know how much time that gives you. By the time the second song starts, you're moving to your second activity. Maybe that's going into the bathroom and grooming doing whatever you need to do. Whether that's taking your insulin or medications or whatever adjustments you need and so forth. By the time it's the third song you're getting dressed. You're moving forward. And by the way, there's no moving back. This moving forward to room to room in the morning so that you learn to stay organized and just go forward in the morning. Music is an amazing brain booster.

By the time the fourth song comes on, you're already dressed and ready to leave the house. Where by the way, you have what's called a launching pad. A launching pad is where you have your diabetes supply bag and anything else you need to have in the morning, aside from what's in the refrigerator that you might need to bring that's already set up and ready to go. So you don't forget anything. And the reason is that morning minutes are really precious. Evening time, we tend to have a few minutes extra to make sure we have everything to go for the

next day. I love doing this with children and teenagers or people who feel a little bit scattered because it takes so much stress off. That you don't have to think about things in the morning because it's set for you the night before. So using music as that brain booster to help you calmly get through your morning routine with all that we have to do with diabetes in the morning and setting up what you need to take for the day on the launching pad are two great pieces of advice that anyone can do anyone can do.

So can I ask, what are your songs? Is that okay to ask?

Absolutely! I'm a big Carole King fan. I saw Beautiful on Broadway too, I just love Carole King. So I wake up to the first song, "I Feel The Earth Move." So that's one that I really love in the morning and then I go to, I also love jazz. I love New Orleans jazz. So, I like that it as the middle songs and then as I'm leaving, I actually like some Justin Timberlake tunes and I changed those over time because that speeds me up at the end of when I'm leaving in the morning.

One other thing, I love to suggest too, for precious morning time is to use an analog clock rather than a digital clock. Because an analog clock shows the sweep of time. You see time move on an analog clock and there's nothing wrong with putting an analog clock in every room of the house for a teenager. The bedroom, the bathroom, and the kitchen, or the workout room, whatever room that it's in, because they can see time moving rather than just looking at it digitally on a phone which does not have the same impact.

Before I let you go, Susan, one of the things that comes up a lot, in those of us who are, let's face it lucky enough to have pumps and CGMs, is some extra stress that can come along. Technology is really racing forward, but there are extra supplies and things to think about.

It's overwhelming at times and it's difficult to keep up with at times because some people feel left behind if they're not using the latest technology. If what you are currently using is working for you and you feel comfortable with it, you feel in range. It works for you with your physical activity. It works with you emotionally because you feel comfortable with it. It's staying on the way that it's supposed to be and you have the supplies you need, then stay with it unless there's a problem with it for the time being. That's really the greatest advice I can give. It can sometimes be more stressful, if you're reading posts on social media, especially of people who might be doing something different. Of course, if there's a way that you think it can better your diabetes care and management definitely look into it and not to be complacent about it. But if you are really comfortable and it's working for you, don't be over challenged by what other people are doing. This is your diabetes life. Not somebody else's.

That is such great advice because I look around sometimes and think I should be doing that or maybe that could help Benny, but what was it you said earlier? Diabetes overwhelms?

Using a phrase from the late, great Dr. Richard Rubin; he coined the term diabetes overwhelms referring to the

anxiety and the amount of work that needs to be done every day just to keep up with your diabetes management.

Thank you Susan. I know, for me, acknowledging that this isn't easy can sometimes make me feel better about being overwhelmed if that makes sense. I'll admit I have a lot of guilt; I feel like I should be doing a better job.

Exactly Stacey. Everything that we're talking about diabetes educators, clinicians, physicians, endocrinologist, pcps pediatricians, it's so helpful to take a step back be in a non judgement zone and to listen to what the person is telling you or what they're not saying. Not use yes or no questions when you're talking to the person with diabetes and or their family, but you watch what they're saying and what they're not saying maybe learn a little bit more about motivational interviewing techniques, open-ended questions. And that's sometimes hard to do when we're trying to share a lot of information, but by golly that has helped me help so many other people just by learning how to listen. I listen, this is funny, I listen by sitting on my hands because I talk with my hands. So if I'm sitting on my hands, I think it's difficult for me to speak. So that's my little technique that I use.

(Laughs) I totally understand that. Susan! Thank you so much for joining me. I really appreciate it. And of course, we'll link up all the information to your book and to your website because there's really just so much good stuff there. Thank you so much.

Absolutely. Thank you so much for having me. It was my pleasure.

More from Susan at: susanweinernutrition.com

All About Insulin Pumps

with Dr. Jonathan Ownby

[EPISODE ORIGINALLY AIRED 02/18/2018]

Dr. Jonathan Ownby is an endocrinologist with Atlanta Diabetes Associates who focuses on insulin pump management for patients with type 1 diabetes, pituitary tumors, thyroid disease and adrenal disease. In 2014 he was selected to be part of the JDRF One Group, recognizing his accomplishments in community education and cutting edge research.

Stacey: Dr. Ownby, thanks for joining me. I'm really interested to see where this conversation leads. Thanks.

Ownby: No problem. Thanks for having me.

All right, so before we get into the specifics, there's so much to go over here. When we're talking about an insulin pump, where do you start with your patients? You know, what's the first thing? I assume it's not: you're diagnosed, let me get you in here and get this pump on you. But where do you start the conversation when you're talking to people with diabetes?

Right. First, I'd really just get their basic understanding of the disease by itself. So sometimes my patients come in and they you know, especially because we're specifically gearing it towards type 1. They don't know why they're on a basal insulin. They don't know why they're on a mealtime insulin. So the first thing I ask them is do you know why you're on these specific insulins? And if so, why are you, why are you on a basal? Do you know what a bolus is, because there's a different degree of education for some folks. Some people already know why they're on a basal plus bolus. Some people say well my doctor just told me to do this. So they have no idea of the importance of the two insulins. Once I get that information from them, then I can kind of move forward.

You know pump therapy unfortunately isn't prescribed to type 1s as much as it should. There's about 60 percent of the U.S. population that are type 1 that do not use insulin pump therapy. And that's kind of a travesty because if you look at really the statistics, they're about five or six times less likely to have a major hypoglycemic

event that's you know, having to call an EMS or get a visit to the ER because of a low blood sugar. So five or six times less likely on insulin pump therapy versus the multiple daily injections.

All right, so when you get the basal and the bolus insulin straight - and we did this in depth with my interview with Dr. Bryce Nelson earlier this year. We went through all of the types of insulin, how they work and what they do. Then what do you talk about when it comes to an insulin pump?

Then, what are you doing with them is really talking about using a pump specifically and correctly. You need to know the carb ratio or how to calculate a carb ratio. So that's what we go to next. Is, can you calculate a carb ratio? Now, of course, it's my job to get the right ratio for the patient, but can they first understand why they're doing that. But basically if a patient is coming and they don't know and they're type 1, I say, hey, you don't have a pancreas. So when you sit down and eat a salad that's a completely different amount of carb versus eating a chocolate cake. And most of my type ones are normal weight. So I say, you know, you're eating in moderation, you know what to do. You're not overweight, but these carb discrepancies you're really dependent on the insulin dosing. And we go from there make sure that they know how to calculate a good carb ratio.

Now when you say you don't have a pancreas, I mean you're exaggerating a little bit, right? I mean, let's not...

Yeah, right. They have the exocrine part of it so they can they can digest the food. It's just their beta cells are going out, but again, that's why hypoglycemia happens too, because their alpha cells are gone. So again, you just don't lose beta cells. But you also lose your glucagon which is your first line of defense for a low sugar. So again, that's why pump therapy is imperative. Because after they can calculate, you know carb ratios, what I tell them is, or what I ask the patient next is, do you like doing the math? And most people don't. The only patients that do are my engineering students that will get a spreadsheet out and this that and the other. Folks on the day-to-day basis do not like calculating their carb ratio, you know, or using their calculator because you can always make human errors as well.

So, the next thing I tell patients is well, what do you do when you eat breakfast and then two hours later you see a donut that you want to eat. Are you going to do the full amount of carbs for the doughnut because if you do that, you're probably going to go low, but if don't give enough you're going to go high. And then the pump really helps you out with that because the pump will have what we call an active insulin time. It'll go back X number of hours and actually see how much insulin's still on board from a few hours ago and subtract that insulin out from the bolus you're about to give yourself. So it does this fancy area under the curve and will subtract out insulin on board. So you're less likely to have a low blood sugar when you bolus within a certain timeframe. While on a pump versus doing injections on your own.

You know, it's interesting. All of the math that the pump does and all of the safety calculations like you

say, such as insulin on board. Those have to be started, as you mentioned, by a person. Usually your endocrinologist or your diabetes educator.

Right.

How do you come to those numbers? Is do you start just on weight, activity? Where do you start when you're putting all those numbers into the pump?

Actually it's been based on studies. There's different rules that folks use but it was actually Paul Davidson who actually founded my office who started coming up with some of these rules. And it's first based on the body weight and it's weight in kilos and divide it in half and that's usually what we call your total daily dose. And then for example, some people use 1800 some use 17 or 1600, but generally I use the 1800 rule where you just divide the total daily dose and the 1800 and then that gets our first sensitivity factor, which we can talk about a little later. And then I usually divide the total daily dose and that gives me a carb ratio. Everyone's a little different that just gives you a jumping off point. So in fact if someone who is coming into me, I'm seeing for the first time I'll use the standard calculations. But if it's someone who I've seen for a while and I kind of know what their carb ratio is and what their basal rates are, then I'll calculate what I think they're, I'll do what they're currently using plus their theoretical multiple daily dose and I'll add them together and take an average. So sometimes I'll do that as well. So that's kind of where the art of medicine comes in. There's not, you know, one-size-fits-all not everyone follows the formulas. The formulas just kind of give you a jumping off point to start up the pump on a patient.

I remember that because you know when my son was starting an insulin pump, gosh, almost 12 years ago. Now, you know, we had to take such careful notes and keep really good logs and check him even more often than we were already doing. So I remember adjusting that of course, you never really stop adjusting with diabetes. But sure it's got to be the kind of thing where you can you know work with your team to make sure the numbers are right. So let's talk about, you mentioned a whole bunch of terms there and we talked about basal and bolus in the beginning. Let's start with basal insulin and how that differs in an insulin pump.

Sure, right. So in an insulin pump, you're using all rapid-acting insulin. And the reason why you do that is this is that basal insulin's in there for 24 plus hours if you're on basal. So just for a good example, if you inject 24 units it kind of slow releases at one unit an hour. But again, you know, we're relying really on the pump to be your pancreas and sometimes when you're exercising you don't need as much insulin because your muscle tissue is an insulin sensitive organ and a glucose dependent organ. So it's going to suck up the blood sugar in the bloodstream while you're exercising. And then there's other times like when you're asleep, you're not as active and your insulin requirements can go down in your sleep, especially teenagers what will happen is they'll have this massive rush of cortisol right in the morning, right when they wake up and that will make you a little bit more insulin resistant. Cortisol is kind of the hormone that gets you ready for your day. So this is what we call a dawn phenomenon.

So it's different for different folks. Some people start at 2:00 a.m. Some may start at 3 or 4 a.m. But if you do see kind of this rise in the blood sugar and with a pump, because it's the fast-acting insulin you can actually adjust the insulin rate with the rapid acting insulin every 5 to 10 minutes if you want. So you can actually hit that dawn phenomenon, whereas, you know on just a 24-hour insulin, if you try to address the dawn phenomenon and have a higher basal rate then the rest of the day they're going to have low sugars. Where and if you lower the basal rate too much then the sugars are going to go high. So really the pump mimics more of a physiologic pancreas.

How does it work though? Does it I guess every pump is a little bit different but is it kind of pushing out that fast acting insulin every couple of minutes in those little doses?

It's usually a little bit more continuous and every minute. Usually it is a fairly continuous rate depending on the pump. There's some pumps that have a motor that you know, just kind of pushes it out fairly continuous. There's others that are kind of like a tube of toothpaste and kind of roll like a tube of toothpaste over time. Those kind of halt more and stop for a little bit. But in general it's more of a continuous flow.

That's interesting. Yeah, because we we find that my son actually needs, I don't mean to make this all about us, but we find our son needs insulin as you say about that dawn phenomenon, but since he hit the teenage years even as soon as his head hits the pillow, I feel like those hormones are all releasing and he needs much more insulin overnight. Which is very much easier to do with an insulin pump.

Yeah, I forgot to tell you previously, you know pump therapy doesn't really change A1C too much. It might lower it a little bit but actually gets teenagers to go a lot better. So to get a teenager to do anything better as you know, is a feat in of itself. So if the pump can get teenagers to get under better control. But yeah data does that show that teenagers that wear pumps have better control through the teenage years. Just don't tell them that or they won't wear it.

But we did skip something as we're talking about how the insulin comes out of the pump and how it works. We really haven't talked about how insulin gets into your body from a pump.

Right.

So let's talk about that. Almost every pump has some kind of catheter, a tiny little one, when you say catheter it sounds so scary, under the skin.

Right.

So, can you talk about how insulin is infused?

Yeah, so there's kind of two broad categories there, the standard pump we can talk about first. And basically when you get ready to put a pump on you'll fill a little reservoir that will go into the pump. And that will store the insulin through the next few days. And generally we recommend only wearing these what we call infusion sets for 2 to 3 days. Then you change it out because as insulin goes through one site for too long, so the subcutaneous skin where the insulin is infusing in can grow as the cells around the site grow, and then it actually impede the flow of insulin into the skin itself. So you fill the reservoir up first, and there's you what we call infusion set or a connection into the body. And that varies from brand to brand but basically you will have an inserter and it will insert a little small plastic catheter into the subcutaneous space. So you connect that to your reservoir and then your pump's going. Usually before you put the pump on, because there is tubing, you'll prime your pump. And there's a prime feature on most pumps where you'll actually see insulin dripping through the end of the catheter before you connect it to the infusion set.

And then you mentioned the Omnipod, which is a little different?

Right. So, yeah, so Omnipod's a little different – it's tubeless but it does have a little catheter that inserts into you. And basically on the Omnipod, it's a patch pump. So you put it on and then you say you start a new pod and then it auto inserts the little small piece that injects insulin into you underneath the pod. So it's a completely tubeless system.

Yeah. And with all of them, as you said the needle goes in, the needle comes out, leaving behind that little plastic catheter, but there are different setups, right? This was something that it took me a while to learn. That there, except for Omnipod, which just has the one because it's all in one, the other pumps have different systems. So different insets, so you can get one that's more angled. You can get one that's steel. You know, there's different ways that they can go into the body?

Right.

How do you how do you advise a person which one to go with?

Really, it's all about comfort. So some people, you know, there's minimal machinery and they can kind of just push it in on their own. Other people want an inserter to do it. But basically I'll have my educator sit down with the patient and show them the different infusion sets and whatever they're more comfortable with. As long as the insulin's infusing in I really don't care how they do it. It's what they feel most comfortable with.

I think it's important. I'm glad you do that because I've had a lot of parents in my local group who say I'm so frustrated, you know, this isn't working. My kid's so skinny and then someone will say well, how about an angled inset and they say what I didn't know there were options.

Right.

It's so important because that's the way it goes in makes a huge difference. If that doesn't work then, you know, you're not going to really get a good infusion of insulin. And you mentioned that two to three days. Let's talk about that for a moment because I know the, you know, we're all looking to cut corners because of cost, but you really can't push that can you?

No, because again, if you're thinking about the tubing, especially because insulin is going through the tubing. There are little crystals of insulin that actually deposit into the lumen or the hollow part of the set itself. So then that is eventually going to change the flow rate and you know, the pump motor is good but can't really sense how much how long that infusion set's been in so flow rate changes a little bit over time. And then where the catheter is in again, the cells will grow a little bit around where that catheter is because insulin's a growth factor so that can impede flow little bit too. So if you're wearing the infusions up for more than three days for sure then the flow rates going to change and then you'll notice by day four or five for sure that the your blood sugars are different. And it's because the flow rates going to be start to become completely different from the pump into the skin at that point.

There's also the fear of an infection as well. I would assume, right?

There's also the fear of infection. And you know, that's one thing that unfortunately insurance companies don't understand, you know, they'll approve you for x amount of infusion sets but again, not everyone's perfect and one's going to mess up every once in a while. So you really need to have extra, so I always try to write every two days for my patients. So they have backup in case something goes wrong.

That's great. We appreciated that from our endo as well. Okay. So we've got the the way it connects to the body. Let's go back and cover the bolus of insulin. The bolus is the thing that the person using the pump controls. How do you how do you talk to patients about that? This is the stuff when people say oh that pump is automatic. Right? And you have to say no I have to do this this and this.

Right. Yeah, they're working on the automatic part, but that's with an integrated pump sensor which is a ways away. But basically you still have to calculate your carbs so you don't have to do the math per se but you still need to know how many grams of carbs you're going to eat in the meal. That's what I want patients to understand before they start a pump. There's unfortunately some doctors that say you've got to get your A1C to a certain level or your

control to a certain level before you go on a pump. But I see this crazy dawn phenomenon where your carbs, your blood sugar is just crazy after eating you're never going to get to that goal A1c to get on a pump. But where the pump really helps you is again, if you do a carb ratio and you count your carbs correctly, then you bolus and then a couple hours later you can bolus again and the insulin on board or the calculations will subtract out insulin so that you don't overdose yourself. There's also the sensitivity factor part. So let's say you're just minding your own business and check your sugar and it's high. Well, the sensitivity factor you will actually just put my blood sugar's high, let's say it's 190 and then the pump will actually calculate how much insulin to give you for that high sugar to get you to a target.

Yeah, and so insulin sensitivity factor always seems to be the one that trips people up. So let's talk about that a little bit more. How do you know when you need to change it? And then how do you change it?

What I tell folks is the best example is the exact formula that's blood sugar minus a hundred which is a normal sugar divided by X numbers. And again, it's a whole bunch of math. But how I explain to the patient's is that let's say your blood sugar is 150 and you want to get your blood sugar to 100. If the sensitivity factor is 50 that would drop you from 150 to 100. So, that's how I explain it to patients because they think that increasing the sensitivity factor may give you more insulin, but it's actually the opposite. Because the sensitivity factor is actually in the divisor of the fraction so to speak. So if you want to give yourself more insulin, you would lower the sensitivity factor. If you want to give less insulin you would increase the sensitivity factor.

Yeah. I've missed that up before.

And how you figure it out is it's, I'll look at a download from a pump and if a patient, corrects, so let's say they're are 200 or 220 and then you know, they give a correction bolus and it's through the pump and you actually see that they gave correction through the pump if it goes from 200 to 50, then I know that the sensitivity factor is giving too much insulin. So I'll adjust that for the patient or if they correct the high and then they don't go to a target that we want it to be, will lower the sensitivity factor and make sure they get a little bit more insulin.

One of the things that I can't say it bothers me, but one of the things that's confusing is that carbohydrate counting is not an exact science. I used to think it was when we started out. I was counting everything; I would weigh ketchup and peas. My son was a toddler and I was determined that we were going to be perfect. And then you realize that everybody reacts a little bit differently to different foods and that this hamburger bun is not going to be like this hamburger bun. How do you advise people when they're trying to get their boluses perfect for carbohydrate counting?

Really to just do their best I guess. It's pretty easy when you're at home, right because you can cook and you can

measure carbs out and that's perfect. But at least in a lot of experience, most of us eat the same thing, we don't, we all like to say we're different but honestly within a month to month, you kind of start eating the same foods over and over, so you'll eventually get really good at the foods you normally eat. So that becomes less of a problem. And what's more of a problem is when you go to a restaurant. Because then you're, you really don't know how, you know the carbs because with the carb counting, well, this is a fist, this is a thumb, whatever but you just really don't know how much extra sugar is added. So what I really see is a lot of the evenings in a lot of my adult patients that are going through the roof and I say how often you got to eat and that's the problem. So I tell him be a little bit more aggressive with your carb ratio when you go out to eat. There's also called an extended bolus or a square wave bolus that you can do. And again, the higher fat meals you're not going to absorb the glucose as quicker so you can actually do a square wave bolus on the pump and it will extend that bolus out a little bit more. So you don't get a lot of insulin up front and will actually help with that delayed spike so it can work with the sugar with the high fat meals.

Definitely and, as you listen, if you're using an insulin pump, different brands do call them different things. So extended bolus, combo bolus, square wave bolus, as you said. Can you talk a little bit more about when that works well? Because we have found over the years a couple of different things that I'll get into in a moment. But as you said the basic understanding is you can give the insulin kind of almost like a time-release, right?

Exactly and that really helps with high fat meals. So most people will associate that with pizza or with Mexican food or a lot of cheese dip. Sometimes if you have a lot of sausage and bacon in with your meals. Especially in the Southeast people love sausage biscuits and gravy. But a pretty good idea is to do a try out the extended from some of those meals.

And a lot of it. I hate to put it in these terms because I am talking to a doctor here but a lot of this is guessing, you know, how do you know how to set it up because what you're doing if you're not familiar, you're setting it up in the pump saying, okay. I'm going to give myself and counting the carbs. It's you know, 60 carbs and I'm going to give 50% of that upfront and 50% over the next two hours? I mean, there's no, as far as I know, there's no formulation that says biscuits and gravy this. Pizza this. You just have to learn it.

Right. It's honestly, it's just experience. So the big thing is, don't get frustrated. We can discuss the technicalities, but everyone, as far as it's in bolusing goes, it's completely different. So there's not a formula to follow. It's really just trial and error.

What do you mean "the technicalities?"

Well, you know just the carb ratios, setting up a square wave, those kinds of things, we can talk to patients about as far as real-world information, you know, they're counting the carbs. The carbs may be a little different, the square

waves for pizza versus Mexican food versus a sausage and biscuit and gravy. It's going to be different for everyone else. That's when you really have to understand why your pump works a certain way. So that you can adjust that on your own.

Let's talk about temporary basal rates because that's something else that almost every pump has. It's a terrific feature and the basal rate as you mentioned is how much insulin you're getting as if you were getting a long-acting shot. So talk to me about temporary basal rates in terms of when you would increase them or decrease them.

Temp basals are great, especially with physical activity. So again, it's all fast acting insulin going through the pump so we can take advantage of that. Especially when you're exercising. And it depends on the exercise and again and this is more experiential but weightlifting can be different than cardio, but we do cardio for example, I usually tell my folks to do, set a temp basal and I like to use percentages because that way you don't have to get into the nitty-gritty of your pump. But most pumps you can set a percentage rate. And say set of 50% temp basal so that means while you're exercising you're going to get half the amount of insulin that you normally do if you set a temporary basal 50% and again, that's really more trial and error. Some people do great with the 50, 50% temp basal. There's some folks that do exercise, like folks on the team type 1, who you know bike for it professionally and they have temp basals of only 5%. So they're only getting 5% of their normal basal rate. Those are muscles are really sucking up a lot of glucose.

Again, that's under-utilized by folks because they either, when you first get a pump there's a lot of stuff thrown at you at once and the temp basal kind of gets pushed back to make sure you know how to do what a basal rate is and what a carb ratio is. That's you really need to use it, especially with physical activity. Another time to do it is before a surgery for example, so of course surgeons have no idea what these pumps are. So they'll tell patients to take it off and I'm like, no you can't take it off. So usually, again, 50 or 40% temp basal while you're not eating so you can get through your surgery safely without a major high or low sugar and then resume your insulin pump as usual once you wake up post-op. And then sickness or steroid use. So if you get upper respiratory tract infection, you actually go up to say a 110% of the temp basal rate for a 24-hour period. Or stress. So you're sick. Again your blood sugars may be higher for two or three days than usual and that's where you can set a temp basal as well.

Alright, I'm going to tell my embarrassing story. Longtime listeners have heard this. But when Benny got an insulin pump, we'd had it I want to say three to four years. And we were working with it beautifully and he was a toddler. He was probably six then by this point by the time I'm telling the story. And the "Friends for Life" conference - they used to have these regional conferences - and it came through Charlotte. So I went, I didn't bring the kids. I just went by myself and they were talking about temporary basals and it must have been a pump session or something and I remember thinking this is so complicated and I had wanted to try it. Our CDE had suggested it for travel. We travel a lot in the car. She knew that he needed more insulin he always ran high from sitting around.

Our CDE Linnet was actually next to me and I kind of whispered to her. You know, I'm so embarrassed and so lazy, I just can't get myself to do that because I don't want to do all the math. She said what are you talking about? I said, well, you said 25% more insulin, and I don't want to have to go through every basal rate. We had four or five basal rates and he was getting you know, like 0.025. I mean these tiny little doses of insulin back then. How do you multiply by .025 or whatever - in my head I had made it so complicated. She said Stacey just go in the pump and say 25% more 25% less. It had never occurred to me that it was that simple. And I know you laugh when you hear that, but I tell people all the time now use your pump for six months and then go back and actually read all of the instructions again. Because we don't know how to use this. We don't know how to get the most out of it. It's not anybody's fault. I'm not I mean, you know, you may disagree as you listen. I'm not a dummy but it just never occurred to me that that would be so simple, you know, do you find that as you talk to people they come back to you that they are not really using all the features because they just kind of didn't get it? We don't get enough education, I think.

Right. I think I would agree with that because you know, you went from multiple daily injections and then you're now on a pump and really the educators for either my office or if my educators are busy, the device company itself. They're really making sure you don't do anything that you're going to kill yourself with on this one.

Oh geez.

Because again, if you give too much or too little you're going to kill yourself. So the big thing is, let's get the basics. These are the basal rates, these are why we set the basal rates. This is the carb ratio, the sensitivity factor and targets are where we want the sugar to be you know, usually we said about 100-120 where we if you're high you would want the sensitivity factor to shoot you to that number. And then the temp basals kind of get by the wayside again, they'll say they'll go over it briefly. But again, most of the first visit focus is on the basals, the carb ratio, the sensitivity factor. So yeah, I would agree and most people just get that education up front and then you don't get any more education unless you ask for it. So again, if you've been on the pump for a few months, I would go back either see an educator or go back and read the manual and then if you have questions ask your doctor about it.

And as what we're talking about while we're talking about the temp basal, I wanted to just from personal experience and I've seen other people talk about this as well. We actually find for my son that a temporary basal rate increase works just as well. If not better for him than a combo or extended bolus for high fat meals. So, I'm not a doctor. This is not medical advice. But what we do is if we know he's going to have a high fat meal, high carb, high fat is we bolus up front for probably 75% of it and then we increase the basal rate for four hours.

Sure.

So that's worked well for us and you're saying "sure," but this was a revelation to me (laughs)

But no, I mean, as I said, the square wave isn't for everyone and I think setting a temp basal like that, it is perfectly reasonable. And you kind of get a hybrid of a square wave or extended wave bolus plus the bolus up front. So that totally makes sense to me. But again, if you've never played with temporary basals before it's something that you would never even think about.

It just is amazing to me how much of a difference even a tiny basal rate change can make. You know, I mentioned that I'd love to go back and see what those values really were. I know and when we started when Benny was two his basal rate was .025 per hour because we needed the pump that had the lowest basal rate. And then probably around age six or seven it was maybe up to you know .8 or almost a unit. I mean, he's a teenager now, we've had, he's up to some hours, he gets like three units an hour. It's crazy.

Oh, yeah.

But it's amazing to me. How much just even a small basal rate change makes. Is that the way that insulin works in the body?

Right. So yeah, so with the rapid acting insulin because it goes in fairly quickly, we can make these exact changes. But yeah physically in the body I mean a person who does not have diabetes makes about 25 units of insulin a day, roughly. But again, it really varies on the time of day. But you know physiologically there is a little bit of resistance on everyone when insulin in everyone when the cortisol rises in the morning. So normally, you know, the pancreas senses it and we'll shoot out the insulin to negate that effect. But you know, we're having to use these pumps as you know, your pancreas essentially. I've seen some patients like, the best one that comes to memory is a young, say 20, 21-year-old college student. Usually her basal rates are about half a unit an hour and then just from 3:00 to 6:00 a.m. it goes to 3 and 1/2 units an hour. And it goes right back. So again, it's crazy. And again monitors help us with that too. But just seeing what time of day you need those insulin requirements. And again, that's why you know pump therapy is so beneficial for type 1s because there's no way you could have a basal rate do that for you on just a 24 hour insulin.

And I think too, we you know, when we knew my son was, and he'd love that I'm talking about this, but when we knew he was going into puberty, I mean his blood sugar would shoot up to 300 and despite feeling we were pouring buckets of insulin into him, it wouldn't come down.

Right.

But then you go ahead and you just change the basal rate and not by a dramatic amount, and it doesn't get that high. Is it it's just harder to bring them down when they're that high right?

Right. And in teenagers, especially they get really insulin resistant in the morning especially. And then they'll hit an age, it's different for everyone, he'll hit his early 20s and then his requirements will plummet.

I'm counting on that.

Right. So, it just like they kind of lose their mind as a teenager and they don't want to do anything you're called to do. Then like they have a come-to-Jesus moment. The same thing happens with their insulin requirements. And it just comes right back to normal and you're like, well, I was all in outer space and now I'm back to reality. And that's kind of what the pump does. The pump mirrors what the teenager's going through essentially.

All right, let's talk about placement of an insulin pump. Because you know tubed pumps and the Omnipod they all need to be rotated. Can you speak a little bit about putting it on and making sure and why you have to move it around?

Yeah. So again, if you keep putting it in the same place and again the insulin's a growth factor, so those places will eventually, the subcutaneous tissue will grow the exact, it's really the fat tissue. So the exact word is lipohypertrophy, which is just means big fat essentially in English from the translation. And that will over time that can actually create some scar tissue as well. So you'll want to kind of, what usually patients will do is rotate clockwise or counterclockwise around their naval, their belly button. But you can also have an infusion set inserted into your upper arm or in your upper buttock area as well. Now Omnipods are a little bit more, because they are tubeless, are a little bit easier to move around but those are the FDA approved sites. But folks, look if we're going to talk off label can put an Omnipod almost anywhere on the body. We have some women during beach season that will actually put the Omnipod along their, the top of where a bikini would go so that no one even knows they have diabetes unless they're really looking where an Omnipod would go.

I've seen people with tubed pumps put them everywhere as well, which I don't know how you do that. I mean, I remember when Benny was little there were a lot of little kids running around with the tubed pumps on their arm. And I was thinking like he would never do that, but they had no issue with it.

Right. But you got to be careful with the tubed pumps because just the physics of the insulin being infused. Because there is a little bit of a siphoning effect. So if you have a pump, and a lot of women do this, they'll have their infusion set inserted into her abdomen and they'll put their pump in their bra. But just like siphoning off gasoline, for example, the insulin itself will siphon down a little bit. So you actually get a little bit more insulin

if you put the pump higher than where the infusion set is. And it takes the pump a little bit more to work if you actually have the pump lower than where the infusion set's inserting. So technically you really should have the pump and the infusion set horizontal with each other. Technically speaking. Now that's not real world and a lot of women are going to put their pumps in their bra anyway. But you would want that infusion set as horizontal with the pump as possible because of that.

I have never heard that. So everybody that I know who has a pump around their waist, they'll wear it, you know, like the belly button line let's say. And then they put their pump in their pocket.

Right. So again, if you're going to do that just be consistent with how that placement is, because again, it's not an exact science. But if you're always, especially women will put their insulin pump in the bra or men like to put the pump in the pocket, then try to keep you know, rotate around the site area, but try to keep that pump as horizontal with the infusion set insertion as much as possible.

And if suddenly you take it out of your bra and put in your pocket, you might realize that your numbers could change and that might be one of the reasons why.

Right. Exactly.

That's interesting.

And then two, making sure that you wear the pump fairly consistently. Because a lot of people will take their pump off to shower for example, but if you're in the shower for 30 minutes, that's 30 minutes of insulin that you're not wearing or getting. And basically for every minute that you don't wear the pump your insulin, your blood sugar value will go up by a certain amount. So let's say you get in the shower and your blood sugar 100 and you take a 30-minute shower, your blood sugar's going to go to go to 130 that's just on the average for folks. So we see that sometimes before I make adjustments in the morning and I see blood sugar's going up, some people don't turn their pump off. So I actually will ask. Well, I don't see that there was a suspend on the download. So when do you take a shower and if the blood sugars are going up in their shower you know, I say try to take a shorter shower. And they say well I really like just not wearing it while I'm in the shower or I said well, that's great, but really connect to yourself right when you get out of the shower to avoid that that peak up in the morning.

Yeah when my son does that occasionally and he'll just bolus for half of the hour that he missed or whatever.

Right. And that's a trick to do it.

We've also found though, don't as you listen, don't bolus right before you get in the shower, to try to avoid that rise. Because the warm water, doesn't that, that can help make you go low, right?

It can a little bit. Yeah, because again the physics of it. Most insulins all work the same if you gave them IV. It's all about how the insulin is formulated to go under the skin that really helps it to get into the bloodstream. And all rapid acting insulin gets in the bloodstream a little bit quicker, once it goes under the skin. And if you have a little bit of a warmer water yeah, could go in a little bit quicker. So again, if you bolus, really the big thing is if you bolus that insulin, you get a bigger amount of insulin. So it's not a basal rate so to speak. So there's a difference between getting a unit over an hour and bolusing a unit right up front. Because again the pumps going to get that unit through, the through the hour pretty consistently. And if you do a full-blown unit right away, then that's going to really change the physics of what happens under the skin.

In your professional opinion, and you don't have to answer this, but I'm curious. Is one pump better than another? Do you see people with better A1Cs do you see people with better usage of one pump brand over another?

It's kind of yes, and no. You know, there are different pump brands out there. And it really depends if you want the most technologically advanced pump versus can you use this in your real life? And that's one of the problems and I don't want to go off on a tangent but United Healthcare right now will only approve the Medtronic pump. And that's a big problem because again that does have an integration with a sensor and the Medtronic pump works really great for that, for a lot of people. But again, you know being tubeless, especially putting a tubeless pump, like an Omnipod on a three-year-old maybe a lot better option for you because the kids gonna keep ripping off those infusion sets. Or let's say you have a teenager who's in high school who plays a contact sport. You don't want them to be wearing a \$2,000 pump out on a football field and that get crushed for example. Whereas an Omnipod, you can actually throw it away. So I give people the options and show them the different pumps and let them decide for them personally which pump is the best for them. Because I don't want to be paternalistic and tell them you have to wear this, because it's not my life. I'm not the person living with type 1. I can guide them with what to do, but it's really their life and I want them to choose the best pump that fits their lifestyle.

Yeah. I've always felt that. And again a little editorial here from me. If there was a pump that was great for everybody, we'd know. Right?

Right.

People would be walking around saying look, my A1C went way down and life is great. And this is the one for everybody! But, it just made me laugh because you know, my son played football with a tubed pump. And

my son was a toddler with a tubed pump. So I know people who could never stand the tubing and love their Omnipods. But, it's all personal preference. So I'm glad to hear you say that. So let's talk about disconnecting because we haven't addressed that yet. When you're taking your pump off, you know, what do you, what do you suggest that patients do? You know a lot of concern about covering the site. I mean we never do anything.

No, I mean if you're just disconnecting for you know a few minutes to a few hours, then there's really not much that you need to do as far as disconnecting. But know that if you're going to be off it for more than say two, three, four hours and you're not exercising then you would probably want to start considering getting on a basal insulin for the rest of that day. Because you're eventually going to have high sugars. Because again the rapid acting insulin's going to be out within three or four hours. So if you don't have any basal on board by that point you have a risk going into DKA.

We were always told, you know, at the beach let's say, we would take his insulin pump off, to check every hour when you don't have a pump on and to make sure to bolus at least every two hours. That was our endo's advice. Do you recommend something similar?

Something like that or let's say that they are playing football or you're going to have a beach day, what you could do for that day is give half of the basal as a basal insulin for you know, let's say a Lantis or Levamir or and then the rest of the half of the insulin through the day's a 50% temp basal on your pump. So again, that kind of negates the issue with having to check your blood sugar so much. So we do this with a lot of like football players and stuff folks who really like the advantages of wearing a tubed pump. But then when you're out there playing football you don't want to go in DKA but you don't want your pump to get smashed either. So those folks we kind of do a compromise for those days and do half basal through a standard injection through a 24 hour insulin and then half through a temp basal while they're wearing the pump. But when they take the pump off, they actually have a little bit of basal go in like a temp 50% temp basal essentially while they're running around and then you don't have to worry about checking your sugar's as much especially if you're wearing a monitor.

Yeah, we've I wasn't sure if I was going to bring this up, but we started that this fall. And I called that, that's untethered as you know, a lot people called it untethered or POLI, pumping on long-acting insulin. And it has been amazingly wonderful.

Right.

I hate that he has to take a shot and we do this every day. We do 50% from the pump now and 50% from we use Tresiba. Obviously talk to your doctor about whatever you want to use. But it has been wonderful because, first of all he's taking these massive, you know, basal rates and it's just very difficult on the infusion set. So that

has helped. And he's able to take the pump off more for sports without worrying about missing the dosing. Do you do a lot of untethered is that something that people ask about?

It's hit or miss. A lot of teenagers do because they're a bit more physically active and they're doing more team sports and things like that. Again to your point, yeah, some of our really insulin resistant kids and young adults, we do give a basal along with the pump. Even if they're not taking it off because again, if you give a little bit of an injection it will help you save insulin in a reservoir and keeps the infusion set in for two three days where otherwise you might be changing infusion set out every one or two, one or one and a half days.

It really is amazing all the different things people come up with. I don't know if it's on your own or with experimentation or how everybody figures out how to do this.

Yeah. I think it's honestly just experience with the product. And again just really having a good understanding of what they can do what they can't do. To really key in on you know, how, how can the pump benefit you. But again, especially to prevent lows, I mean because we can change the basal rate so precisely there's a lot less lows especially overnight.

I don't know if you know the answer to this one, but when, one of the things that I get asked a lot is, what the heck are those little pitchfork shaped doohickeys that come with the infusion sets? These are things that you're supposed to put in your inset, your pump site when you're on the beach or you know you. Is it first of all, do you know what I'm talking about?

I know what you're talking about. I think it's to protect the little infusion set. But honestly, I don't know anyone who uses them.

Okay, because what I was going to say is we only used them when my son was little and we'd go to the beach because there's nothing that you know, no one attracts sand like a magnet like a toddler. And we hadn't thought about using it until we found that we couldn't reconnect the tubing because his inset was full of sand. But you don't need to protect the inset from dirt and water and things like that. It doesn't let things in until you click in the tubing right? It's kind of like the top of an insulin bottle is how it was described to me.

Yeah. I mean, it's very hard to get stuff in there as being an adult and not shoving sand in your side this is probably safe. Just not to do anything else. But yeah, you know three-year-olds or two year olds, who knows what they're going to do. They're going to shove sand up their nose. So you do want to protect the site for them. But for adults you don't really have to do any protection.

That's a concern I hear all the time about, you know, I'm taking a shower. I'm going in the pool. Do I need to use this thing? And then half the group says, oh, that's what that's for.

Right.

I have a couple more questions, but I want to make sure I'm not really missing anything obvious that you wanted to talk about.

I don't think so. I really would like to hit home the overnight basal rate because especially if patients are, so I guess most type 1s would really benefit from wearing a pump because of the features we've talked about today. But unfortunately a lot of them aren't. Most type 1s, I would feel more comfortable unless they're seeing an internist that's very well versed in type 1 diabetes, actually seeking out an endocrinologist to take care of their blood sugars. Because as we talked about blood sugar surging overnight, you don't know if you don't have much experience with pump therapy or type 1s, whether that blood sugar is going up overnight because they, again like your son he's having this rush of cortisol, all the sugars are shooting up overnight. Or you're having lows and what I've seen a lot of times with especially some primary cares is they'll see that the blood sugar is high in the morning and they will tell the patient go up on their basal injection, you know, 10%, 20% because the sugar is high in the morning. Whereas that's really self-perpetuating the issue with low sugars overnight. And they're looking at A1Cs in the morning blood sugar but not really asking the patient, what's your blood sugar when you go to bed? Are you having low blood sugars overnight? What's the blood sugar in the morning? So all my type 1s where they're on injections or pumps, one of my first questions is, "Have you had a low blood sugar?" Because most of them are coming in thinking, Oh, my gosh, my A1Cs going to be high and he's gonna be mad at me." My biggest concern is have you had a low? And if you have a low, when did it happen? And did you need help from someone or were you able to do it on your own? Because you know low blood sugars can get you today. They can get you overnight and you won't wake up in the morning. High blood sugars will get you in 15 years and that's a problem and we'll fix that. But really want to work on the low sugars and make sure those are minimized.

I want to come back to that thought but you brought up a good point earlier about the pumps that work with sensors. You know, there are more and more of those happening.

Right.

I can't go in depth on this because they are so new. You know what I think we're learning a more about that. But what's your, what are your thoughts on those? I mean, this is a pretty exciting time. We just started with the Basal IQ in the fall; we use the Tandem and the Dexcom together. I know people having great success with the Medtronic 670 system. What are your, you know, what are your thoughts about that?

I think that the integration is key because especially just sensors in and of themselves because wearing a pump and a sensor again, you know, the less lows the better. And patients that wear a sensor at least 50% at a time have their A1C drop by at least a half or one percentage point. So let's say they're seven and a half, or six and a half or seven without any increase in low sugars then that's remarkable. So again, you want as tight control as possible without any major lows. And with sensors what we can see is when's the blood sugar going up and what how I explain it to patients is, you know, the sensor blood sugar isn't the same as your finger stick blood sugar. It's kind of like a roller coaster and the front car is your blood sugar and the back car is the sensor because it's really measuring what we call interstitial fluid or fluid in between cells. So that's why we tell people to calibrate these sensors right when they when they wake up and they've been fasting and sugar should be stable. When you eat the blood sugar shoots up. So the front car is going to be a little bit higher than the back car. When you correct and the blood sugar is going down, the front car, which is your blood sugar, is going to be a little bit lower than the sensor itself. That's kind of the sensor a nutshell as far as how I explain the blood sugar's to them. But we can actually see those sensor tracings 24/7 and in really fine tuned. Well, you know your blood sugar went up above target with breakfast only, let's change your carb ratio at breakfast. Or your blood sugar is dropping overnight, let's back off on your basal rate overnight. So those sensor combos are key.

And then yeah the integration so Basal IQ will notice that if your blood sugar goes below a certain point, the sensor pump integration, the pump will send, will get messages from the sensor and say your blood sugar's too low, turn off. When the blood sugar goes back up to acceptable levels the pump will turn back on. And then you know, with a Medtronic pump when your blood sugars are above even 120, which is the target set; unfortunately they made Medtronic do 120 instead of 100 because the FDA was worried about low sugars. Which virtually never happens unless it's 70. But again, if the Medtronic pump sees that you're above target at any time that will micro-bolus you back down to target. And then if the blood sugar's less than 120, it will hold basal rate until you go back up to target and turn back on. So the future will be when you, and this is kind of you know, what will happen in the future as far as new products is targets will be set a little bit lower, and then let's say you forget to bolus when you eat, if, that eventually that pump sensor combination will notice the blood sugar rising and that trajectory, and will bolus you without you having to put carbs in your pump. So that will be some of the next kind of generation things. Again right now, you know, the pumps will notice overnight that if your blood sugars starting to trend down, let's back off on the basal rate a little bit. If sugars are going up overnight, let's give you some boluses and that's what the 670 will do on the Medtronic.

Yeah, it's been wild. I mean, I don't want to make a commercial here for Basal IQ, but we had an amazing endo appointment recently, it's probably been almost four and a half months. It was our first full Basal IQ, you know, with A1C and it his A1C came down by half a point, which was great. But interestingly he had virtually no lows below 75 for that three-month period. He doesn't get a lot of lows, I'll be honest with you. But it's never been like that. I mean, it was pretty amazing to see how that's working.

Right. And that's kind of the wave of the future with these pumps is eliminate the lows and that's why that was at first, because again, if you have one really bad low sugar, you're not coming back tomorrow. So that's when, it's actually a lot easier to program into a pump's sensor combination then fixing the highs for example. Because

everyone's a little bit different as far as carb ratios goes. That's why the basal suspend, what we call threshold suspend, or stop when your sugar goes low. That's why that was first integrated with, with the insulin pumps.

I want to address something. You've said several times, you know, you're not coming back from that low or people die from lows.

Right.

I gotta push a little further on this. My son - I know many, many, many, many people who've been very low 20s, 15. I think that sometimes newer diagnosed families, you know, children's parents, especially feel like well if my son hits this number he will die.

Right.

Or if I don't jump out of bed, you know, my child is going to die tonight. And that's not my understanding. And I could be very wrong. You're the endo.

So I don't I wouldn't want folks to freak out that their sugars get below 50 than you know, they're at a higher risk. It really is more of a frequency issue because your body adjusts. Like you just like people especially type 2s will adjust to having a blood sugar 3- or 400 and say, "Hey, I'm perfectly fine. I don't need to take insulin." The same thing can happen with low sugars as well. So it's over time your body has to have a lower and a lower threshold. So again, like I said earlier, you don't just lose beta cell function. You lose your glucagon, which is your first line of defense. So your blood sugar has to get maybe 70, 60 and then your growth hormone, your cortisol, your adrenaline levels will go up. But then your body's like well that wasn't so bad. I've survived that so then the blood sugar has to get the 50 then the 40. There's some people that walk around and are completely fine until their blood sugar hits 30 or 20 and those people were what we call hypoglycemia or hyperglycemia unaware, hypoglycemic unaware. So they don't even know their sugar's low and those are the people that are most at risk because they're fine one minute and then their sugar gets to a certain level and then they're out. They're in a coma because the brain really only uses glucose as energy. So once the blood sugar gets to a certain level the brain just turns off. So it's a gradual process.

I don't, I don't want to scare folks. It's just I don't think a lot of folks appreciate the fact that lows are just as bad as the highs. Because a lot of times when I have people come in, they're focused on their A1C, getting their A1C down. And I agree with that, I think that A1C should come down but we want the lowest blood sugar possible without a major low. So in that major low is an EMS visit, you have to go to the hospital.

I'll give you the perspective of someone who talks a lot more with parents of young children. It is just

the opposite. I think people now are so terrified of their children being low that they're letting them run higher. And I'll be honest with you. My research does not bear that out. I mean I had a conversation with my endo. And I frankly said, you know, you've been in practice 20 years how many kids have died?

Right.

And he said three. Two committed suicide which is a terrible, terrible thing. I mean, it's horrible no matter how you look at it and one died because they were drinking alcohol and didn't factor it in correctly and their type 1 diabetes management, which is also tragic.

Sure.

But you know, this is someone who's seen hundreds if not thousands of patients and nobody's died from a low overnight.

Right.

So I just - I just go back and forth about how much fear we should be having and how much we should be letting it rule our lives.

Yeah, it's more just an instantaneous nature of the low causing a death. We've seen a little bit more as far as a low that maybe why I'm more a little bit hypervigilant about lows compared to that. But the lows do really happen. So again, if you just look at national data about 10% of type 1s may have this dead in bed. So it's not it's not marginal. I don't want to do a scare tactic, especially with the newer pumps because you're less likely to have a low with a Basal IQ or a 670. But that's always in my mind. And that's one thing that I do want to talk to patients about is making sure they're not having lows.

I'm not here to argue with you, but wait a second. 10% of people with type 1 are going to have dead in bed?

Potentially. It depends on the studies. Now, those are older studies. It'd be interesting to see when Basal IQ and Medtronic throw out their data. Because like a 670 it's been out for several, you know, two or three years now. There's virtually no lows on the 670. And I think most of these folks again, that's why I pump therapy is so important. I think most of these folks aren't being managed very, very well. They're probably not seeing endocrinologist and they may be having a primary care that's just jacking up their basal insulin overnight on the 24-hour insulin and not paying attention to what the sugars are doing overnight.

Got it. Okay, so we're I mean, I'm just think I was just doing the numbers in my head because I have a group. I have a group in Charlotte we have about 500 kids let's say. So you're saying 50 of them could die from low blood sugar?

Statistically. That's what the old data shows.

Because nobody's... I mean, I've run the group for six years and everybody's there.

But again you guys, so the only thing about that is you guys are probably be managed by endocrinologists.

Right. Okay, so now I get it.

So globally, yeah primary care's, you know, really if you're if you're type 1 you should be seeing an endocrinologist. I don't know what's going on in primary care world, but sometimes it's just crazy what's going on out there. Because again, they're just, they're telling patients that, "Your sugar's high in the morning. Let's go up on your basal insulin because your sugar's high in the morning and that's what happened. That's what you need to do." For example, I had a little old lady who her basal rate should have been or she was on a 24-hour insulin when I first met her and calculating her basal dosage should have been 10 units. And when she came to see me, she's on 75 units of Lantus. And her husband was waking her up every three hours to give her glucose overnight to prevent her from going low.

So scary.

So again, it depends on, it depends on who you're being managed. So yeah, I have no doubt if you're being managed by an endocrinologist, lows overnight, because we're aware of it, probably isn't happening too much. But if you're in rural Georgia and the only person is your family doctor, you're probably having a lot of lows.

It's a good reminder for somebody like me, who talks all the time with people who have the latest tech, you know, the best insurance. You know, we live in this bubble. So I do appreciate you letting me kind of argue with you a little bit because I'm always learning.

Good. So yes, I would bet you I don't have ten percent of my type 1 are going to die from low blood sugar.

You can understand how it sounds.

But just in the United States, in the US in general, because these folks aren't always being managed by or getting the proper care. Yeah 5-10% depending on the study you read are going to have a low. And that's why it's really important if you have type 1 to make sure you have confidence in the doctor that's taking care of you.

Again, I appreciate you going through it because sometimes I need to be led to the obvious point. But it's really important to learn more about it. One more point. I'd like you to make before I let you go, people are leaving the hospital now with CGMs. They're getting diagnosed, at least kids, and again with really great access and insurance and terrific doctors.

Right.

And you know, it used to be that you had to wait at least six months for an insulin pump. Can you just talk a little bit about, look if you want to get it quickly fine, but you know making sure you understand the fundamentals?

So again, really knowing what a basal insulin is. What does it do? And what does bolus insulin do so really sitting down with either your doctor or the diabetes educator and making sure you have a good understanding of that. And then law to carb ratio. And understanding why the carb ratio is important. Because if you don't get those then you're really not going to get the pump very well. But some people are really quick learners and some people it's depends on the degree of education you have, but some people can get basal and carb ratio within a few weeks. And again, that's one of my pet peeves, is some insurance companies will make sure, will tell you that you have to have type 1 for six months and that's just complete baloney. They should get the pump right away. Whenever we feel or as a provider deem that you are good to go on a pump. You should go on a pump. It shouldn't be dictated by a medical director working at an insurance company.

Absolutely and then just make sure that you keep some insulin, we keep a pen or syringes on hand just in case right?

Right, right. So always have backup basal. So you never know when that pump's gonna break. Usually for me, usually patients are calling me my Friday or Saturday night.

Of a holiday weekend.

Usually it happens, right on a holiday weekend. So always make sure, and you don't have to really. I mean most endos especially have basal as far as samples go. I'll either give a vial or a pen. Especially if you're traveling because

you don't know if it's in a break when you're traveling either. So always have a backup basal insulin just so if the pump breaks. The other thing is to really know your pump well. Which again, you know, we've kind of talked about that. But know what your basal rates are. Know what your carb ratio is. So if your pump breaks and you get a new pump, if you don't know that you'll have to go to the doctor's office and have them reprogram everything for you. But too you want to know what your basal rate is so, you know how much you better give yourself while your pump is broken.

Yeah quick tip. I always tell people obviously you want to write down all your pump settings, but also go ahead and just take a picture with your phone of all the screens because that way I have to use it all the time when I'm not with my son, especially when he was younger if I was calling the endo. So you have it on your phone. We always have our phones. And then you have it written down somewhere. So you can have it in both places. Well Dr. Ownby thank you so much for joining me and going really in depth on this. I really appreciate it.

No problem.

All About Teens and Type 1

with Jill Weissberg-Benchell PhD, CDE

[EPISODE ORIGINALLY AIRED 11/27/2018]

Jill Weissberg-Benchell has a PhD in psychology and is also a Certified Diabetes Educator. She is a professor of psychiatry and behavioral sciences at the Northwestern University Feinberg School of Medicine

Stacey: Jill thank you so much for joining me. I've been looking forward to talking with you ever since I saw your presentation this summer. Thank you so much for making time for me today.

Jill: Oh, it's my pleasure.

Before we get started and I have to warn you and I'll have to warn the listeners as well. I do feel like this may be a therapy session for me. So we'll see how it goes. I don't want to make it into one but I may not be able to help myself. Can you talk a little bit about why did you get into this field to begin with? You don't have a child with type 1, you don't have type 1 yourself, what led you to this path?

So it was one of those, I was in the right place at the right time and it was the best sort of accident that ever happened to me. I was in graduate school and thought that I was going to probably spend my career literally working with juvenile first offenders. And then I did a full year of intensive clinical experience for an internship, which if you're getting a PhD in Clinical Psychology, that's the last piece before you graduate. And I was lucky enough to be embedded in a consultation liaison program in the hospital, which is where you meet with families who are admitted to the medical side of a hospital who are coping with all kinds of really scary things. And I thought oh my gosh, I don't want to work with juvenile first offenders. I want to be a pediatric psychologist and I want to work with families, who are living with a chronic illness and trying to live their lives in spite of these additional challenges.

When I realized that I thought, but I don't have enough training to be able to do that. So I looked for a

postdoctoral fellowship in pediatric psychology so I could get the training that I wanted to be competent. And I was so, so lucky that the fellowship I was offered was at Children's National Medical Center in Washington, DC embedded in the diabetes team. And I have never been more lucky. I have never been happier and I've also never looked back and that was in 1990.

Jill, I have to say I have been one of those families that comes in and gets a team, get some care. It's not something I would describe as never been happier. What did you do for those families when they first came in? Give us a kind of a hands-on look at what happens there?

Well, It kind of depends really a lot on the age of the child and also the family's experience with diabetes in their own personal lives because you probably already know most families have no experience with diabetes. Nobody that they know that has it, but there are some that have very strong family stories about diabetes. But I think the biggest and most important thing is to give families a message that they're not alone, that there are many people on the diabetes team that are there to support them through the entire journey, not just a diagnosis but throughout. That even though it's really scary and there's a lot of unknowns, you know at diagnosis or you're just learning what the heck is all of this and what do you mean insulin? What do you mean carbohydrates? What do you mean glycemic variability or whatever other big words people might use but also that your child is going to, we're going to work with you to make sure the diabetes does not prevent your child from achieving all of their goals, whatever they are. Whether they're violinists or hockey players or artists or readers or just really great friends or you know, thoughtful to whoever you know, the children are we don't want diabetes to ever get in the way of allowing them to grow and develop and have joy in their lives and whatever it is that they do.

I think it's so important to make sure that that message is so clear and often times the psychology folks are the first people to give that message. So that's one piece. I think a big piece is that you don't change your parenting just because of diabetes and that's a hard one, a really hard one. And yeah, so I think those are some of the basics. I mean I can go into more detail, but I think that that's sort of a good overview of some of the things that we try to give as messages to families. And that every blood sugar, oh this is so important, every blood sugar number is a good number. Because you can't fix a number if you don't know what it is. So to be able to not flip out over numbers that are out of range but to praise and thank your child for sharing the data with you. Whether it's a finger poke or a CGM share. And to be able to look at that number and say, "Wow, this is great that we have this data. Now, what do we do with it?" is a very different message than the old-time messages of high numbers are bad, our low numbers are bad and only certain numbers are good, which just gives this horrible sense of shame and blame and badness that we never want to be part of the ups and downs and frustrations the diabetes already offers.

All right. So with that lead in I'm going to jump right into what I want the majority of this episode to be about which is teenagers.

Okay.

I'm a little biased because I have one. But I also think your talk was so empowering that I want to try to share as much of it as I can. So you did two sessions at "Friends for Life." You do lots more than that, but two really stood out to me. One was called "Parenting your Teen" and the other one was "Raising your Parents" and it was for teenagers. But let me start with you if I could with that language of there's no good or bad numbers.

My son was diagnosed before he was two and we were very fortunate to have that advice early on so we never, well I shouldn't say we never. I know I had my moments where I would be, you know, I would gasp or have these terrible reactions, you know, and you wouldn't want your child to know that there was good or bad but they pick up on it. But now that Benny's older I find myself saying things like, "Hey, sweetie, no answer's a bad answer. There's nothing wrong here, but I just have a question for you. Did you blah blah blah or can I see blah blah," and he rolls his eyes and he shows it to me. I feel kind of silly saying those things. But you're saying it's still worth saying it after all this time.

Absolutely. It's can be so exhausting especially during the adolescent years to manage diabetes in part because biologically it is absolutely the hardest time to have blood sugar numbers that are in range given all of the hormones and all of the growth and the development and the changes that are going on. And with growing and having a bigger body and with puberty and hormones, there's also just an increased hunger and so both the hormones and the food and the more or less structured or schedule all of those things just make blood sugar numbers just harder to keep in range. And so to just remind our children that we get it and that it is a hard time. But that continuing to just engage in the behaviors, the monitoring blood sugar numbers, the counting carbohydrates, the giving insulin is so important because there are days when it's going to work and everything's going to be beautiful. And there are days when it's not and that's life with diabetes especially during adolescence. But that we should never give up on the behaviors we know that help people stay healthy.

Let me back up a minute. You're mentioning all of the factors that really do make it more difficult for teenagers. Now, I have to say, even with all the education I was fortunate enough to have, I really misunderstood what was on the way for my son. I thought that it was all kind of in his head in terms of that, you know, ding dong teen behavior that we see in every teenager diabetes or not. That it was about forgetting and rebelling and not wanting. Can you just reiterate a little bit about hormonal changes because I was blown away. I'm not going to say diabetes was ever easy to manage but ages 2 to 10, 2 to 11, you know you work hard and you can you can see the difference. Sometimes with my son and we've shared this with each other, he's doing everything he's supposed to be doing and we're out of range and that's not atypical, right?

Yeah, no, that's incredibly frustrating too. Especially if you have the belief or the hope or have given the message that somehow if you do exactly the right things the numbers will always make sense because that's just not true. It should make sense a lot of the time but it won't always. So I'm going to defer a little bit of your question to endocrinologists who are more expert in the biology. But what I do feel comfortable saying is that when you're in the middle of puberty, if you don't have diabetes, so if your body makes all of the insulin, it's supposed to make, it can produce somewhere between two and eight or even 10 times as much insulin per day every day to compensate

for the hormones that your body is making. And so the only way that we know that children whose pancreases aren't producing insulin need more insulin, it's because their blood sugars are wonky and we can't figure out why. It's not because they skipped a bolus and it's not because they sat down with their best friend and ate an entire pound of M&M's. You know that there's something else that's going on that isn't so in-your-face obvious. And often times, you know, that's the biology piece and that's you know, such a good time to be in close contact with the diabetes team to get more close advice about how to change doses and how to ride the ride.

Got it. That's definitely an endo level decision. And I urge you, as you listen, to please talk to your endocrinologist just from our personal experience, Benny's basal rates more than doubled in one year's time and continue to go up and our endocrinologist is really helping with us. But I'll tell you Jill, I felt like, I felt like a failure when that first started happening because you know we're using so much more insulin and I thought it shouldn't have to be this way. So let's shift back to the psychology of this. How do you start with a family maybe even like mine who comes in and says, this is so frustrating. It's not working. I'm mad at him. He's mad at me. You know, where do you start to have these conversations with your kid?

Well first I would actually start by saying yes, it is definitely frustrating and it's not surprising that everybody's a little bit irritated with each other. And that's all about love. It's all about wanting the best. And so I would actually start by listening a little bit before we talk about diabetes just about what's going well in your relationship to begin with and what each of you enjoy about each other and what the teenager likes doing outside of the family and is good at and is confident in and what the parents enjoy doing outside of diabetes so that I get a sense of the whole family. Because sometimes families come in so focused on diabetes and what's not going well that they sort of lose perspective and lose attention on all of the things that are going well and I want to sort of start from that that base of strength. So I would say that. I think the other thing that I start with is try to get a sense of what families do to cope with stress and frustrations that have nothing to do with diabetes because oftentimes especially children and teenagers have incredibly creative and amazing strategies to cope with frustrations and disappointments and stress and they forget to use it in their diabetes life.

Do you mind, I don't want to catch you off guard. Can you think of an example of that? I'm trying to think of what you mean?

So perhaps when I'm overwhelmed with too much homework and a project and an exam and I'm not sure I'm going to be able to pull the grades that I want, what I do is I reach out to my best friend who's really good at math and ask them for help. And then I go to my social studies teacher and ask them for guidance. And then I also asked my dad to read a paper that I'm outlining. And so I bring in experts in different areas to help me get through the stressful times. So I know who to reach out to. Or perhaps what I do is if I'm really stressed about exams and doing well, I pay a lot more attention to whether or not I'm getting enough sleep and I try to prioritize getting enough hours of sleep because I know that I learn better and I cope with stress if I get enough sleep. Or

maybe what I found is that if I can do yoga twice a week and maybe run once then just that exercise and taking my mind away from the stress and doing something that's different with my body and taking care of my body in that way helps reorient me and allows me to focus on the studying I need to do. So that would be examples that have nothing to do with diabetes, but they are just as appropriate when you're managing diabetes related to stress. And so sometimes I like to listen to the different strategies that people use that help them get through tough times that have nothing to do with diabetes because if they work in one area of your life, they're likely to work in another.

That's really interesting. We forget about that sometimes. You're right.

And then the other thing that I try to help families think about is the language that they use when they talk about diabetes the tone of voice that they use when they talk about diabetes and whether or not the messages that are intended by the parents are heard exactly as intended by their teenager. So what I mean by that is that sometimes when parents say things like why is your number this high? Why did you forget to bolus? Why didn't you check? Why did you turn me off from share? Those kinds of things. It's almost, so those intentions, the intention of those questions is almost always to say, "I'm worried about you. I want you to be healthy. I want you to be safe and I need you to do a better job of it communicating with me what's going on so that we can work together, and I know you're well." But often times the way in which the questions are phrased, teenagers don't hear that as worry and concern and love and a desire for collaboration. Instead, they hear it as, "I don't trust you. I think you're making really boneheaded decisions. I think you're irresponsible. I think you're not taking diabetes seriously enough and I don't trust you."

Wow.

And so if that is not the intended message, but it is heard that way it can set the stage for all kinds of miscommunication and mistrust and unhappiness that was never intended. And so to help, you know, a parent and a teenager think a little bit about how the messages are given and how they're received can sometimes really change things in a lovely way.

How do you do that? I mean, I don't need to give all the trade secrets here. But I can't help but ask, how do you get your teenager to understand? As you're saying it, it makes so much sense that they may not.

They might not but sometimes asking them to give us some guidance as grown-ups is really helpful and very empowering to them. Let's say that somebody has a Share and the parent says, "When I'm at work and I see that you've got a double arrow up and you're already over 350 and I text you to say I need you to take some insulin to correct and you ignore me and then I'm still seeing the double arrows up and I'm saying correct and you ignore me and now I've texted you seven times and you have ignored me and now I'm going to call you out of class and

you don't like that, but guess what now I'm mad at you cause you've ignored me," right? And so instead if the teenager says listen, "You know, this is what I do. This is how I'm doing it" and then the parent says, "But you're not communicating that with me," then now you have an opportunity for changing the interaction. So I would say to the teenager how can your parent let you know that they are aware that you are double arrows up and you're already 350? How can you let your parents know that you are aware of it and that you've done something to correct it? How do we do that so that they don't have to text you seven times and then call you out of class because you don't want seven texts. You don't want them to call you out of class. So what can you do to let them know to improve that communication so that the annoying nagging intrusive parent doesn't come to that. Does that make sense?

It makes perfect sense in fact, go ahead.

So again, like reaching out to the adolescent him or herself for some ideas and strategies that might work. Sometimes they come up with amazing strategies. Sometimes they're not so good but it's okay because now all of a sudden you have a collaboration and you have communication and it's the diabetes that is exhausting and annoying and unfair and frustrating. It's neither the teenager nor the parent. So once you guys are working together to try to solve a particular diabetes specific event or problem or situation then everybody's on the same team and communication gets less likely to be misunderstood.

It's such great advice. And again, I'll just use us as an example, we are far from perfect as you well know, but I do sit down and I have since Benny was very little, with him at the beginning of every school year and say, how are we going to do this this year? When he was very little I would say what's one thing you want to do this year that you didn't do last year? And in first grade it was "I want to eat lunch in the cafeteria." You know in fourth grade it was "I want to you know, check in with my teacher and not the nurse at lunchtime" or whatever, you know, but every age appropriate thing. And then as he got older now it's, he asked me to text him 20 minutes before lunch because he couldn't remember he wanted to pre-bolus. This is something he found worked well for him at lunch and he couldn't remember. He didn't want an alarm, he tried it and he didn't like that it was weird for him and then he would forget anyway, so I text him every day and I've done that since 6th grade. This is the third year.

And what do you text? What are the words that you use is it "bolus?"

No I'm going to look let's see what it is. I used to say a lot more. I used to say "here's the amount of carbs, and here's what your blood sugar is right now." Today was, "Please bolus for lunch 70 carbs XOXO." That's it.

Fantastic.

Yeah.

And he finds that helpful.

You know, he I hope so. No, he does. He told me to do it.

Well he asked you to do it which is amazing.

He did. In seventh grade. I said to him. “Do you want me to do this? I feel like I’m nagging” and he said “No Mom, I it helps me just think about school. I don’t have to remember and I don’t have to think about diabetes. I know you’re going to keep on it.” Sometimes, every once in a blue moon I do forget. But you know, I have a reminder in my phone and it’s just bolus for lunch and I used to write out all the carbs and put in his lunch box, but he doesn’t really want that anymore either. So I just text the number to him and he can look at his pump or his phone now and see what his blood sugar is so I don’t have to tell him that. But I did ask you in the (Friends for Life) session. I’ll ask you again for the benefit of the listeners. When do I know that it’s time to stop texting him? I can’t imagine he’s going to be 35 years old and I’m texting him, “Hey, it’s time for lunch.” How do I know when it’s time for me to let him completely handle that?

So absolutely our children will let us know when our support is no longer perceived as supportive. When our help is no longer perceived as helpful. I love that you asked him and check in with him because he gets to change his mind over time. So you’re recognizing that, you know, every four to six months, he’s just kind of a different person because his brain is developed more but his interests are or different. Adolescents is such an incredibly rapid stage of change and cognitive development and it’s hard to see, just as like their clothes are no longer fitting and there you know eating us out of house and home and you know causing all kinds of costs for new clothes all the time. Their brains are growing and developing at alarming rates. And so, you know, they’re thinking, their ability to problem solve, their judgment is constantly changing. So I love that you’re checking in with him. I would suggest above and beyond let them tell you when they no longer want the support. In general, people are pretty much done asking for support around the age of 25.

I thought you were going to say like 17 or 18.

No, truly around the age of 25 a little bit after, as people go to college a little bit after college. I really mean it. It sounds funny but I am honest. And part of that is truly again going back to science and going back to biology. The part of our brains that are responsible for judgment and a sense of risk taking and organization and planning ahead are the last parts of our brain to develop and those parts of our brain aren’t done until we’re about 25. So our brains are continuing to grow past High School, past the university years. And so even though in general we think about

people over the age of 18 as adults because they get to do all kinds of adult things legally. Their brains are not yet done. And their ability to plan ahead and organize and recognize danger and risk is really not fully formed which is why college students sometimes get into really amazing bits of trouble. You know with the choices that they make in parties and other things like that because that part of the, “This is really not a brilliant idea and I could get into big trouble,” it’s not quite there. So if our children/young adult children are still saying, “Gosh if you texted me or reminded me or called me or whatever it is that they needed our help with it would be great.” Then I say, please please do it because it will help them.

That’s great. You know, it’s funny as you were talking about the age of 25, you know, I have a 17 year old daughter and I don’t think anything when she says things to me like I don’t know how to call the bank. Can you help me or I need to do this on my college application. Can you help me? For some reason in my head I was thinking diabetes was going to be different. Like, he’d be 17 and not want me to text him or do anything. But we do give diabetes a different spot on the shelf for some reason. I don’t know why that is.

Yeah. It’s kind of funky isn’t it? And in fact, I would suggest that because diabetes is not something that everybody deals with it’s not every single friend of your children that has diabetes. It’s not everybody in their school or in your community that has diabetes but everybody your child’s age has other goals right? Like being able to get your homework handed in on the due date or making really good choices about who’s a true friend or being maybe in a social environment where you’re thinking this is probably not a really cool place to be I need to get myself out of it. Or making decisions about learning how to balance a bank statement or how to call in prescriptions or any of those kinds of things. I think that in some ways being completely on your own with diabetes has to go even slower, than being completely on your own for other things that everybody is doing at the same time.

It’s a great point. You mentioned bad decisions, or really that part of the brain that makes good decisions not being quite developed yet.

Right.

Can we talk a little bit about that? Because there are so many bad decisions that teenagers make that I think parents can kind of roll with, but parents of kids with type 1 fear so much more. Can you address a little bit of how can I talk to my child about that? And I know we could talk for hours, but for kind of glossing it over a little bit, how could I talk to my child about parties and alcohol and things like that? When it comes to diabetes.

So first, most important message I have, is whatever each parent’s values and morals and beliefs are they have to share them with their children and be very overt about them and very clear, diabetes or not. Whatever is important

to you as parents, it's very important to not just assume that your child gets your beliefs and thoughts and feelings by the way you behave but they need to hear it from you directly whether that's cigarette smoking, drinking, being intimate with somebody, all of those things. It's very important that parents share their thoughts and beliefs and morals and values overtly and repeatedly actually with their teenagers, even though they will be miserable that you're sharing your thoughts and beliefs. So I think that that's sort of the very first thing I want to say.

If you are a parent that feels comfortable talking to your children about the risks of drinking then with diabetes, I think it's important to first make sure that you have all of the knowledge. It is perfectly reasonable and okay to get your diabetes nurse educator or your endocrinologist or whoever else you feel really close to on your diabetes team to facilitate that conversation with you. So you don't have to do it solo. You can always do it with your diabetes team. But I think it's about having accurate information and protecting a person's safety. So from my perspective, the number one most important thing is that if children are going to engage in drinking or even adults that they are very much aware of what happens biologically when you drink and that they are engaging in behaviors that protect them to avoid low blood sugars in the middle of the night while they're sleeping. So, just some facts that I think that teenagers and adults need to know is that for pretty much every alcoholic beverage you drink whether it's a shot of whiskey or glass of wine or a beer, your liver stops producing glucose for an hour. Because your liver has to process out the alcohol and that's its primary goal when it's exposed to alcohol. So it stops its other job of producing glucose. So if you think about sort of the stereotypical college party where there's lots and lots of alcohol and no food. If you drink and you have no food in your body and your liver is no longer producing glucose and you potentially have insulin on board, you increase your risk for a pretty frightening low. And so my message to teenagers is I want you to eat before you go to the party. I want you to eat in the middle of the party which means bringing granola bars or whatever else it is because there's going to be no food there. And then I want you to eat when you come home from the party because I'd much rather you wake up with a high number than not wake up because you went low and you were too drunk or wasted to be able to wake up. Does that make sense?

Sure. Yeah, I'm taking notes.

But that that message might be really off-putting to many families because they might feel very strongly that the message needs to be: you don't drink.

Sure.

And so again, I don't want to take away for a minute that everybody has the right to their morals and their values and their belief system and their children need to hear it. But if children are going to and if young adults and adults are going to drink and they have diabetes they need to understand what happens when they add alcohol into their system around glucose production in the liver. And if you have any insulin, that's still around and on board.

Such a tough choice for parents as to how to present it.

Yeah, yeah.

You know, you have to have to figure out first, how am I going to talk to my kids about drinking and these choices? And then how am I going to talk to them about drinking and diabetes and these choices? So I appreciate you being so straight forward.

Absolutely. And you know other things like basic safety things have nothing to do with diabetes, right? You never accept an open bottle or an open glass. You never put your drink down, it's never unattended. You never go to a party with somebody and then leave without them or let them leave without you, you know, those kinds of just basic health and safety messages are important whether the person chooses to have alcohol or not. Somebody can spike a Coke so or a Diet Coke or water. So you want to make sure that when you're at these big parties, you know that children understand some very basic health and safety rules and my perspective is that it's really good idea for them to hear it from mom and dad.

Do you find that, again speaking from personal experience, that as you said, these are the worst conversations to have and the kids hate having them but they listen. They do hear what we're saying, even if they're cringing and wanting to run out of the room.

They hear what you're saying loud and clear and they hear your voice often, even if they won't acknowledge it. So you can't have a conversation just once which means it's going to be hard for you and your teenager more than once and it's going to be like, oh my God, I can't believe we're talking about this again. But I think it's really important because it lets your child know that this is super serious, that this is really important to you. Because this is all about health and safety right and making safe decisions.

One of the things I took away when I heard you speak for the first time was this sense of: it's ok not to be perfect. I think that - I know - I put a lot of pressure on myself and I feel like we fall short all the time. My son is a great kid. And he's a good kid when it comes to responsibilities and things that he's supposed to be doing. But you know, I don't share his numbers and that's not because they're terrible. I don't think it's anybody's business but his. But you know, we are not straight line.

They're not terrible. They're just they're just numbers.

Right but they're not straight...

There are no terrible numbers.

Okay. Alright, I'll try again. You're right. You're right. Well, they're not, we don't have an A1C of 5.2 with straight lines 24/7, you know, that's not going to be his experience. But I left your talk feeling so good about where we are because of milestones. Like, he is still talking to me and asking for these texts that we mentioned earlier, right? It's okay for me to be involved. We have a plan as you mentioned. Like, when am I going to text you if your Dexcom says this or says that. And you mentioned problem solving which really made me sit up straighter because I hadn't even thought about that as a milestone. But Benny started doing more of that for himself really a couple of years ago, and it's getting better and better at it. Can you speak a little bit to that as a milestone for parents to look for?

Yeah, you know as children get older and you can start to see some really great problem-solving even when they're much younger even in the sort of late elementary school years. But they're not always there consistently when you need them to engage in those decisions right? And then as they get older and older you just start to see better and better problem solving skills. I think catching children when they engage in great decision making and praising them going, "Wow, that was just incredible. I'm so proud of the way you solved that problem," regardless of whether it's diabetes related or not is lovely because we don't always catch our children and comment to our children about what they're doing that makes us so proud of them as often times we just kind of remind them and point out the things that we wish they had done differently. So that I think is really important and then, you know as they start to make great decisions.

Sometimes we can back off a little bit, but it doesn't mean that there won't be then a challenging moment in their lives a stressful time. Like for example, I'm thinking junior year in high school and everybody's really stressed over their grades, over what colleges or universities they want to apply to, over ACTs or SATs. So there's just a lot of pressure especially towards the end of junior year in high school. And so sometimes teenagers just need to say, "You know, what? I am problem solved out. I am sort of not able to really deal with some of the ups and downs of diabetes stuff. So I would like to give this job or these jobs to you mom and dad back even though I've been doing it just fine for the last few years." So, you know being able to do that as well, because that actually is great problem-solving. That's knowing that I'm so stressed right now that I can't handle everything. So I'm going to get the people involved that can do it well that I trust and get them back into my life.

Well, that is really interesting to think about it that way. I mean just asking for help can be a really great sign of success.

You do a talk as I mentioned earlier called, "Raising your Parents." Can you share a little bit? I know not a lot of teenagers listen to this show, but I'm wondering if you can share for parents kind of what goes on in there.

Well, I try to remind teenagers that they are part of a dyad right? They're part of a family. They're part of the

interaction and it's not just that their parents are raising them but that they have a role in raising their parents. And so what I mean by that is I want our teenagers to recognize when their parents are stressed or distressed or worried or nervous or anxious what role they have in reducing their parents stress, distress, or worry or anxiety. And then what the good things are that can happen when they recognize that they have a role and helping their parents be less distressed. So teenagers have been able to talk about when I check my blood sugars more often or when I pre-bolus meals or when I let my parents know what my blood sugar is before I turn the key in the ignition in the car, my parents look at me as being responsible. They also know what it is I'm doing and that I'm doing making safe decisions. When they see that when I preemptively share this information with them, they're more likely to say yes to something I asked them that I want to do.

And what are the kids' reactions when they kind of realize that or talk through that?

Well I don't sort of say it the way I just said it. We have a conversation so that they come up with. Oh gosh. Yeah. When I do this, my parents are more chill. Oh, well why are they more chill? Because they're not so worried. Oh, huh. So you have a role in helping them not be so worried. Oh, yeah, I guess I do. So, what's the good things about being better at communicating with them before they you know, get you know on your case? Well, then they're not nagging which makes my life easier. Okay, great. So you just helped your parents not nag you. So I help them sort of make the connection through conversation. That's a great point because I gotta believe that they don't realize that we don't like nagging them, until.

Oh no, they think we love it.

Right? But we don't and so how, so part of that talk is to help them recognize actually where does the nagging come from? Is it really the parents wake up in the morning and say what can I do to irritate and annoy my child today? Or is it that they're really worried about your health and safety? And invariably teenagers are really great at recognizing the good that is sort of under underlies the nagging that my parent loves me. My parent wants me to be healthy. My parent wants me to be safe. Definitely, you know, sometimes teenagers feel like their parents are hoping and expecting for more than is biologically possible or reasonable. But they do, they most of them do recognize that their parents really are coming from a good place and that if they are a little more proactive in sharing information than their parents are way less worried and stressed and then everybody gets along better.

So what's your advice? If there is a family where this really just isn't working, you know, there's a teenager who is not doing the minimum to be safe to take care of themselves with diabetes and the parent is very frustrated doesn't know what to do. I assume some of this is to call a professional, get an endo involved. But what would your advice be on how to handle something like that?

Yeah. I think that that's exactly right. After you've tried to talk. You've had some conversations about gosh, you know, I feel like I'm a nag I don't want to be a nag but I'm worried about you. I need you to be healthy. I need you to be safe. Do you have advice for me about how to communicate with you more effectively so that we're all on the same page and we're working together? If those kinds of conversations are not helping in a parent or teenager's feeling like they're you know, that things are still really unpleasant in the home and that there's a lot of conflict especially around diabetes tasks. Then I think reaching to your pediatrician reaching out to members of your diabetes team for referrals for Behavioral Health Specialists, whether it's a social worker or a psychologist or a psychiatrist that understands diabetes is really the next step. And it could just be one or two visits or could be longer but you know working with somebody that can be helpful that understands families and teenagers and diabetes is going to be helpful.

And I hate to say it but of course there really still is a stigma about seeking help like that and I think some parents might feel like they have failed if they have to. Can you just speak for a moment about how, in my opinion, it would really be the opposite. You know, you really would be helping your child and succeeding by trying to get more care like that.

Yeah, because what you're talking about is teaching your children that not every challenge is easily overcome on your own and that part of being a successful adult is knowing when you've really given it the good old college try so to say. You've really put energy and effort and it's just not getting you where you want to go. And if family members are finding themselves really having unpleasant conversations and the joy and fun of being together as a family is no longer there, then I think everybody deserves to bring in somebody with a slightly different perspective and a different skill set to just be a consultant to guide them and give them some new thoughts and new ideas. You might reject them, which is fine. But at least you've tried because not everybody can be an expert in everything.

So, you know for me if my car makes a funky noise, I am not going to look under the hood and try to figure it out. I don't have that skill set. So thank goodness, you know, I can go to a mechanic. That's sort of a little bit of a silly sort of way of describing it. I don't mean for a minute to suggest that it can be that simple but I but my point is that we can't all be expert in everything. That's why we live in a community. That's why we partner with people that have different skill sets. And so I would encourage families to just think that this is about consulting with somebody that has a different set of training and a different skill set to determine if they might have any thoughts or ideas that are useful or helpful. It's not about it's not about failure. It's not about shame. It's about reaching out to other people and gathering some new ideas or new information.

One of the things I've seen in the community Jill and I know this is a debate is do you talk to your child about do you use scare tactics? Right? If you're if you feel like your child needs to be doing more to help with their management or things aren't going the way you'd like that you say to them, you know, you could have long-term complications or take, I mean, I've seen people who suggest taking their children to a kidney dialysis

center. Do those kinds of things work?

Sometimes they can work for maybe a couple of days at most a week.

Oh.

But that's about the length of time it will work. And it works because it instills a great amount of fear into a child. It's very frightening to see people that are very ill and not doing well. The problem is children are really not capable of connecting those people with their current behavior. So if you look at what works for a child who is very now oriented, who is not at all future-oriented really, and the concept of a future might be next week, but it's certainly not when you're 45 or 50 years of age. I think that a more effective approach and one that protects the relationship between the child and the parent is to think about what's immediately relevant to the child. So when your blood sugars are really high do you wake up a lot in the middle of the night to go pee? Wouldn't it be lovely to be able to sleep through the night? Is you know, an immediate consequence of tighter blood sugar control, right? Because most people would like to sleep through the night. Or do you feel like your mouth is dry? Or do you feel like your vision isn't so great? Or do you feel like you know, whatever that person's symptoms are when their blood sugars are higher that just doesn't feel great. Do you feel like your thinking is slower? You know, do you feel like you're not as fast, you know, whatever it is. That would be that person's symptoms or again for low blood sugars, you know. Do you feel you know, sweaty, shaky hungry? So when you know in different people have different symptoms, so if you don't want those symptoms don't feel great in the immediate, I would work on what it is that we want to do now to improve those not great experiences now. Because as grown-ups, you know, that that's going to have long-term benefit, but children don't quite understand that you know? So if I say, "If you check your blood sugars, or if you monitor your blood sugars and you pre bolus and you take your insulin and you count your carbs and you exercise every day from now on. Do you know what's going to happen in 40 years? Nothing." Like how could that be motivating?

That's a great point.

Yeah. So again, I think I think it's about finding a way to encourage the behaviors now to develop really great health habits now to reduce some of the not great experiences when blood sugar's are out of range now. And that will set the stage for future.

A lot has changed since my son was diagnosed 12 years ago now and one of the biggest things is social media. While that has connected me to a lot of wonderful people and I love the support I get, it is also brought this level of, "Am I good enough as a parent" that I'm not sure was there when my son was first diagnosed, you know, people sharing flat Dexcom lines and particular ways of eating that work for them. And you know, just I

did this and you must do that or just showing examples that you know, I personally I can't live up to that. I feel like there's almost more stress by seeing that. Have you noticed that as you talk to people?

Absolutely. But I would just remind you that we see that in that diabetes social media as well, you know, the families that are what we call quote unquote Facebook happy, you know, the perfect family on Facebook. They only post the things that are awesome and amazing and wonderful. And then if you get to know some of those families for real, you realize that there's not everything is sunshine and butterflies. So, I think just sort of taking a step back and wondering like why are people posting this? You know, well, what good are they trying to sort of like share with the world. And so sometimes it's okay to just kind of turn that stuff off. Or to just say, oh, I'm so happy for them. They had a great day. Mine wasn't so great, oh well. You know and to be able to just kind of just not personalize it which is so hard if you're, you know overwhelmed with it all the time.

But it's a good point. It happens with now, you know, not in the diabetes community as well every day too. I see my neighbor's posting their beautiful floral arrangements or their gorgeous living room that doesn't have mail all over it and towels that need to be put away.

Right, or dog hair or little bits of yesterday's meals and dinner that somehow wound up, you know in the living room even though everybody ate in the kitchen.

Of course.

So, you just kind of wonder really? Like really is that their life? I think also just being comfortable with your own, you know. Hey, I have a lived-in home, right? So you or whatever it is or hey, you know, this is a month where I have a child who is doing an enormous amount of growing and the most important thing is for us to just focus on the basics and get through carb counting and monitoring blood sugars and administering insulin. And just sort of keeping the amazing persistence that we all have that we haven't given up and we keep on going. And that's that's so amazing, right?

Yeah. It really is. And just to say, great job today. Guess what? We get to do it all again tomorrow. Before I wrap it up Jill. Was there anything in particular you want to talk about that we didn't get to?

I don't think so. Again, I think that the more that people don't, this is so hard. It's so easy to say, but it's so hard to do. But the more we don't get sucked into what's not going well. And instead focus on the typical behaviors that we need to engage in day-to-day to just manage diabetes and persist in spite of ups and downs and frustrations. And the more we give children the message that we're all in it together and that it takes a team. I think the better people are going to be and the less exhausted they're going to feel.

Jill, thank you so much for joining me.

Oh yeah, you're so welcome.

It's great to talk to you. I always feel like now I have something I have a goal and I'm focused and I just and I feel like I'm not doing it all wrong. So, thank you so much.

Oh my gosh. You're so welcome.

All About Insulin

with Dr. Bryce Nelson

[EPISODE ORIGINALLY AIRED 1/29/2019]

Dr. Bryce Nelson is a pediatric endocrinologist who has been working with children and their families for 20 years. Dr. Nelson is the Division Chief of Pediatric Endocrinology, Medical Director of the Pediatric Diabetes Program and Associate Professor of Pediatrics at the Children's Hospital of Richmond at VCU.

Stacey: Thanks so much for joining me. I'm so excited to start these educational segments and see what we can really learn. So thanks for making some time. I know you're very busy.

Bryce: Well, thank you. This is quite an honor. I appreciate it Stacey that you've allowed me to be your first endocrinologist you're talking to in this series.

Well, sometimes that's good. Sometimes you're the guinea pig. So I'll see you again at the end. We'll see how it goes.

Yeah as a researcher, you know, that's okay.

Before we get started talking about the basics of insulin. Let me just kind of let my listeners get to know you a little bit more. You're a pediatric endocrinologist and we met several years ago at a conference. You really seem to go above and beyond for the families in your practice. Tell me a little bit about the camp you started. This is just a couple of years ago. Right?

Right. We started Camp Buddy about three years ago and it was it was in response to a need. We didn't have a day camp for young children. So this is a camp that for children ages 6 to 12 that they can come to for the day and

really just gives them a chance to be around other kids with diabetes. At school or elsewhere sometimes kids can feel, you know, outside of the quote-unquote community and our camp is really a celebration of the community. The kids get to come together and learn that they can be a kid with diabetes and that's an important theme of everything that I do in my practice and how I work with these children. They're not "diabetics." That is a word that I really, really don't like. They are children who happen to have diabetes. They're not defined by this disease and we want them to start learning in an early age. They can still do all of the things that children can do and be children and just but learn how to manage their diabetes through those things. I think that the earlier we start to do that where it just becomes second nature and it's just part of how they live with the condition then the better off these children are long-term. That's something that I maintain throughout all of my practice and something that at all ages I try to really really push. Because I think that's what leads to success in life with this, learning how to live with this and learning you can still make your dreams. You can still set all your dreams. You can still set all your goals and achieve all of those. Just have to learn how to manage your condition and then the world is your oyster.

You see a lot of patients who are tiny, you know who are six or under. I know you see toddlers as well, as a pediatric endocrinologist. But a lot of what we'll talk about today is for people who are newer diagnosed, adults and older kids as well. I'll be honest with you. I have a great endocrinologist and a great CDE and I still feel like I'm learning all the time. That's one of the reasons why I wanted to get into this basic info. So let's just dial down and get really basic Bryce. My first question, about insulin.

Let's do it.

Yeah, let's do it. My first question about insulin is why do people with type 1 diabetes need insulin?

The reason that people with type 1 diabetes need insulin is really based on the disease process itself. We know that type 1 diabetes is what we call an autoimmune disease. We all have immune systems that are built to protect us from things outside of us. So things that could potentially harm us. The most common thing that we think about with that is infectious disease such as bacteria, viruses, those kind of things. The immune system is exquisitely designed to be able to help you with that. But because it is so well designed there can sometimes be hiccups in the system. So it's like children can act up from time to time. Right? So it's the immune system is acting up. It's not supposed to attack us but in the case of type 1 diabetes the immune system got tricked and you know Stacey we still are just now understanding what are some of those triggers are and by what process the body starts to develop diabetes.

It all starts before people develop symptoms of diabetes, which we'll talk about in a second. That autoimmune process gets triggered and so the immune system start to attack the part of the body that makes insulin and that part of the body is called the pancreas. The pancreas does several different things for the body. But in this case what we're talking about is it makes a very important hormone called insulin. Insulin is the hormone that our body uses to lower blood sugar. As we all eat, that food is being broken down in our digestive system into different things and one of the things that's being broken down into is a sugar called glucose. Our body uses

glucose for energy. We use it to move and to walk to do all the things that we do and we store excess energy in fat. Insulin is the hormone that tells the body to put the glucose where it's supposed to be. So it's that trigger. It's what keeping our blood sugars, in addition to other hormones in check, and where it's supposed to be.

When that initial autoimmune process gets started, it's killing off the cells of the pancreas that make insulin. And that's a process that takes time. It doesn't happen right away. So that's why people can have that happen and never have any symptoms initially. It's not till their body reaches a certain level of those cells that make insulin, once they've been destroyed to a certain level, the body can't compensate anymore, it can't keep up. As that happens, the insulin levels drop and blood sugar starts to go up because there's not the hormone there to tell the body to put that sugar where it needs to be. And as those blood sugars go up, that's when people develop the symptoms. That's why people get thirsty because the bodies recognizing there's too much sugar. The body is also trying to get rid of that sugar in any way it can so people start urinating more frequently because the kidneys are trying to get rid of that extra sugar. Because you're urinating more frequently, that's making you more thirsty. And because the sugar is not going into the skeletal muscle and to fat then the body thinks that you're not getting energy. So that starts to make people hungry. So that's why you get the three classic signs of people who have diabetes: increased thirst, increased urination, and increased hunger.

I always thought the hunger was tied to the thirst. But that's because your muscles aren't getting what they need?

Yes, your body's thinking that it's deprived. Your body thinks you're starving. And that's also why people start losing weight initially; insulin is a storage hormone. It tells fat to store energy for a rainy day. In the absence of insulin, you don't have that signal anymore. So your body, because it thinks it's starving, it's tapping into its stores in fat and so people start breaking down their fat and that's why they start losing some weight and as they're breaking down the fat that starts to develop those dreaded ketones.

I'm going to plan a future episode talking about ketones and illness and lots of things but let's just touch on that briefly. So you said dreaded ketones. What are they? And why are they so bad?

Ketones are actually intended to do a good thing. Your body is breaking down fat and it breaks it down into those things called ketones because your body can convert those ketones into energy. But the problem in diabetes is that you have excessive amounts of that breakdown and the ketones start to develop at too high of a level. It can change what we call your acid-base balance so it can make your blood acidic. It doesn't literally turn your blood into battery acid, but that's the concept. I use with my patients is that you know, as that becomes as your blood becomes more acidic, it becomes caustic and so your body doesn't like that. Your liver doesn't like that. Your kidneys don't like that. Your gut doesn't like that. It makes you sick to your stomach and makes you want to vomit. It gives you a headache. It can dehydrate you further. The ketones start out as a normal physiologic response - it's what our body is supposed to do when we're breaking down the fat. It makes

us ketones so that your body can turn that into sugar for energy, quick energy. But in diabetes, without that insulin, your body is out of sync. So those ketones develop at too high of a rate and too much and it makes your body acidic.

Okay dumb question. Can you define caustic? What does that mean?

Yeah. So caustic, corrosive is what I mean. So when people think about that the concept that I use for teaching purposes with patients is, you know, imagine if you had battery acid on your finger it would cause a burn it wasn't painful because it is corrosive. So it's eating and burning down the skin tissue on your finger. When your blood stream gets acidic – remember your blood's going to all parts of your body- imagine that same process happening to all parts of your body.

Wow. It won't surprise you that I know the definition of caustic as the second definition which is more, you know sarcasm and caustic in speaking.

Yep. That's right. Corrosive is a better word.

That's really interesting. Okay. So back to insulin, let's talk about the different types of insulin. I don't want to talk about brand names necessarily yet. But you know regular, long-acting, can you take us through. Let's start with the older versions which are still around.

What we do and why we treat with insulin is really a tenant of something that we all do in endocrinology which is hormone replacement. The medicines that we use, the insulin that we use, is trying to replace what is not there, because as type 1 diabetes it's a insulin deficient state. This started back in the 1920s, obviously, with Banting and Best. They were able to isolate and find the hormone insulin and Lily was able to scale that up and market it as regular human insulin. But we can only give insulin as an injection, we have to bypass the digestive system because insulin is what we call a peptide and your stomach is very good at breaking down peptides. If you try to get insulin as a pill your stomach just breaks it down and deactivates it. It doesn't work. Now who's to say what's going to happen down the road. I'm sure some very smart person will figure out how to do that. But we don't have that capability right now. So that's why insulin can only be given as an injection underneath the skin.

Most of us now practice using the two main different types of insulin. The concept is what we call basal / bolus insulin. This is really derived from us trying to be physiologic. The way that we get insulin is so that we can quote unquote think like a pancreas. Now that's I am quoting that from Gary Scheiner. I don't know if I can do that on your show.

Oh yeah, Gary's a pal. That's a book, if you're not familiar, as you listen, the book is called "Think Like A

Pancreas.” It’s a terrific book and no, he would certainly not be upset at you mentioning it.

Great. So basal/bolus is a tenant of what we try to teach. Because the way that our body makes insulin is it puts a little bit of insulin in our bloodstream all the time; it does all the background work of insulin. It’s what’s keeping the ketones in the right range they should be. It’s what’s telling the liver to deal with sugar as it should. It’s what’s telling muscle to deal with sugar as it should. And then when we all eat our our digestive system recognizes that big shot of sugar that we just got and it secretes insulin in response to that. And so you get what we call a bolus of insulin secretion from the body in response to a meal that has sugar in it. And so we try to mimic that in the clinical setting by giving injections of insulin.

And in order for us to do that. We have to use two different types now in the past, we’ve had several different ways that we had done this.

Initially, it was just with Regular insulin which starts to work in about an hour, peaks after four to six hours and has gone about six to eight hours. Not many of us use that as a go-to for how we treat patients anymore because that led to a lot of problems with how it doesn’t really match how people eat. It doesn’t match people’s daily lives. So it led to a lot of blood sugar variability. It led to into a lot of low blood sugars, high blood sugars, and it didn’t lead us to good control of the blood sugars. And so very smart people figured out that well one type of insulin is not going to be enough that we just can’t manage this and think like the pancreas because I have the the pancreas thinks with this so they developed other what we call basal insulins. These are insulins that do that background work that I was describing before. The basal just works in the background. They don’t adjust, they don’t change blood sugar very much, but they do a lot of background work.

One of the main ones that was used at the time several years ago was NPH. That was an insulin that started to work in about four to six hours and was gone by about 8 to 12 hours. So you had to give that insulin twice a day. And so initially people were doing a combination of the regular insulin and NPH doing two daily injections and they with that they had a lot of variability with their blood sugars from day to day. Also between different people, people absorb those insulins a little bit differently. Then some very smart people figured out well we can adjust the insulin molecule a little bit and make it more rapid acting and actually make it be sustained longer into the bloodstream if we mix it with certain chemicals. It will stay in the bloodstream for longer. So that’s where we’ve gotten to in our current treatment is where we have basal insulins that do the background work and that typically last about 24 to 36 hours. So they’re doing a lot of the background work and then when we all eat or if we have a high blood sugar, we use a rapid acting insulin that typically starts to work anywhere from about 12 to 15 minutes. It peaks in about an hour and then is gone within three or four hours. That makes it ideal for helping control a rise in blood sugar after a meal or if the blood sugar is high, to help bring it down.

And you’ve mentioned this, but I was going to ask about onset, peak time, and duration because all these insulins have different timing. So when clinicians talk about those things like on set would be when it starts working, peak time is when it’s strongest and then duration, now as a lay person who’s been dealing with diabetes for more than a decade, it seems to me that peak time and duration is different person to person even with the same insulin. Is that true?

Absolutely. It's true. I mean, I see that clinically all the time because there are so many things that can affect how the body is dealing with that insulin you're giving as an injection. It could depend on the different body site that you're injecting into. It could depend on whether or not you have been injecting in the same site and developed scar tissue so that you're not absorbing that insulin as well. And also I see some people who develop what we call an insulin resistance, so they are not as that, the insulin doesn't work quite as well and is strongly in certain individuals or it might peak at a different time. And so clinically, after you see thousands of patients, you see that. You see that people have different responses and we know that through studies too.

People report these onset, peak time, duration, you have to remember that those are the averages and standard deviations based on a research study. So that means that 95% of people will have a rapid acting insulin that will start to work in about 15 minutes, will peak in about an hour, be gone three or four hours. But five percent of people won't do that. There might be earlier onset. There might be a little bit later onset in terms of when it starts to work and that's where that's why one of the statements in the American Diabetes Association recommendations for clinical care is that care should be individualized because not everybody is going to react that same way. It can even vary from day to day. It can vary when people are sick and vary if they've had intensive exercise and it's why diabetes is such a variable disease. You have to learn how to live with it and just recognize when you're having the problems and know what to do about it and if things don't react the way that you expect, well, you move on. You do your best and you move on for the next day and fight the next day.

No doubt. And as you listen too, if you use an insulin pump or plan to, it's good to talk to your educator or whoever helps you set it up and realize that things like duration are actually variables within the pump. You can tell the pump how long you think the insulin will last, that's the insulin on board. Right Bryce? I don't want to say anything out of turn here, but we have changed that over the years. It seems like insulin used to last longer when Benny was teeny tiny and you're able to adjust that in almost every insulin pump.

Yeah, and and so some of that is I mean that that's glad it's that you recognize that because that is absolutely true Stacey. It can vary over time especially boys. When puberty hits wow, I'm sure you saw that.

Oh my goodness.

Puberty can be a boogerbear (*note: this is a southern colloquialism. It means anything scary. The boogey man, etc*)

I have to interrupt because you see you gave me the funniest advice. I think when we met Benny was maybe 10 or 11 and we were talking about what was already starting to go on. And in addition to the physical changes and I've shared this on the show and Benny knows and is mortified, but he knows I talk about it. It's the mental stuff too. And I think you said something like, "that's a head in the bucket phase."

Yeah right, the head in the bucket. That's a quote from my father. Head in the bucket. Tweens and teens can have a lot of trouble focusing!

Let's go through the brands of insulin if we could. Let's start with Novolog. We're start with the faster acting insulins. Novolog and Humalog have similar durations and peaks, right?

They do. So Novolog and Humalog are similar in their reported onset, peak and duration. We use them interchangeably in practice and there's really not much difference from patient to patient and within patients from day to day in terms of how those insulins work. Now the thing to point out in what you learn in clinical care when you see a lot of patients is that there can be some variability. I have some patients that prefer particular brands and they swear that they see differences when they are on different brands. And I support that. Because one - the patient is living with it every day and they're seeing those things and you need to listen when they're telling you those things. But the other thing is that if they're perceiving it there or they feel like they're having success with that, you know, we need to support that and continue to individualize that care. But when you look at the research studies, there's really not that much difference in terms of how those two insulins act.

We see that question very often in lots of parent Facebook groups and adult type one Facebook groups, "you know my insurance need wants to switch me from Novolog to Humalog or vice versa. Am I okay?" And I think you've answered that in that you should be but definitely talk to your Endo just in case.

Right. Yeah, if you if you start noticing differences being switched to a different insulin that is definitely something you should let your endo know about. Your endocrinologist could then do something that's called a prior authorization. The way that I view that is if we have to switch to say from Novolog to Humalog or from Humalog and Novolog because of an insurance change in preferred product, if that causes a rise in blood sugars that's treatment failure. Because if we switch brands you can make the case with the insurer that the product has led to worsening care and they should be back on the non-preferred product. I rarely see that that, though, so I always urge my patients don't be concerned if your insurance company is making a change in the brand name.

Virtually all of the rapid acting insulins work very similarly on paper. But we would just have to try and see what's going to be the change and it would only take a week or so for you to know. If you start seeing higher blood sugars or lower blood sugars let your endocrinologist know so they can help you get that recognized as a treatment failure and get you back on the non-preferred or the product that was working better for you. Most insurance companies, do require that trial period. You've got to at least show them that that you had a problem with it. And they you know, they don't want that either. They don't want people to have worse care or have worsening problems with their diabetes care. So that's why I haven't really had a problem with, once we can demonstrate that they've had worsening blood sugars, that we can get them switched back to their preferred.

That's great. And it's good advice. Thanks for fighting for us. Okay. The next insulin is another quicker onset, fast-acting, Apidra. What's different about Apidra as compared to Novolog or Humalog?

With Apidra, they changed the insulin molecule in a little bit of a different way than Novolog and Humalog. All three of those have a little bit of change in the insulin molecule that makes it more rapid acting and the change they made in Apidra made its onset of action a little bit faster. So it supposedly starts to work at about 10 to 12 minutes as opposed to 15 minutes. So it's a little bit earlier onset of action. Me personally in clinical practice, I haven't seen that much difference between Apidra, Novolog and Humalog. So clinically, because most people don't really notice the blood sugar's coming down a lot for about an hour after they eat, they all have pretty similar peak onsets. Now, there are some people for whom Apidra does work better. So if they're having problems and they're more of an insulin-resistant person or they're having a problem rising pretty fast after a meal with their blood sugar. I'll try Apidra to see if I can get a little bit better control for them. But it's another one that I don't see that much difference clinically in terms of how it's helping me. I certainly hadn't seen changes in A1C switching people from Novolog to Humalog and to Apidra.

Apidra too is a little bit different in some insulin pumps. We use the Tandem and I believe it's not indicated for that. Is that is there something with the makeup it doesn't work well in an insulin pump?

That's correct and they're not approved to use it in that pump.

Okay, and then the other really new insulin is Fiasp. What is that? What you know, what makes that different is it really much more fast acting?

It's similar to Apidra. It's onset of action is pretty similar to Apidra's. Clinically it behaves similarly to Apidra. I have not found it personally to be that much of a difference. However, here in South Carolina, that's not one of the preferred. So I don't have much opportunity to use it, I don't have that much clinical experience with that one yet. But the data is that it's not that much different than Apidra.

We'll have to wait and see. But it is, it works the same if you were on Humalog or Novolog you could talk to your endocrinologist about Apidra or Fiasp. Let's switch over to some of the longer acting insulins. When Benny was diagnosed we started on Lantus. Can you explain the differences Lantus and Levemir and we can talk about the other long-acting?

Yeah. There's been really an explosion of new basal insulins over the last couple of years. The one that really kind of revolutionized the basal/bolus and how we treat diabetes was Lantus or insulin glargine is the generic name of it. And it's insulin that they have mixed with a certain chemical that will permit the body to slowly

release it from the tissue underneath the skin. It was the first insulin that we really had that lasted a full, in most people, a full 24 hours. It was relatively what we call peakless. Meaning that it didn't really rise much in the bloodstream. And so you saw that clinically most of the time. But when you really look at the how that insulin works, you do get a peak at about three hours. It's a smaller peak compared to the rapid acting insulin. So it doesn't drop blood sugars that much. It's just doing background work. But some people had that peak so, like in very young children less than three, that particular insulin, I would give in the morning because I would want them to have that three hour peak during the day, not at night. That's not based on any data Stacey, that's just personal practice. But that's why in younger kids, I would tend to give that first thing in the morning as opposed to giving it at bedtime.

I know a lot of people to split up their dose of long-acting. They'll do half of it in the morning. Have of it in the evening. Does that make sense?

Yeah, with Lantus that really is more of what we call a dose effect. So once you get to about more than 40 units of of Lantus a day, it really works with it better to split it up. And the reason is because the higher the dose of Lantus the more that peak is at three hours and the more the risk of hypoglycemia starts to creep in. You minimize that risk of low blood sugar by splitting the dose and some people feel like they get better steady control.

Another insulin, Levemir, is also a basal insulin. The generic for that is insulin detemir. It lasts about 24 hours. It tends to be a bit more variable and more people require that insulin twice a day as opposed to once a day. But again, it's designed to last about 24 hours. So some of that is just trying to figure out how you know, whether you need that Levemir once or twice a day. An advantage of Lantus is it more consistently lasts 24 hours. But a disadvantage to Lantus is that it burns when you get it. So it's one of the few insulins that we had that you actually feel when we give it. And in children that can be a big thing. That could be a barrier to care for some kids. So there are some that if they're really having a problem with the burning with Lantus will switch to Levemir. And for a while those were really the two main basal insulins that we had on the market and most of us were using Lantus as our main basal insulin.

Another, more recent insulin came on the market about two or so years ago. That's Tresiba, the generic for that is insulin degludec. That's actually approved for children down to age two. And it's an insulin that lasts for 36 hours. And so what you can do because it last 36 hours is, it actually develops what we call a steady state. You get a much more flat insulin release from the tissue underneath the skin and so it is in some ways a much a little bit better basal insulin that you use. Some advantages we have in kids is that there's actually information that there's less low blood sugar overnight with Tresiba because there's less of that peak. You have less peak in effect. It's just doing the background work and in practice I've really liked to I've been switching several patients over to Tresiba. I've liked it as a basal insulin.

I'll be honest with you when I described Tresiba, because Benny has used it, I feel like I'm talking about

whiskey. There's no burn. It's smooth. You know, it's funny when you think about it like that, right?

It's great.

It is a really interesting difference. My question for you is you mentioned it's got a 36-hour, I've heard even a little bit longer duration, but you give it every 24 hours. But it doesn't tank you. How does that work? Is it that steady state you were talking about it?

It's steady state. It's the same principle we use for oral medications. In general, oral medications take you about four times to take it for your body to reach what we call steady state, where it's in a consistent level in the blood stream. With Lantus, you don't get that. So when you look at Lantus it never really develops a steady state because it starts to come up at about three hours and then by about 18 hours, the levels of Lantus in the bloodstream start to fall and it's usually gone by about 24 hours. So between 18 to 24 hours people can see some differences in their blood sugars on Lantus. With Tresiba, it doesn't stack, because you have that 36-hour you have a little bit of overlap. It doesn't cause low blood sugars by giving the doses. It also gives you a little bit better variability with when you can dose it. So like in children, so I this is what I see as I'm a pediatric endocrinologist, using the concept quote-unquote bedtime. Bedtime can vary a lot for kids, especially for our teenagers, right Stacey?

Oh yeah.

Yeah, wait till you get to the summertime, you know, so bedtime might be three am. Bedtime might be 10 p.m. And Lantus, you really have to give within about an hour of the same time every night to maintain a better basal state. Tresiba, because it has that tail that goes 36 hours, you can get it at true bedtime. As long as they take it before bed, you don't really see much difference in terms of how it acts and so that gives people a lot of better flexibility for how their dosing. Which is an advantage because that's what life is right? Life is flexible, life is messy, life is variable. And so if we have an insulin that can better work in that situation, we've got a better chance for patients because people want to be able to live their lives. They want to be able to go to their son's football game or their daughter's baseball game or softball game, you know? And so that that tends to lend itself a little bit better to that. And it's part of the reason I've really liked it as a go-to basal insulin.

Before we move on, when we talked about Lantus did you say it's also, is it Basaglar? Is that a brand name?

Yes, Basaglar, is a brand name. It is what we call a "bioequivalent." So, it is the same molecule as Lantus. It was just made by different companies. So it's a generic Lantis, is how people can kind of think of it. It's the same molecule that works the same as Lantus. But if it, because it's bioequivalent the FDA doesn't require bioequivalence to go through quite the same rigorous study as say you had to go through with Lantus, but it's insulin glargine. It's the same thing.

So if your insurance company puts you on Basaglar, it's the same thing as Lantus as we've discussed?

Bryce: It's the same thing correct.

Ok, just checking.

And I haven't seen clinically honestly much difference switching people over. There can always be exceptions. That's why you need to talk to your endocrinologist, to your provider if you're noticing problems, but I haven't seen any real problems if insurance companies are switching over. Because it's because it's a generic it's cheaper.

Got it. Yeah, I've heard it more and more in the last couple of months. Let's move on and talk about the so called Walmart insulin. This is different from what we've discussed. This is the NPH we talked about a bit earlier, the older insulins.

So, it's NPH and Regular is what they mostly prescribe. Those are cheaper and for some people without insurance, unfortunately, those are the ones that that we sometimes have to use. I don't face that situation much in children because children are typically if they're not covered under private insurance, they're usually covered by Medicaid and so I don't have that problem that often. It's not till people, children become young adults and emerging adults and around 18 and 19 and are aging out of Medicaid and they don't have insurance yet that that that we have to consider using some of those. But I rarely do that. It still can be effective but it's an older way that we use insulin. So it's you have to either mix those insulins together and it's going back to doing to two injections a day.

So definitely talk to your endocrinologist or an educator if you do need to do that because let's face it, unfortunately people may have to and if you find yourself as you're listening in that situation, it's not interchangeable with these newer insulins. So please make sure to find out how to use it if you need to.

Right. Yeah and you so you can't mix those with the newer insulins. So those older insulins NPH and Regular you can mix those together, but with the newer insulins, you can't mix them together. You can't mix them with those and if you do have to switch over that you really need to let your, I agree with you on that Stacey, you need to let your endocrinologist, provider know. Because they'll have to look at your total daily doses of insulin that you're currently taking and figure out your new doses and work with you on that to get to the right dose. On those insulins you tend to have to be a little bit more strict with your diet in terms of the timing of when you eat and what you eat in and it can work quite well. If you're pretty consistent and regimented with how you eat and making sure you get those insulins at specific times. It can still work well. Because it's the hormone, it's insulin, it's going to bring your blood sugar down.

I'm also seeing an insulin called Toujeo. This is a longer acting? What is this one explain it if you can?

So, it is a concentrated glargine, so a concentrated Lantus. It's not really more potent. It's just there's more insulin molecules per volume. And so what they have found is when you do, when you're able to concentrate that insulin, it's secreted a little bit more slowly and you actually get a reaction more like Tresiba. Now, it doesn't work the same way as Tresiba, but the way the body handles it is similar. There's less of a peak compared to Lantus. Lantus is kind of the gold standard for basal insulin. So they all get compared to Lantus in terms of how they work. And this one is less of a peak at that first onset and you develop a closer steady state. Like I was saying with regular Lantus, it starts to decrease in the bloodstream around 18 to 24 hours. Toujeo stays a little stays more flat. And again, that's one that I don't have as much experience with because it's not approved in children yet, but have used it in some older kids and it's quite good., too, as an alternative to Lantus. Not all insurance companies cover that one yet so it's not always a first line that we're able to use it just based on what insurance coverage may be. But it's the same molecule as Lantus. It's just more concentrated.

These are all injectable insulins and we're not going to go through the differences between syringes and pens and pumps. Maybe we'll do that down the line in another episode but these are all injected as you mentioned at the very beginning. But there is an insulin that's on the market. I know it's not pediatric which is your specialty but let's at least touch on Afrezza, the inhaled insulin. Can you just speak to what that is and how it works?

The concept of inhaled insulin has been around for a while and part of that is people just don't like to take injections. Looking at alternative ways that we can provide insulin and as I mentioned we have some barriers that we can't get by the digestive system at this point to take it as a pill. So again, some very smart people, at Mannkind developed this molecule. It's actually human insulin. So it's like regular insulin, but they were able to develop a particle delivery system and take advantage of lung delivery. To explain, this is an inhaled insulin - this is something that you inhale like you would an inhaler for asthma treatment something like that.

The lungs have a lot of surface area and things can get into your bloodstream pretty quickly. Obviously, we want oxygen to get into our bloodstream very quickly and we want carbon dioxide to get out very quickly. The lung is specifically designed to do that. And so they took advantage of that saying well, why don't we try to inhale insulin to get into the bloodstream faster to see if it works faster and to see if it mimics the way the insulin normally works. Because even our rapid acting insulins, Stacey, they don't, while they're great, they can peak in about 15 minutes. That's a lot slower than the way human insulin works. When the pancreas is working, it can put out insulin, it can vary that peak, minute to minute. And that's hard for us to mimic, even though we try to think like the pancreas, we still haven't been able to do that yet. Afrezza gives us a way to possibly do that and by inhaling the insulin it gets into the bloodstream faster so they can actually detect insulin within about a minute of getting that when you inhale the insulin. You start to notice the onset within about 10 to 12 minutes which is a little bit earlier than the injectable insulins. And it's typically gone within about two to three hours; the duration is a little bit shorter. On paper when you look at the graph of how that insulin is getting into the bloodstream, it

looks more like a physiological insulin response compared to other insulins. So it's a step towards trying to be more physiologic with how the insulin is working in the body. It's still not perfect.

With Afrezza, the concept of how it's dosed is a lot different than injectables. So that takes some people some time to really kind of get used to. There's been less hypoglycemia with Afrezza. There has been improved A1C with Afrezza especially in type 2 diabetes. There's been some really good data in type 2 in adults. Most of this is in adults, they're still studying children, so I don't have any information about children. But the other thing that I really like is, you know, we often don't think about the role of the liver and how our body handles blood sugar. But the way the body does this when it makes insulin and puts insulin in the bloodstream, the first place it goes is the liver. A lot of how we regulate our blood sugar has to do with how insulin is working in the liver. Afrezza is delivered pretty quickly in this state and what happens is liver is what is making sugar for us and you want to turn that process off. So when you are eating sugar, you don't want your body making more sugar. So you turn that process off in the body. And in people with diabetes that process is impaired. But if we have an insulin that gets to the liver quicker, that gives us another way that we can try to better control diabetes. It's a theory that still has a lot to be tested and proven but I like the concept of that.

Another thing we know from animal studies, I got to get my research plugs in here, when you have mice that are genetically engineered to where they do not respond to insulin, you can genetically engineer them where they don't respond to insulin in specific tissues. So I can block that in the liver, that can be blocked in skeletal muscle, so all the places where insulin works to do all those things that we talked about earlier in the show. When it is blocked in the liver, those animals develop diabetes, but when it's blocked in muscle, which is where you would think they would develop diabetes because that's what we think of is that you're not able to bring sugar in because you can't respond to insulin, those animals don't develop diabetes.

Wow.

They develop in the liver knockout but they don't in the skeletal muscle knockout. So the role of the liver in this I think is very important. So that's why I've been intrigued by what Afrezza can do. The improvements in A1C and type 2 have been really pretty good. In type 1 it hasn't been quite as good, and you know, some of that I think personally is that it's there's some dosing issues. Just trying to figure out how to titrate the dose. It takes some adjustment because you have cartridges. It's an inhaler that you put a cartridge that contains insulin in that inhaler and then you put that inhaler to your mouth, and you take a deep breath to where it powder goes into your lung. And the cartridges come as 4, 8, and 12 units. We in Pediatrics are used to dosing things in half units and 1 unit.

Right.

So there's a lot of yeah, there's a lot of people that are like, 'Wow, I can't get as fine of control.' But you still do, because what you have to take into account is that the four unit starts to work faster and is gone faster. So there's less issue with stacking with that. So a lot of the Afrezza users - and there's a lot of Afrezza lovers and if you look on Twitter.

Oh yes.

Yeah, they are there are a lot of Afrezza lovers out there and but it takes some time to figure out what you can use. But some people figure out what their meal dose is and then they might just take an extra cartridges that you just snack and they figure out what how much they need for the snack and so they can mix and match those cartridges. It takes a little bit more effort to fine-tune what you might need. But there's less risk of low blood sugar because it's acts so fast and it's gone so fast. At least that's what's touted. Because it's not approved in kids yet, I don't have much practical experience with it. But just reading the data and the information about it, I think it's exciting.

People who – sorry go ahead.

The other thing, it's not an injection. That's the other advantage is, you know, that that's still a barrier to a lot of people, is having to give insulin as an injection.

Yeah, the people who use Afrezza, as you say on social media, are quite passionate about it and we've done entire shows about it. I think it's really exciting and interesting stuff. So thanks for touching on that. You mentioned stacking a couple of times. Let's talk about that. When we mention insulin stacking, what do you mean and how do we avoid it?

Insulin stacking is a concept that has developed really as we started to do more what we call basal/bolus insulin. It's also become more of a problem as people have access to their blood sugar now every five minutes really. I mean, with continuous glucose monitoring people can see what their blood sugar is, but they can also see arrows are they going up, are they going down, are they going up fast, going down fast? Stacking has actually become a little bit more of a problem using those devices, continuous glucose monitoring, because it has to do with how long the insulin is working in your body. The duration of action, where you know, we've talked about previously. Peak action, when the insulin is working at its best. And then the duration of action, when most of that insulin is out of your body. Stacking has to do with the duration of action.

Insulin pumps have made it really easy for people to potentially stack. What that means is giving multiple insulin doses very close together that you don't give time for the previous insulin dose to really work. So for instance, say Benny eats breakfast and you notice that an hour in or an hour and a half into his meal is blood sugar is 300 and he's wearing his Dexcom G6 that I know he wears, and you've got two arrows still going up. You want to try to bring that down. But he's an insulin resistant teenage boy and he had a big dose of insulin with his meal and it's still kind of around his peak time of working. But you want to get that blood sugar down. So you give another correction dose based on the blood sugar and it's so easy with the pump. But when you do that, you're stacking that new dose on top of the dose that still working and that can lead to people dropping rapidly after that. So the problem with insulin stacking is the post-bolus low blood sugar. That can happen at varying times. Often insulin stacking happens because there may be a mismatch with what the basal rates for the pump may be or what the carb

ratio may need to be. And some people will try to adjust that. The way the pump tries to handle insulin stacking is that famous active insulin time.

Right.

Right? And so the most people use an active insulin time of about three hours. But remember that that dose really lasts for about four hours. Some people might last a bit longer. Some people it might last less. So three hours may not work for everybody. But and when you use that this is the concept I worked with my patients about. That's just a mathematical calculation. Okay, so the pump doesn't really know how the insulin's working your body. All it is saying OK at this particular, so at one and a half hours, the pump will assume 50% of the previous bolus is gone. Does that make sense?

Yep.

Then, depending on how long it's been since the last bolus and it says that at three hours none of that insulin is working anymore. So if you decrease the active time, if you say go from 3 hours of two and a half hours, you're saying that all the insulin from the previous bolus is gone at two and a half hours not three hours. And that your peak time, for where 50% of it is gone, has now shifted from an hour and a half to you know, an hour and 15 minutes or something like that. You wind up stacking that way because you're adjusting active insulin time when actually what probably just needs to be adjusted as either a basal rate or carb ratio. Insulin stacking is something that we need to be watching out for especially for people on pumps and on continuous glucose monitors. Because there is that tendency we want to try to get that blood sugar down and there are other special situations where your endocrinologist may say, 'Ignore what the pump tells you I want you to go ahead and get that dose of insulin.' Because they know that you're insulin resistant or you're sick and you need that full correction dose. But in most situations, you generally want to wait two or three hours before you try to bring a blood sugar back down so that you can try to prevent that insulin stacking. If you are having problems with going up too high after a meal or you're dropping too much after a correction dose, those are things to talk to your provider about to look at your settings to see if there's something else that needs to be done.

As someone who was very confused by stacking in the very early days. I had a 23-month-old and I thought my doctor said you can't feed him in between the three hours of the dosing. That's the most common bit of confusion I see among newly diagnosed families, parents of kids, and even adults. Which is the stacking refers to - and feel free to jump in and correct me if I'm wrong - the stacking refers to treating a blood sugar. It does not refer to dosing for food. Because by the time we figured it out, you've met Benny, he's a hungry kid, that dude was up to like 8 to 10 shots a day because he was like, 'I'm going to eat. Okay, I'll have a shot. I'm gonna eat. Okay, I'll have a shot.' Now, that makes it more difficult to get an accurate blood sugar every couple of

hours, I will give you that, especially at the beginning. You may want to talk to your doctor about planning that out a little bit more to get, you know, good blood sugar measurements. Because if you are grazing all day long that can be difficult. But that's true right you can't stack insulin if you're giving insulin for food is my understanding?

That that is the way that we teach correct. And because you're needing that insulin to cover the carbohydrate that's being consumed. And you're taking in carbohydrate more the more problems with stacking you get and it can still happen Stacey. So even some of those people who are eating all the time, they might have, they might eat, you know, once an hour for five or six hours and then because they bolus throughout all of that. They might have a low later on. Because they've stack some of that. And part of that gets to the to the problem is that you know, as good as our insulins are, you know, we still can't be the pancreas. All that we can do is think like the pancreas. And the pancreas can handle that grazing. That's why you know medical nutrition therapy is so much a part of diabetes care, because it's not just about the insulin about what you dose it. It's about how you're eating and what you're eating. I tell people all the time grazing is something that's tough for us to handle with our insulins. Because it does tend to lead to higher blood sugars. But in general no, the stacking doesn't always happen with food, but it can if someone is a grazer.

Keep in mind, my experience is with a toddler as well. It certainly got easier as Benny started eating at a more routine time. Although as you know, and I was so happy when you mentioned bedtime could be 3 a.m. I mean, you know over the summer there are times and hey listen, it's you can criticize me as a parent I don't care. But there are times where he'll be playing video games and I go to bed and then you know, he's been in the kitchen at midnight or 1 a.m. But he's given insulin for it. So thank goodness for that.

A good pediatric endocrinologist should recognize that. I know that I'm making changes. Once school gets done, and I'm not saying I'm a good pediatric endocrinologist,

I'll say that for you!

You need to recognize how children's schedules change when they go into the summer. You might have to make basal rate changes. You might have to make carb ratio changes because they are eating. While we can live in the great world of 'no you shouldn't eat in the middle of night,' I mean, they're teenagers. This is real life and you have to know how to handle that. And so sometimes I have to adjust carb ratios in the middle of the night. I have to flip flop basal rates because they're staying up all night and sleeping during the day. And so and again that gets to my main theme of how I care for our patients is, I want you to live life with this. I don't want you to not be able to stay up with your friends and play video games. I still want them be able to have that experience and not let diabetes take that away from them. Because I can adjust their insulin doses. We can talk about how to eat better at that point. So that they can learn to do those things. Because I'm actually really happy that I mean Benny knows it. 'Hey, if I go and eat, I got to check my blood sugar or I've got to look at by CGM and I gotta bolus for what I'm

about to eat.' There's some kids that won't do that.

Trust me, I knock wood all the time. We're really very happy with that. One more concept before we start wrapping things up here. I do want to make sure to talk about pre-bolusing and why that is effective. We've mentioned the onset of insulin. It's slower than food. Right? So, you know generally speaking it's a good idea to bolus before a meal. Can you talk about that?

That's the main reason, Stacey, that we can't be the pancreas we can only think like the pancreas. We have to wait about 15 minutes on average for those bolus insulins to start working and some of our more higher carb meals, so the higher the carb meal, the quicker your blood sugar starts to rise. So it becomes a mismatch. That's also why liquid sugar beverages really are not a great part a regular diet. They're not a great part of the regular diet anyway. But for people with diabetes it's particularly problematic because those will make your blood sugar go up within a matter of a couple of minutes. But we got to wait 15 minutes before insulin starts to work.

We see this a lot at breakfast. I'm sure you've seen this with Benny. I mean it and it doesn't matter how much whole grain he eats first thing in the morning, you know, it's still tends to rise. And that could also be some hormone things as well. But you know, the there's with those, our breakfasts in the United States tend to be pretty carb heavy in the morning. Breakfast cereal is notorious for this. Where you'll have that that that blood sugar start to rise and not even that it's peaking. It's just it's starting to go up and you're having to wait for the insulin to work and then when you mismatch those, you have problems down the road later on in the day. And so pre-bolusing is an attempt to try to mitigate some of that. Or to prevent some of that. So if you give insulin of 15-minute head start, then it's starting to work as you're starting to eat so that you better match the insulin's peak action with when your blood sugar is actually going up. And it's very effective but it's also very intense. So that's always not the easiest thing for a teenager that wants to sleep in til the very last minute and roll up out of you know out of bed and just roll out to school and is eating a Nutrigrain bar on the bus or in the car. It doesn't always lend itself easily to life. We certainly try to encourage that as much as we can because it does tend to just match it. It thinks like the pancreas better that way.

I will get on teeny bit of a soapbox if I could and again, this is my opinion and my experience as a mom of a toddler. We didn't have a CGM. I think Benny was diagnosed before Dexcom was even out, but we didn't have a CGM when Benny was diagnosed. And we always dosed after the meal for a very long time because who knows what the two-year-old is gonna eat. I see a lot of stress of parents who will say, 'Kids are so smart. My two-year-old has learned that if he doesn't eat dinner, he will get ice cream anyway, or he will get a juice anyway, because we've dosed him.' What do you tell parents of toddlers or any children who are struggling with the pre-bolus because they love to see that smooth line after a meal but dinner or lunch has become a battle.

I tell them not to fight that battle. I agree with you on this. Most of our toddlers, I'm bolusing after the meal. The way that I conceptualize that is, if we were in school and we were grading, how we did in terms of dosing insulin,

the A answer is we want to pre-bolus. Does that make sense? But the B or B+ answer is you can bolus after the meal. It's just not as effective as doing the pre-bolus but you know, and it also gets back to that tenant that it's about individualizing care. I don't want parents to have that battle and because I know toddlers will do that. I mean they're that they operate under Pavlovian Theory. Can I say that?

Yeah.

Classically conditioned. Just like you said, you know, they learn pretty quickly with wow, I'm going to get ice cream if I don't eat my lunch. So I think it's always safer in those kids and still effective to bolus after the meal. You might deal with more after meal rise, then otherwise, and the way that I try to handle that is I tell parents, 'Well, you have to have a timer. You give the child 15 minutes to eat and after 15 minutes, you count the carbs and that's what you bolus for.'

That makes sense.

Try to mitigate that some ways. Because you know toddlers will also, they'll sit there all day at the table just pick at their food. You just have to try to do the best to still be able to live life. Another thing is you really don't want to have those frequent low blood sugars because while you might get a good A1C, those that those frequent low blood sugars can have, there are studies, and with very young children, less than three, there may be some cognitive effect of frequent hypoglycemia down the road that you'd be dealing with. You wouldn't see it until they're older. So you're putting the child at risk for a severe low blood sugar event. I try to avoid that if I can. I still do after bolus, I still bolus after meals in toddlers or people who don't eat a consistent meal. If I can't count on they're going to eat what you put in front of them like in school because I don't want them to have a little blood sugar at school. I want them to stay in class. I want them to do those things. Then I'll take the B+ answer and I'll bolus after, I'll advise parents to bolus after the meal. There's no data that I've ever seen that says, you know that bolusing after the meal is inferior. You might have to deal with some rise after the meal but you're not dealing with the low blood sugar. And I don't want to get to an A1C a seven a half or less, having twelve percent of your blood sugar's less than 70. That's not the way I want you to be there.

Wow, a lot to take in. A lot of great education here. Before I let you go two more questions for you. You've given some terrific advice throughout this interview for newly diagnosed families and adults with type 1 about not letting diabetes rule their lives. That's a great philosophy. I'd also like to ask you what excites you about the future of endocrinology and type 1. You know, what what gets you excited that's happening?

A lot of things get me excited about what's happening with diabetes and I think you know really what's been exciting over the last five years is just the explosion of technology that we've been able to use to help families live

their lives with diabetes. I'm excited about the technology that's here, the technology that's coming. I'm also excited still about the cure. You know, I think that that still a viable option. I'm also excited about the research that's going on with TrialNet that's looking to try to prevent people from ever getting the disease. So, you know your listeners who are at places that help that participate in TrialNet which is the largest study for Type 1 diabetes, looking at understanding the natural history of the disease so that we can prevent people from ever getting it. And that's just a good principle of pediatric care to me. We practice preventive medicine in Pediatrics. And so if I can ever prevent people from getting there, but I want to learn how to do that and there's some wonderful researchers and very smart people, smarter than me, who are looking at those things.

The technology that I think has been the most exciting thing over the last five years and it's exploded since really since Dexcom came on the market in pediatrics. I mean things have just dramatically changed. We saw in another study there was about a 30% increase in CGM use in kids over a five-year period. I've seen that in my clinical practice and what I love about that is that it's giving life back to people. Parents are now sleeping through the night. Parents are more comfortable sending their child to go spend the night at their friend's house because they can see what their blood sugars are doing. And using technology like texting they can text their child say, 'Hey, I see that you're dropping you might want to eat a snack. Hey, you know, you're going up you need to take a bolus? Did you eat?' But it's giving those children and parents back some freedom that I think is just remarkable because it ties into to my practice that I want them to learn how to live life with this.

The technology that's coming out, I'm really excited about the Medtronic 670g pump. I know you're going to deal with that in another show, but that having an automated insulin delivery system. Us having the artificial pancreas on the horizon. I think it's great to where, you know, if we can use the technology to have people think less about their diabetes, wow what the future could be. We had a man named Bill Woods come talk at one of our diabetes days. Bill Woods, he was involved in one of the earlier Bionic Pancreas studies. (The Bionic Pancreas, also known as the iLet) uses both insulin and glucagon in the pump to manage diabetes. And he was in one of the home studies about that. And he said something about being that said that just strikes me is that he went to the zoo with his children and while he was wearing that bionic pancreas, and he said normally when he goes anywhere his first thought is, 'Okay. What am I going to do if I have a low blood sugar? Where can I go? Where are my snacks? Where can I find, where are the refreshments if I need to get a drink? Or where are my things?' It's planning the the zoo trip around the diabetes. He said while I was on that, I went to the zoo. And for the first time in my life that I could remember I didn't think about diabetes as the first thing. I just went to the zoo with the family. And that is powerful. We still got a long way to go, but the technology is here.

Just imagine the first cell phone that came out. That's where we're at. And I can't wait till we get to the iPhone or the Galaxy 6 or whatever. I'm an iPhone guy, but I can't wait to get to that point in the technology. And also, you know, we're getting smarter about the data. Now that the data can go to the cloud and we have smart mathematicians that can you know, as this is going to the cloud, they can look at that big data and say okay if we know you've had this many steps per day, and you've eaten this, and your blood sugar's have been running this, we can predict better how your blood sugar is going to respond to a certain insulin dose and we can tell you what insulin dose you need. So I think that the future is so bright you definitely gotta wear shades.

I love what you have to say there! Let me just, if I could, step to the past before I let you go. Because you decided to become an endocrinologist for a reason that I think is worth talking about. Would you mind sharing that story? I know it may be difficult, but your uncle lived with type 1 and he was diagnosed a long time ago when care wasn't what it is today, right?

He did. So my uncle, Mitchell Dreiman, he was diagnosed when he was 12, and this was back in the early 60s. And as you know Stacey, it was a much different time. It, you know, the continuous glucose monitoring and insulin pumps in regular use now were just really a myth. They were science fiction at the time. We just didn't really have access to that and my grandparents did the absolute best they could. He took Regular insulin and he didn't have glucometers, you know?

That's amazing.

It was a much different time and he did the best he could. My grandparents did the best they could with what they had. He really is who really showed me that you can live life with diabetes, but you fight it. Because he didn't let diabetes stop him. He was always, you know, really the life of everybody that he was around. He was the light. When Mitchell walked in the room, you know, the place just came alive. I remember coming home to visit with family at Christmas and he was the one I was looking forward to get to meet. Because he always just loved hanging out with us and hanging around with the kids and making us feel special and that really started our friendship, and his mentorship to me, even if he didn't know that. He didn't know that he was showing me those things. When I was a kid, I didn't know what diabetes was. I just knew that he had it. But we had an experience one Christmas where he had a pretty severe hypoglycemic event and had a very low blood sugar that I had to help him overcome. It was scary but that was when I started understanding more about what the disease is and I started understanding more and realize, man, this could really take my uncle and someone I love away from me. And I didn't like that at all. You know, the fight was on.

We always stayed really close and he was with me when I graduated college. I had always had an interest in diabetes because of my uncle and I knew that's what I wanted to work on. That's what I wanted to be my life's work. He knew that and was always supportive of me. Through college through medical school, he was there the day I graduated from medical school and graduate school. And he was actually the very first patient with diabetes that I examined. After I graduated from medical school, he came and just grabbed me and said, 'Bryce grab your stethoscope.' That's what he told me. He said 'I want to be the first patient that you ever examined who has diabetes.' So it was an experience that I never forgot.

About that same time I was graduating medical school he was starting to have some of the complications of diabetes. He was having kidney failure. He was losing his eyesight. He was really fighting. He had a kidney transplant, but unfortunately that he was rejecting that kidney that was donated by his sister. And he then went to Duke and had a dual pancreas/kidney transplant. So for the last year of his life, he was diabetes free and was living a real wonderful life, but unfortunately the years of immunosuppression, he actually developed pancreatic cancer. And in my intern year of pediatric residency, I lost him. He died from pancreatic cancer. But you know, the thing

that I always try to remember, while I love him and I miss my uncle more than I can say, the legacy that he left, I think is bigger than himself. And I think he understood that. You know that when I graduated medical school, he had told my mom that you know, if I have to live this fight so that Bryce can someday help other people, than this fight is worth it. You know, those are the kind of things that stick with you. And I knew that I wasn't going to let my uncle down and I wasn't going to let my future patients down. All the families that I work with now it's all because of my Uncle Mitchell. What he did and the passion that he instilled in me. You now, even to this day, I hope that he's proud of me.

Bryce it's amazing to think of what that means to you and the impact he had on you. And looking at all of the things that are coming, you know, I don't want to get too cliché here, but you have to think about your uncle in terms of the difference he made in bringing you to medicine, the people that you help, and the advances that are being made. Do you must think about him all the time with that?

I do. I think about him all the time and I you know, I think about the legacy that he started and the analogy I use is a tree. My uncle helped sow the seed in me and help this tree take root about helping improve the lives of children and family with diabetes. He sowed that seed. He helped that tree take root. Every family that I get to work with, we're just adding new leaves to the tree. We're adding new life to that tree. And it's ever-growing. So whether I'm in Greenville or whether I'm somewhere else, that tree is always growing. It's growing, its thriving, and it's adding new leaves every year. And so that that's how I think about my uncle and the legacy that he had. And why it's so much bigger than him, is that my love for him and my interaction with him is what's put me where I'm at and you know, help me be in the place that I feel like I need to be. That's why taking care of families with diabetes is more than just adjusting insulin, it's about improving their lives and helping them live their lives to the fullest.

Bryce, thank you so much for joining me, for talking about insulin and so much more today. I really appreciate your time. This is extremely helpful. Thank you.

Bryce: Oh thank you Stacey. This has been quite an honor and I am so thankful that we have you in the fight and have you as an advocate and you're such a strong voice in your shows, and your your presence is omnipresent. We're really, I'm happy to have you as an ally and an advocate.

Wow. Thank you.

All About Ketones

with Beth Silvers, CDE

[EPISODE ORIGINALLY AIRED 03/26/2019]

Beth Silvers is a Certified Diabetes Educator and a Registered Dietician with Carolinas HealthCare Diabetes Care. She was diagnosed with type 1 diabetes at the age of 5 in 1962.

Stacey: Beth, thank you so much for joining me. I really appreciate you taking some time to talk about this very important topic today.

Beth: I'm glad to be here.

Let's just jump right in on ketones. When you meet with patients when you see people who are diagnosed with diabetes, what do you tell them in the beginning about ketones?

Beth: When they're early diagnosed, I usually don't have that conversation because they're so overwhelmed with the diagnosis. So usually my first session with them is getting them acclimated to what does it mean to live with type 1 but very quickly, very shortly after I talk about extreme lows and extreme highs. And the reason we talk about those extreme highs is they can lead to this condition we call diabetic ketoacidosis. Ketones are a waste product or a leftover of the digestion of your own body's fat. That sounds like a really good thing. Let's get rid of all that fat. But, when I do that, my body becomes ketotic or acid-based and my body is not designed to be acid-based. And so if I have a lot of ketones then I have this acid floating around inside my bloodstream which then can cause a very acidic problem and it leads to severe pronounced dehydration. And the dehydration is what leads us to the hospitalization and sometimes can lead to death. It's a very scary part of blood sugars that are extremely high.

So I know it's complicated, but why don't people who don't have diabetes, why don't they get ketones? Why are they not at risk?

Beth: Well, sometimes they do. The new regime today is the ketogenic diet, which is forcing them to go into ketosis. So let's kind of compare that type of ketosis to the ketosis that a person with diabetes has. Both of them are burning off their own fat tissue to produce these ketones. The difference is that the person who doesn't have diabetes is forcing their body to go there by eliminating all carbohydrates from their diet. So there is no carbohydrate. There is no glucose in the bloodstream and the body burns off of ketones because of that. In the person with diabetes the blood sugar is so high that the muscles can't get to or access that glucose and so they're starving because all the glucose is in the blood and there's not enough insulin to get that glucose into the muscle and into the cell and so they start breaking down fat tissue for a different reason. But both of them end up with ketones and this acidic blood that leads to the problem.

Putting the ketogenic diet aside for a minute. I do want to get back to that. Let's focus on people with diabetes. You said, you know, the blood sugar is so high but you can get ketones and not have high blood sugar right?

You can. If the diet has been poorly balanced. If the diet was low carb or the, you typically don't go into ketosis unless you either have a high blood sugar or an infection that leads to the body having to burn off the fat because it can't get to the glucose that's in the bloodstream.

Well something like an illness. I'm thinking of a couple of kids I know that had normal to low blood sugars, but they were ill

Right.

You do you have to check for ketones because of that, right?

Correct. So anytime I have nausea, vomiting, or any type of a GI illness, I want to check for ketones. Anytime my blood sugar is over 250, I want to check for ketones. Because I want to avoid that before it gets into moderate to large ketones in my urine or my blood.

All right. So here's a dumb question for you. We will talk about how to measure ketones and maybe we should just jump in on that. But when you say, you know, small, moderate, large, it's to me, I always have this mental picture of the cells in my body, you know, and these giant ketones or these smaller ketones. Is it really a question of size? Is that how they're measured?

No, it's actually measured in amounts. Just like you would measure milligrams per deciliter of blood glucose. They're measuring the amount of ketones in the amount of urine that you put your dipstick in. So we put these

little strips into our urine and it tells me rather there is a small amount of ketones in that urine, a large amount, or moderate amount. Typically, if we are negative or no ketones in the urine to small ketones, we tell them just increase your water and keep it posted. Let us know if you have any worsening of your symptoms. So there's not a lot we do with the negatives and the smalls or trace. Some of the companies will call it trace, some will call it small. When you get to moderate or large, that's when I've got to intervene and if you're on insulin, which all type 1s are we're going to give you some additional insulin to prevent that ketosis from progressing any further and getting into that severe dehydration.

So you need insulin and water to get rid of ketones.

Correct.

But if your blood sugar is not super high and I know that everyone scenario may be different, but let's say someone has a blood sugar of 100, but they have medium to large ketones due to illness or something else, who knows. Would they then take extra insulin, extra fluids, but no extra carbs?

If they were, you know, anything less than 200 I would say that their fluids need to contain carbohydrates. And then I need to cover whatever I would do, so if I'm a one unit for 10 grams of carb and I drink 20 grams of juice then I'm going to cover that. If my blood sugars are less than 200, I'm going to drink fluids that may have carbs and I'm going to cover that but I'm only going to cover the amount of carbohydrate in my beverage. If my blood sugar is high, I'm going to take extra insulin to correct that high blood sugar and very importantly drink non-caloric fluids at that point.

You know, you mentioned the dehydration being so dangerous. When do you know that it's time to go to the hospital and get an IV of fluids? I mean, that's the one thing we really can't do at home. You know, it's a big reason why people have to go to the hospital. I know there's not a light that goes on or a signal that you know, we all look at but what do you tell the people that you work with?

I typically tell my clients that if you're nauseated and can't keep anything down, that's the time we need the emergency room for IV fluids. If you can swallow and you can keep it down stay home. The reason that I say that is, hospitals are built for acute care, emergent care, not chronic care. And diabetes is a chronic condition. And so therefore if I can keep my client with diabetes at home, I'm going to do a lot better job than if I take them to the emergency room. Those places are designed for car accidents, heart attacks, gallbladder surgeries, kidney stones. The people there are not designed for caring for people with diabetes because that's a chronic condition. They're not trained in chronic care. It's not their expertise.

Let's talk again about testing. We'll talk about urine and then let's talk about blood. So you said test your urine or your blood for ketones when your blood sugar is higher than, there's different guidelines. I've heard 200-250, you have symptoms, you know, you are throwing up, you're nauseous regardless of your blood sugar reading. Is the urine test still considered state-of-the-art? This is what we can use?

Yes, because the the only meter that we have to test blood is the Precision meter and it's very hard to come by because not a lot of people use it because you don't need to check for ketones every single day. And so they don't make a lot of money selling that meter or those strips. And so therefore it's come becoming harder and harder to get the meter to monitor the blood ketones. So typically only in the hospital setting or the emergency room would we measure blood ketones instead of urine ketones.

So you're saying,

But urine is sufficient to tell us.

Great, that's what I was going to ask, you're satisfied that even though it lags a little bit behind, it's ok to use.

Correct.

Do people have trouble, because I know I might, would luckily we haven't had a we haven't had anything over small ketone since Benny was diagnosed, when you're looking at the color change cause that's how this operates, you know, you dip it in the urine, you look at the color. Have you had a lot of calls from people saying I can't tell if this is dark purple or red or you know? Any advice on reading it?

Yeah, right. Not really, even the color blind because that's the reason they chose purple is because color blind people can usually identify the purple and if it is questionable, then you have moderate to large ketones. Okay? The pink the pink and the beige neutrals that small negative, trace that's not enough to worry about, you know, I don't care if it's pink or if it's beige colored. I don't care. But when I get to purple, any shade of purple, any degree of purple, that's when we need to start intervening because then you've got moderate or large ketones.

Stacey: When my son was diagnosed, he was 23-months-old and I will never forget being in the hospital and they wanted to test for ketones and they had to figure out how to get the urine out of his diaper. So they were putting cotton balls in and then squeezing the cotton balls out. It was, it was a mess, but it does work.

Yep, if I can get the urine from anywhere. I'm get it from a diaper, either an adult diaper or child's diaper. And I

usually don't do the cotton balls. I'll just take the the strip and let it soak into the diaper itself. Saves a couple of steps, you know, as long as I can get urine on there and then tell rather I've got any, you know any purple and that will guide me as to what my next steps are as to what I need to do with that child or with that adult.

So there would be no concern that there's a chemical in the in the diaper?

Yeah.

Okay great. Now that with blood ketone machines as you said, there's only really the one and in my experience the machine itself is pretty inexpensive, but it's the strips that are can be very difficult.

Correct. It's just hard to find them because they're not routinely used so you've got to have a pharmacy that's willing to order them for you when you need them. And then you know, it's like any other strip. Once you open that bottle they expire, you know a certain period of time after that. And because I'm not using them every single day. It's like, oh my gosh, I went through another thing and I only use two out of that whole box. Yeah. So that's the reason that we don't do much with the blood ketones. Whereas with the urine ketones my strips don't expire as quickly and you know, I can get them. There are some companies that will actually do them individually wrapped.

Yeah, I've seen that. I've seen that. Okay quick timeout from ketones. Let's talk about you for a moment if we could because you have lived with type 1 since 1962 when, things have changed quite a bit since then.

Yes quite a bit.

Can you tell us your diagnosis story? Do you remember?

I don't really remember much about the diagnosis story. I remember that I was very, very sick for several weeks and Mother took me to the doctors several times and the doctor could never figure out what was wrong with me. He kept saying she must have a flu. She must have this. She must have that. Because all I would do with sleep, drink, and pee. And sleep, drink, and pee and it was an ongoing continuous cycle. And back then they didn't think about checking for diabetes because it wasn't as common or as well-studied. And so the doctor kept thinking, you know, he was a good pediatrician. He was a good man. Loved him to death until he passed, but he you know, he was trying to do the normal pediatric stuff is let's find out what bugs she's got and give her the right pill to take care of it.

And then finally I went to sleep and they couldn't get me to wake up. And so my dad picked me up and carried into the emergency room and announced, 'Beth is not going home until you find what's wrong with her. My baby girl is sick and you need to fix her.' And they laid me out on a stretcher and I was in a diabetic coma

for three days. They weren't sure I was going to pull through. I had lost about 20% of my body weight during that period of time with the urination and the you know, I was basically in diabetic ketoacidosis. And so it was a very scary situation for my family. I have two older sisters and a younger brother. My younger brother was in diapers and so he doesn't even remember any of it. My older sister actually went through candy striper training while I was in the hospital for 32 days because she was going to learn how to give me an injection so they'd let me come home. Back then, back then we were using glass syringes and Daddy was taught to sharpen the needle to go another week. And they wouldn't let me go home until at least two family members had learned how to give me an injection. Well, Mother did it, but Daddy refused. So my elder sister Jane, she's 10 years my senior, she came through and said, 'I'll learn I'll do it. I'll take care of it.' And so she actually went through the candy striper program because back then we didn't have diagnostic groups and there was not limitations on okay, you have this diagnosis. You can only stay ten days or so that was way before any of that. So I was in the hospital and I was perfectly fine once I came out of the coma, you know. And so I was going to crafts and I was going to you know paint rocks and do all kinds of fun stuff while Mother and Jane were trying to learn how to take care of me. And so I remember that.

I remember getting refused, they wouldn't let me go to Girl Scout camp and they wouldn't let me go to the Lions Club Camp because I took an injection and that required a nurse and they didn't have one. So my father got together with two other men in South Carolina and said, 'Our children deserve to go to camp. There's no reason why we can't do something.' And so they created what was then called the Carolinas Camp for Diabetic Children. There are now 42 camps in the two Carolinas because of those three fathers. Adam Fisher, JD Gwynn, and Bob Bagwell were the three fathers. My dad was JD Gwynn and they all had children with type 1 diabetes then called juvenile onset diabetes. And so they created this camp and they went to Bowman Gray (medical school) and they said, 'We need some doctors to come down and take care of these kids while they play at camp and you know, don't you want to volunteer and send some of your residents and interns down here?' And our very first camp we had ten campers where I met by my two best friends who were bridesmaids in my wedding. But Dad arranged this camp and there were 10 campers. There were 12 medical students, 4 dietitian students, and 12 nurses for 10 campers. You want to talk about guinea pigs? We felt like we were guinea pigs. We were watched like hawks. But the cool thing was with that was the first time at age 10 that I gave my first injection because before it always been Mama or Jane. And then at age 10, the nurses said, 'I'm sorry, we can't give you an injection. You have to do it yourself and you can't go to breakfast until you do it. So do it.' And we sat on that bunk bed for about 35 minutes crying, but I finally got that needle to go in my thigh. And I went to breakfast.

Do you remember

I had cold eggs that morning, but

Do you remember what you felt like after you did it?

Ecstatic. It was I finally did it. I finally did it. You know I can do this. I can do this. And you know, there was a big celebration and the other campers were, you know, patting me on my back and you know playing. And but again you have to think about this was in let's see 1967-68. We did not have blood glucose meters. They had no idea what our blood sugar was. Our insulin dosages were one injection a day. We didn't take multiple injections. That was not the standard of care at that time. They looked at us and decided whether, we were high or low just by the way we looked. And they gave us juice, it was always juice to treat lows.

It's interesting and wonderful that your father could not give you a shot and yet he found a way to improve and even change your life and change the lives of so many people now. Because I know those camps. I know those names being in the Carolinas. You know, looking back on that any words about your dad? I just think that's so interesting.

My father was a typical Southern gentleman and he felt that caring for children was his wife's job. His job was to take care of the finances and to take care of the family as a whole. He was our defender. He was our protector. He was our awesome dad but doing medical care was not his job. And he was not up for that. My father was later diagnosed with type 2 diabetes. Probably 1974-75 and did, he basically ignored it because he thought my diabetes was worse than his. And so he never took care of his own type 2 and ended up developing complications because he delayed going on insulin so long. And died from those complications. He basically his heart gave out because his sugar had been running so high, so long because he refused to take the injections himself. And Mama finally started him on insulin and got him going but it was too late. The mini strokes had started and Dad was shortly gone after they started the injections.

I'm so sorry to hear that. It was such a different time for both conditions.

Yes and we didn't know what we know now. We didn't, we didn't have near the care that we had. But my dad was awesome, even though he never could bring himself to even prick my finger later on in life. You know, I didn't start doing that till I was high school, college. And he never would you know even discuss it with me because that that was not his role. His role as my father was to make sure that I had everything I needed, a college education, resources for camp. Does she have you know, Dot can you afford to buy her insulin? Of course back then it didn't cost but 15 bucks. But he was the one that took care of those kinds of things and it was Mama's job to take care of the day-to-day care of my diabetes. You know. Mama was the one that checked my urine for sugar. Mama was the one that gave me the injections until I could give them myself and you know, so it was that was Mama's job not his.

In your experience with type 1 and you were diagnosed when you were five, you were four? I'm trying to think of the math.

Five.

Okay in your experience over the years, did you have issues with ketones? Is this something that you have experienced a lot of?

Not personally, my only case of diabetic ketoacidosis was at that diagnosis. So I have had spots of ketones but they've never lasted long enough for me to develop into diabetic ketoacidosis. Because I would check, I would go take a walk. I would you know, drink my water drink my Diet Coke, you know, I wasn't letting it go back to that again. I just, I was not going to go back to that. So again, the pre-emptive side of care is that's why you check any time the blood sugar's a little elevated. So anytime my blood sugar tops over 250, I pull out ketone strips and I check the urine.

Do you still do that now?

Yes, because I don't ever want to go back into diabetic ketoacidosis again. Because even though I was quite young I remember how scary that was to my family and to my, just to to me, you know being out for three days. Three days I laid in that bed and they did not know if I was coming back around. I don't want to go back there.

So let me ask you and this is mostly anecdotal I would think. I haven't seen many studies on this. It seems to me that some people do not produce ketones as easily as others and I'll use my son as an example. He's had diabetes for 12 years. He has had many highs. He's had many normal illnesses and he's had many sustained highs when we're trying to figure out if something happens, who knows, you know, he's been over 300 for more than a day. He has never had medium or larger ketones. And I know kids that hit 251 and they have to you know, drink, drink, drink, and take insulin. They have large ketones. Is there anything that you've experienced or anything that you've seen that that really says that some people are just less prone to it than others or is it just luck?

I don't know that it's luck. I don't believe in luck. I believe in either blessings or not. But I think there are some individuals that are more prone to it than others. Why that is, we do not know. Rather there have been any studies looking at it, I do not know. John Buse at the University of North Carolina at Greensboro has done a lot of studies on why we're having so many diagnoses of late onset type 1 and more type 1 up diagnosis. We know why there's more type twos it's diet and exercise or the lack thereof. But why are there more type ones? You know, it's it doesn't make sense. So they're looking to see you know, why are people more prone to this condition than we've ever had before? Why is it developing so much and why are some people more prone to that than others? Because a lot of people come in and they're not in diabetic ketoacidosis with extreme high blood sugars.

Yeah.

I had a patient last week that came in with a 600 level blood sugar, but they were not ketotic. So we don't know.

Stacey: Let's talk about exercise and ketones. Many people get the instruction if your blood sugar is high you don't exercise, but they're not told why can you explain?

Sure, because if my blood sugar is high because I have a lack of insulin and I go exercise, my lack of insulin is just going to cause my sugar to go up because my muscles are going to demand the release of that glucose from my liver and from its cohort muscle cell. And so the muscles have to have glucose to walk or to run or to get on the treadmill or jump in the pool or whatever exercise you're doing and if I can't get to the glucose in my blood then my body is going to demand it from other sources and that's just going to make my glucose go even higher. So I'm more prone to go into ketosis if I'm in that situation. Now if my sugar is high and I'm not spilling ketones and I provide some coverage insulin, I can exercise no matter how high my sugar is. You know, where's the high sugar coming from? And if you know that okay, I've already covered that elevated blood sugar with some insulin. I've got it on board and I did it with an injection not through a pump that may be faulty or you know, maybe my tubing's occluded or something. I did it with an injection. So I know it went in. I can go take a walk and get myself feeling better to get that sugar to come down.

Is what you're saying about exercise, and I wish I had a better understanding of physiology, also including the build-up of lactic acid? Because that's what I was always told. Is that ketones are very acidic and when you exercise you build up lactic acid, and then the two together is a very poor environment. Is that what you're saying as well?

Yes, it's the same thing. So the lactic acid comes from the fat digestion. The ketones are the waste product and the lactic acid is how that ketone becomes energy for myself. So they come in hand in hand.

Yeah, I find that to be very confusing because we, we were able to change our school orders in about second or third grade to say that Benny could go to recess even if his blood sugar was over 250 as long as he didn't have any ketones. And I think that's a really big point because you one of the best ways to bring down a higher blood sugar is with exercise, but you don't want it to be dangerous.

Right. Right. So again, if I don't have ketones then I'm less likely for that to push me into trouble. If it pushes my blood sugar up a little bit and I'll test for ketones again and then if I'm still keeping them free, then I can keep exercising. But if it's cause the ketones to start being produced, okay, then you need to go back inside and get some more water and take some more insulin and not worry about the exercise until we can get rid of the ketones.

After you've had ketones to the point where you do need to go to the hospital whether you're very close to DKA or in it. What is it like after that? In other words, is it like a low blood sugar where you'd take the glucose and you're fine? Or are there things that you need to look out for in the in the following days?

Well, the concern is is where did the ketones come from? Is there an underlying illness that needs to be treated? Do I have a viral or a bacterial infection that I didn't know about that led to the DKA or is it just my insulin was not working and I need to replace this bottle with a fresh bottle. Or an occluded tube line that I need to replace or cannula in my pod. You know, where did it come from? And then you're going to feel some nausea and some discomfort for 24 to 36 hours after you come out of the DKA. So once I fix it, once I give you the fluids, and get the ketones cleared out of your blood and your urine, you're still going to feel a little off for a while. So it doesn't respond as quickly as the lows do. You know, lows I can keep right on working once I treat my low and give me 10-15 minutes for it to get back in the bloodstream and I'm good. But if it's a high, you get a little bit more of a longer lasting, I just feel kind of sick.

We mentioned the Keto diet, you know earlier in the interview here. Can you talk a little bit more about that? I mean, is that okay, is that safe?

No, and if there's any question no. End of that conversation. The Ketogenic diet, there's been some good research that says it will cause you to lose weight. So it's a great tool for weight loss, but it is not available for long-term maintenance and for my clients living with type 1 diabetes and the risk of going into ketosis, rather it's coming from a Ketogenic diet or from my uncontrolled blood sugars, either way, that's a dangerous place to be. So I don't encourage particularly my type ones on insulin or any of my type twos that are using insulin to control, I don't like them on a Ketogenic diet. If you insist on it, I will monitor you closely and I'll limit it to one month. You can stay on it one month and then you're going back to a regular, sensible lifestyle maintenance meal plan instead of anything that strict.

Well, I was going to ask you with your nutrition background, you know are there advantages to learning about the keto diet because as we know many of people, myself included, we know we eat too many carbs, you know? Are there advantages to at least learning about it or experiencing it?

Well, there's a difference between lowering your carb count and going ketogenic. Ketogenic is less than 30 grams of carbs per day. That's an extreme and that's not recommended. Lowering your carb count is good for everybody, particularly the processed carbs. So if I'm eating cookies and cakes and Little Debbie's and donuts and regular sodas all the time, that's just unhealthy for anybody whether you got diabetes or not. You don't need that much of processed carbohydrates sugars. That needs to go. But if I'm eating healthy carbs, like graham crackers and oatmeal and fresh fruit and skim milk, there is nothing wrong with those carbs. And up to a 130-150 a day even 200 a day, if you're extremely physically active, you know if you're running marathons and working out all the time, you can

take the carb up to that and there's no harm to it. If you're inactive and you got to stay around that 120-130 grams of carbs per day. That's what my body needs. That's what my body is designed for. If you think about how your teeth are inside your mouth, if you take your tongue and run across the surface of your teeth, you'll find that two-thirds of your teeth are molars and and grinders they're designed for chewing and grinding fruits vegetables and grains which are all carbs. I only have one third of my teeth that are canine teeth that are designed for tearing meat. So you would think that your body's trying to indicate to you two-thirds of your calories need to come from fruits vegetables and grains and only a third needs to come from your meat. Because that's the way my teeth are.

That's really good.

The way my body works. Yeah. My brain has to have glucose. The most efficient and effective way to get glucose to my brain is carbs in my diet. So if I cut back so much on the carbs in my diet, my body has to go searching for unnatural sources of glucose to feed my brain.

Did I miss anything with the ketones? I feel like we pretty much covered everything I wanted to talk about. So I make sure I didn't miss anything that from your perspective.

No, I think we've got it. I mean ketones are the waste product of fat digestion. They routinely occur if I'm sick or if my blood sugars are elevated and they can lead to severe dehydration. And that's the key point. I don't want to go into that dehydration because that can affect my brain function and other parts of my body. So that's why you want to always be prepared to go the emergency room if I need those IV fluids. But if I can keep them down by drinking and take enough insulin to get my sugar to come down and call my doc if I need a pill for my bacterial infection, then you can do that at home.

Beth, before I let you go, you have lived with type 1 for almost 60 years now.

Yes.

You see people every day, you've made this your career, your calling as well as your life. You seem, when I talk to you, you seem really optimistic. And you seem kind of no-nonsense too. I can't let you go without asking you just could you share your perspective? You know, how do you do it day in and day out for this long? And, do you still enjoy working with people who have type 1 and teaching them?

Yes, I enjoy any working with clients on helping them to live healthier lives. That's why I became a dietitian and then I became a certified diabetes educator so that I could specialize in clients living with diabetes. I am very much

about appropriate language and positive optimistic outlook. My faith is what keeps me going strong. It's the reason that I have the optimistic outlook. As my pastor says I know the end of the story. I know how it's going to end up. And so my philosophy is, is while I'm in this sinful broken body that has diabetes and few more pounds than it should I'm going to constantly fight this struggle and this battle. And if I can help others to do it well, at the same time, then that's my purpose for being here. That's why He put me here and so it is very much my faith, and my belief in my savior that allows me to function as well as I do with what I have.

And when you say sinful broken body, you don't mean sinful because you have type 1 diabetes?

That is correct. That is correct, be perfectly clear. My belief as a Presbyterian is all of us since Adam and Eve have lived in bodies that are prone to do more sinful things than on sinful things. And I, the only reason that I have the hope and the optimism that I have is because I know that my Savior has already suffered the consequences for my sins. You know, my outlook on life is that the time down here is temporary training ground for what I'm going to do when I reach heaven. My first husband passed away when he was only 36 and left me with a three-month-old. So my goal is to get back, you know with my mom and dad who are in heaven, and with my husband who is in heaven and celebrate the life that we've been able to live here, but also to praise and glorify my Lord Jesus Christ.

Thanks for clearing that up. I know it was probably obvious to you and many listeners, but I think it's important to just clarify.

I think that's, exactly. Good question.

Well thank you. I hope that's respectful as well.

Definitely.

But I really appreciate coming on. This is a very important topic that I think is misunderstood. So I'd love to have you back on perhaps in the future to keep talking. But I really appreciate it. Thank you.

Certainly. You're welcome. It's good to do it Stacey. Thanks for calling me.

All About Lows

with CDE Shannon Johnson

[EPISODE ORIGINALLY AIRED 05/02/2019]

Shannon Johnson is a CDE & RN who trains people with diabetes on insulin pumps and CGMs. She is part of the MercyOne diabetes team at Mercy Medical Center at Mason City, Iowa. Shannon was diagnosed with LADA (Latent Auto Immune Diabetes in Adults) in her early 20s.

Stacey: Shannon thanks for spending some time with me today. I think this is a really interesting topic that we think we know about but I'm really interested to learn more. Thanks for being here.

Shannon: Absolutely. Thanks for having me.

Before we even jump into lows and all the physiology and everything behind them. Can you share your story a little bit? You live with type 1 when were you diagnosed?

I was diagnosed at a older age, actually I was 22 and they thought I had type 2 diabetes in the beginning. I actually have what's considered latent autoimmune diabetes in an adult (LADA). But it acts more like a type 1, so that's why I can actually say, you know, I have type 1 diabetes as opposed to type 2. Because like a type 1, I also have to have insulin every day to continue on. And so I juggle all of those things that all my patients have to juggle as well. So I've been living with it now for about 25 years. This might be 26 years now. So, been a very long time.

Dumb question because we've talked about LADA on the show, as you said. Is is that something that stays LADA? Do they still consider it that or do you eventually say no, I just have type 1 in terms of the medical diagnosis, not how you live your life?

Well, so yeah, I mean if, I saw a provider they would document that I have LADA but for you know, say for Medicare, those kinds of things, insurance purposes, they are going to say that I have type 1 diabetes.

Got it. I was just curious if LADA and again, this is probably a really dumb question. I know it's kind of slow going when it's first raising its ugly head, but I was wondering if it kind of becomes just general regular old type 1 if the different diagnosis or the differentiation in language matters after 26 years.

Right. Yeah, I mean I'm not real too concerned about which diagnosis it is. It's just I know that I don't make insulin and I have to have insulin to live. So yeah.

It doesn't matter what you call it. You know what you have to do with it.

Exactly. That's exactly right.

When you were diagnosed, were you already on a healthcare track to get those degrees?

I was actually. I was in my first year of nursing when I was diagnosed. So a lot of stress already with just being diagnosed with or going to school as a nurse and all of that. And then being that diagnosed with diabetes as well. I've done several presentations and at this point my PowerPoint picture is like a tornado has taken out a whole house. That's how I felt. Totally devastated when I was first diagnosed. You know your whole life changes. It's a life-changing disease for sure.

Well, it's always great to talk to somebody who's had the amount of health care experience that you have because you know, you talk to people, you train people in the pumps and CGMs and everything, but to actually live with it as well just gives that other layer of understanding. So let's just jump right in because when I talk about low blood sugars, I think we all think we know what we're talking about. But you know, I've learned in these deep dive episodes that even after 12 years, I'm just scratching the surface. So let's just start with the basics. When we say somebody has a low blood sugar what's happening in the body?

An actual low blood sugar is a blood sugar below 60. However, we like to think of it, we start treating it and start teaching people to treat it when it starts to become below 70. There are a couple of things that are happening when you actually have a hypoglycemic episode. One is you have too much insulin for whatever reason - whether it's you took a too much insulin for your carbs or you got maybe some extra exercise or you know, you skipped a meal and you had already taken your insulin. But for some reason you have too much insulin and then you don't have enough glucose or sugar in your body to use that insulin. Because the insulin is like a key

that's what we use to get the glucose to the cells to be used for energy. So if we have extra insulin going there in throughout the body then our glucose can't get to where it needs to go. Because we don't have enough. So that's when it you start to feel shaky. You might feel drowsy, might not feel real clear-headed those kinds of things and then your body lets you know, what's going on most times. So those are the couple of things that are happening when you're experiencing low blood sugar.

I guess in people who don't have diabetes, their bodies are grabbing that extra emergency glucose that they can. But when you have type 1 you don't have those sources. You know, I've heard that it starts in your body and then it kind of goes to grab the glucose from your brain and does that even make sense?

Yeah, I mean because our body uses lots and lots of glucose. Our liver stores glucose for times when we need that. And so when you know, our body gives us as much as it can afford to and then to the point where it can't give it any more it's told not to do that. So then that's when we start to feel those lower blood sugar symptoms.

How exact are the numbers? You mentioned below 70s when you start to treat. Below 60s when it's really low. But my understanding is that the lower the blood sugar reading on a meter is or even on a CGM, the less accurate it is and the same thing for the highs, you know, we get to the extremes, it's less accurate. Is that true, and should we be concerned about that?

Well, the the FDA will approve a system as long as the values that they're getting anywhere from 95% of the time to 99% of the time, the values have to be within the lab values, 20% either way. So what that means is, so let's say you check your blood sugar on your meter and it says 190 it's still considered accurate if it's 152 or up to 228 on your meter. Okay, but your labs even though the lab says 190, it's still considered accurate. So when your blood sugars are higher, because the number's higher, that 20% is, whether it's lower higher than your lab number is quite extensive. There's more space in between your 20%. But when you have let's say a 70, your 20% below is 56 and your higher range is 84. So it's not quite as inaccurate.

Got it.

As for your higher range, I used to get really concerned about that. I thought, you know 20% that's huge living with type 1 diabetes, if I only take .25 units or whatever. I just I used to think that was not acceptable. But then I started looking at it and started thinking about it. Let's say again, I check a blood sugar and it comes up of 190 and actually it could be 152 to 228 with my correction scale. Am I really going to do anything that much different if it's 152 as opposed to 190? Probably not. You know, so that's how I kind of have come to accept that discrepancy. So best-case scenario, we get this question all the time. I get this all the time, you know as you get older when you have type 2 this especially, you make less and less insulin, everybody does that's just the way of the of the body. So I hear all

the time, I don't think my meter is working. I don't think my meter's working. So that's the first thing they think of so the only way that you really can tell if that meter is accurate is when you check a blood sugar, have a lab draw the blood sugar as well and then compare it to that lab draw and if it's within twenty percent either way then your meter is accurate.

So you've got to bring it with you when you go to the lab for your blood test?

Right? Yeah. Yeah, and we have a lot of people will do that especially if they think there's something wrong with it. A lot of times they've just gotten older they're making less insulin, you know, maybe they haven't been following their regimen or they need a different regimen. But that's always a first concern for my patients and then we just put that to rest and then we move on to see what's really causing the higher blood sugar readings.

Got it. You know, I think we were very fortunate because at the very beginning our endocrinologist told me, "Look diabetes is as much of an art as it is a science and you can't worry about the exact numbers."

Right.

We were really lucky that way because I do have a lot of people and parents that I talk to who you know, they'll check a finger three times to get three different numbers and be really concerned. So I'm glad to hear you say that you know to explain it the way you did.

We've also learned to kind of go off feelings if that makes sense, because sometimes Benny, my son, he can be 65 and feel great, but then he can be like 95 and say, "I'm low and I need to treat" and he's almost always right. Even if the arrow isn't showing up on the Dexcom up or down. Do you find that a lot of people and yourself tend to do that? That at some numbers sometimes you feel okay and at other times when you should be quote "in range" you're really, you're not.

Yeah, I find sometimes I'll sit down to eat a meal and check my blood sugar and it'll say you know 52 and I'm like wait a minute. I don't feel 52 and my sensor is not saying 52, you know, or maybe arrows aren't going down. So I'll check it again. I always double check to make sure if I have a question. But yeah, I've had that happen and then other times I feel like I'm low and I'm not low. So I always want to make sure that I know what my blood sugar is with the meter. But I think one of the things that's happening is it's just the rate of change. You could be dropping very quickly and at 60, maybe you have just dropped from let's say 90 to 60 very quickly and your body's just telling you that you know, you're dropping or you have dropped quickly and maybe your 95 is a little bit more stable or slowly dropping or slowly rising. So I think that's the difference that one can feel that little rate of change.

Yeah that makes sense. Again, this may sound like a silly question, but why are lows dangerous? Could you talk to me about, we mentioned what's going on in the body, but why is it something to be concerned about and to treat quickly?

Well our bodies have to have glucose for energy and to continue, you know, our brain function, our heart function, everything that functions needs glucose. And so if your insulin levels are high and your sugar levels are low, then your vital organs are not getting what they need and they start to deteriorate. Eventually it can lead to - and that's why if you start not having enough sugar for the brain - that's where you start with the loss of consciousness and then maybe into a seizure and then maybe even to a coma. So that's the part that we worry about with the lows. The other thing is, as people get older, not just our kids but we have an older population now that is becoming more and more type ones. We have to worry about when they're low when their blood sugars are low, that can cause some arrhythmias in their heart. And their hearts are very fragile. You know, 79-years-old, 82-years-old. So we want to make sure that we really avoid the lows with those people. And as a matter of fact, we teach them, you know, we drill in their head, your A1C has to be less than 7. But then as they get older, we have to change that behavior and actually try and get it a little bit higher. We keep them around 7.5% to 8%. And that's really difficult for them, 'Well, you told me I have to be less than 7% all the time. And now you're telling me I have to be higher, that doesn't make sense.' So then we have an opportunity for education there. But there's lots of different things that can happen from those low blood sugars.

I've actually I heard very recently some statistics about how as we get older many people feel their lows less. That many people over the age of 65 are spending more time under 70. Which you don't want to do.

Right.

You know, how do you get people to, is it just checking more often? Using a CGM? How do you try to tell your older people to, I don't know, to pay more attention to it?

You know as you get older and especially if they've had really, really tight control, that ability to feel those lows because maybe they've had so many or because everything declines as you get older. It becomes kind of a mystery to them like, 'Well this has never happened to me in the past.' So that is one of the best things that ever came out of Medicare is the coverage of the CGM. So pretty much all of our type ones in the older generation especially, are on CGM. There are several different systems out there. But the one that we prefer is the Dexcom for our older folks just because it will alert them if they have lows or if they're trending down and especially if they don't feel them then they will get that alert. Other systems not quite so much will do that. But we really, really use a lot of Dexcom here. Type twos we use the Libre a little bit more. But the Dexcom is one of our favorites and so Medicare just started covering that for those folks and then they can only have the G5 right now, but hopefully they can get the G6 soon, now that it's been approved. *(Note: G6 is now available for Medicare)*

Sensors are just game-changing whether you're two-years-old or 82-years-old. Not checking quite as much, being able to see where your blood sugars are. When I first started working with sensors, I would always tell people because they had to calibrate - they don't have to do that so much anymore, but when they had to I had to kind of help them through. They'd ask, why would I want this system? I just would compare it to like an insurance policy or a GPS system. Because right now without the arrows telling me where I'm at, if I get into a car and my blood sugar is 99 and I'm going to take a trip three hours away. How do I know if I'm going to make it without a low blood sugar or if I'm going to have a high blood sugar? So that's kind of like how I compare my GPS system. This is telling me where I'm going. I'll know if I'll make it there without a snack or I'll know if I need to take a snack, you know. I also compare it to an insurance policy, whereas now you have a little bit more leniency to check those blood sugars and make sure that you have something that's backing you up as well. So but they've evolved a lot since then, so they're only getting better.

It's great. No, we're thrilled. Obviously, we've used Dexcom for several years and it really has been a game-changer all around. You know, you mentioned seizure and coma, things like that. I'm not trying to scare anybody but this is an episode about low blood sugar. So let's talk about that if we could. The risk of seizure, again, I'm a lay person, seems different for different individuals. I know people mostly parents of children with type one whose child has had a seizure and it hasn't always been because of a low blood sugar. It hasn't happened at a number that you'd expect. And then I know many, many more, I mean, I have 600 parents in my local Facebook group whose children have been down to 20 and 25, you know 17, and not had a seizure. Can you speak to what's going on there?

We had a type one of several years walk into the clinic with a blood sugar of 19. We check blood sugar every time somebody comes in. Totally talking, alert, you know, he was starting to get a little ornery but he was fine. But then as time went on he couldn't remember being that low. So, you know, the threshold is different for each individual. You can see somebody has a 10 blood sugar and they recover very well. Somebody else might have 32 and they are just deathly afraid of ever getting that low again. But it's just dependent upon the threshold of where their brain is saying, 'Okay, I need more sugar and I'm not getting it.' And then that will put them into to that seizure as you have more lows, you know, you don't get those early signs and symptoms if you're used to getting several lows so it might be you know that you're getting to not getting the early signs and it's getting to the later signs a little bit quicker than what you think it is. But it's just your whole body, your brain is just really needing that sugar. Everybody's individual.

So that last part - everybody's an individual - that's what I wanted to ask about. Once you've had a seizure are you more at risk of other seizures or is there anything in the literature or studies that have said well this this person is at less risk. I mean, are there any through lines or commonalities that we can look for?

You know, I'm not really sure about that. I haven't really looked into that so much.

Because I've never heard of any. And you know, we get that question a lot especially from the newly diagnosed families. Some people seem to think, well if my son hits this number he's going to have a seizure or pass out.

Right.

Where that's not something that we ever talk about.

Yeah. That's not really something that we teach people. I've had to teach my children because they've asked 'If I find you unconscious what should I do?' It could be that my blood sugar is too low so you might want to give me a shot of glucagon, but it could be that I'm too high and I'm you know in a coma or whatever because my blood sugar is you know, 800 or 900, 1,000, whatever my threshold would be there too. So it's kind of a check and a balance all the time. So like I said, I haven't really read much on the levels of where people will actually have a seizure. I get that question a lot. 'Well, where will I actually get a seizure' and my answer is always it's individual, you know, if you feel like you're having a symptom, check your sensor, check your blood glucose, whatever you have to do. And just to make sure that you're safe.

And that is another part of low blood sugar. It's not just the risk of these we're so terrified of seizures and coma but it's what can happen when you're low people could fall, you know, simple things like that.

Right.

That was the first thing my son did - it was two weeks into diagnosis, maybe three weeks and he got clumsy and fell while he was playing. We know now, of course I would know but we kind of said, 'oh, wow, I wonder what that's about' and didn't think to check his blood sugar until he really was almost falling asleep. I mean, he was a toddler. And of course then he was really low. But that to me is almost more of the danger, right, is the regular activities. Can you speak to that a little bit?

Exactly. And that is one of the things that we really push at our clinic is safety. It's not always about the numbers, and the seizures and the heart attacks and all that kind of yucky stuff. We want people to be safe. You know, if you come in with a 12.7 A1C, you're not safe. You know, you're going to be falling asleep at the wheel and you're not going to be productive. If you're a basketball player, you're not going to play your best. But if you also come in with an A1C of 4.8 you're not safe, you're having low blood sugars that maybe you're not catching. Or you know, someday will catch you while you're sleeping or might not wake you up. So the most important thing when you're teaching somebody about diabetes whether it's type one, type two, gestational is to keep them safe, you know, keep their blood sugars well-controlled, but to the point where they're not unsafe.

Okay, so let's talk about how to treat low blood sugar because it's simple, but it's not that simple.

Right.

I was amazed, I remember and I'll go back to that first story. I think my son was 52 or some crazy number when he was stumbling on the playground and we you know, we ran and we got the juice and we got everything we needed and then I called the Endo because we were three weeks in and I said, 'Okay, what else do I have to do?' And they said 'What do you mean?' By then his blood sugar was 120. He was fine. He felt good. He was kind of hungry. I think we got him some lunch but they said, 'you don't have to do anything.' and I was amazed it was the power of this simple sugar. Oh, so this is a miracle drug. You know and all it was, was juice. But he was fine. And to me it was absolutely amazing, but it's not really that simple. Can you explain how we're supposed to treat low blood sugars?

Well what we teach our people, our patients is the rule of 15 just because it's just it's kind of an easy, you know when your blood sugar's low you're not thinking very clearly. And your body is starving, it needs sugar. So it's telling you to eat, eat, eat. I'll tell my patients, 'I know you want to go to the pantry and eat till you feel better or drink till you feel better or go to the refrigerator and eat and drink till you feel better. But then, you're blood sugar is going to come up obviously, but then you're going to go from feeling crappy, you know, 52 or whatever 48 to feeling really yucky again now over 300 probably from everything that you've eaten.'

It does take longer and I think people don't like it because it does take longer, but it's, I'll say again, it is the safe way of bringing that blood sugar up and and getting you back to feeling better, of course. So the rule of 15 is our common rule. Of course, you can change that a little bit based on the age of the child or the adult. Children don't need as much sugar because they don't have as much blood and mass so they don't really need as much sugar. But typically, a good rule of thumb has been the rule of 15.

So what you do is you check your blood sugar and then if it's less than 70 you're going to treat it with 15 grams of fast-acting carbs. That's when people you'll hear that's when I get to have my Snickers or that's when I get to have my M&Ms. That's not the best time to do that because actually chocolate doesn't work as well, as say like a Lifesaver would just because of the fat content it takes longer. It'll work but it's going to take longer and we want to bring that sugar up. So the best thing that that works is a liquid like maybe four ounces of juice. Whether it's orange juice, grape juice, regular soda works well. But I always encourage my patients to carry the glucose tablets because they're portable, you tend not to cheat on them. You know, if you have a bag of Skittles sitting in the bottom of your purse, you might tend to see those and take a few here and there so you're not going to do that with glucose tablets. They have lots of different flavors. But what I find is people don't take enough. I'll come into the clinic and I'll hear, 'Yeah, I had a low blood sugar last week and then I took one glucose tablet and then later that night I was low again. Well, they didn't bring that blood sugar up high enough. One glucose tablet has about 4 grams of carb in it. So they have to take, the literature says about three to five. I always tell them to do 4, that's 16 grams and then you can refill them as you need to at any pharmacy. It's really easy. They're portable. So that's typically what we do.

So you would take the 15 grams of fast-acting glucose. And then this is the hardest part, you got to stop

what you're doing wait 15 minutes and then check it again. And it doesn't matter and I have to tell people this all the time. It doesn't matter if you eat 15 grams of carb or 50 grams of carb. It's still going to take you 15 minutes before you start to feel better because that's how long it takes for sugar to get to your bloodstream. So then after that 15 minutes of waiting then you check it again and if it's come up above 70 that's good. Then you want to eat something like a sandwich or you know, something like that. If not, then you want to treat it again. You do the 15 grams, wait, 15 minutes and treat it again. So sometimes when you're not thinking very clearly because of the low that's a little bit easier to grasp.

Okay, so you mentioned little kids who might not need quite 15 carbs and older people who might need more or bigger people who might need more, but that's a great way to just start and then go from there. So if you find that 15 carbs is skyrocketing you up you can always cut back a little bit but I'm curious and I'm always biased as a parent here. So let's kind of try to take people treating themselves and talk about people who are treating themselves because frankly it's a lot easier for me to say to my son. You have to wait 15 minutes, right? I mean, you just make him wait. But when you're in a room by yourself and you want to eat the entire refrigerator - you must go through this yourself. How do you cope with any tips or tricks to kind of get yourself out of that mindset when you're not even thinking clearly?

Right yeah. So what I've had to do and what I usually tell them to do what works well is just go lay down if you can. That works for me like I will I will if I have let's say a low in the middle of the night. This is how unclear I think, I have a bottle of glucose tablets right on my bedside table, but I wake up if my sugar is low, I automatically think I have to get something to eat. Well when my glucose tablets are right beside my bed. So I go, you know have a fruit snack or whatever my 15 grams and I'm still not feeling well, so I want to keep going but what I'll do is I'll go lay back down because I tend to, when my blood sugar comes up I tend to get cold and then I will shiver a little bit. So I'll lay down for about 15 minutes. Just don't do anything whether it's sitting in the recliner, just remove yourself from that situation as much as you can and just relax and do nothing. And then after 15 minutes, I will check it again. The CGMs have helped a lot with the low as you know, we automatically think it's the 15 grams that will bring you up it sometimes it doesn't take as much and so we're learning a lot more with those continuous glucose monitoring systems. And I think they're really helpful for patients to see, you know, if I just have this little bit of cookie, you know without insulin I'm going to be fine. But really if you they take that and they see what happens then they learn a lot more. Well, then maybe it doesn't take quite as much to fix a low blood sugar either. So the CGM's are great teachers too.

They really are. We've learned so much from that and there's something soothing at least as a parent, I can't obviously speak as person with diabetes, when you're you see the number of maybe going up slowly but the arrow has turned so that at least I know okay, something's going on. Here it comes. Here comes the arrow. So it does make you feel better about that.

Yeah. Absolutely.

You've mentioned hypoglycemia unawareness a couple of times. Let's talk about that a little bit and let's start in children. I've got to tell you I kind of thought my son had that when he was very little but then I realized it was just that a four-year-old isn't communicating well about anything, and so I realized that I think most kids and this is a generalization on my part, most kids really can't tell you how they're feeling until they're at least seven-year-old. Is there a true hypoglycemia unawareness among children or does that really take longer?

Yeah, that is something that comes over time unless your child has lows constantly then that can, they can lose that feeling but it's usually the protective hormones. So when your blood sugar gets low your body kicks out some hormones that protect us like epinephrine, glucagon, adrenaline, and lots of other things but over time if especially if you're telling those to be kicked out a lot from low blood sugars, those stores will get depleted and then it's not able to tell you when your blood sugar is low. So you typically, I will tell people we don't see as much of it until you've had diabetes for you know, at least 10 years or so. Unless you're running a lot lower too. So, I think the I would agree with you as far as the hypoglycemia unawareness in children is just more of, I really can't tell you how I feel because I'm just a child, you know? But the unawareness really comes, in my experience anyway, as they get older.

And then you mentioned if someone's having a lot of lows. They may stop feeling them. Can you quote unquote "fix" that by running a little bit higher or more in range for a while?

Yeah. Absolutely. When your blood sugar is low but you're not telling your body to release all those hormones and they start to you know, get back to where they're working better again. And yeah, you can get that back. Sometimes not always but sometimes.

That's interesting. Okay. Let's talk about emergency treatment for lows. Let's touch on glucagon and how that works and what we're supposed to do. First, as you listen, you're probably familiar, this is a red or orange emergency kit and you've got to have a couple of steps to put it together. Your endocrinologist or educator probably has had you practice once or twice hopefully. But what does the glucagon do Shannon? Let's talk about what it's actually doing in the body because it's not a sugar shot, right? You're not putting glucose in your blood.

Right, exactly. The liver is storing the sugar or glucagon. So for times when you need glucose, so a person without diabetes, when they have the fight or flight response, your body needs this surge of energy we get the energy from sugar. But if you're not eating anything at the time you have to get it from somewhere and one of those places is the liver. So when you have type 1 or type 2 diabetes though, the liver's not working the way it should be. And the pancreas is doing lots of things but they're just not working as well as they should be, they're not talking to each

other. So what happens then is you take the glucagon when you have a low blood sugar if your liver has given you sugar but it's given you as much as it wants to give you, because it doesn't want to give you all of it. When you take the glucagon what you're doing is you're just telling the liver to release all that it has in it. All that it can possibly give. And it does. So that's what the glucagon does.

I have fortunately have never had to have a glucagon shot. So I don't really know what that feels like, but I have heard that you don't feel well and I'm sure you don't. It's probably just the opposite of just kind of like when you eat a whole bunch of food for a low, you don't feel really well. So what I teach my patients, I always teach the significant other, the mom, or the dad, you know, I'll show it to the patient, but they're really very rarely going to use it. So I usually show it to the support person and tell them how to use it. Always tell them to put the person on their side if they have to, if the patient's unconscious. Give them the shot. Put them on their side because you know, a lot of times people will throw up when they start to feel better. Then they have to get something to eat. I mean, they just really don't feel well, but that's what that medication is for. So that's the worst case scenario, you know, blood sugar, somebody finds you unconscious. They give you the glucagon, somebody else has to administer.

Usually we give about half the dose for kids who are between like 5 and 16 or 5 and 15 we'll only give them the half the dose. We'll give anybody over 15 usually the full dose and then the little guys we use about a third of the dose. So like 30 units for a little guy, five or less, 50 for 5 to 15, and then over 15, we will give them the 100 units of that.

Do you talk about mini glucagon shots in your clinic? I know that's an off-label use, you know, it's not FDA approved but do you talk about that at all?

Yeah, we do. And actually I had a pregnant mom calling me the other day who has type 1 diabetes, had some pretty aggressive settings in her insulin pump, but couldn't keep anything down and she was throwing up and she was having low blood sugar. So I did have her take just a little bit of that glucagon because if you can't, if you can't eat or if you can't drink anything you got to do something. So the low dose glucagon works pretty well. What we teach patients is one unit for every year of age until you're about 15 and then you can use the 15 units or so.

For a mini dose, you mix up the glucagon kits but you use a syringe right? You're not using the big needle that comes with the glucagon kit for the mini dosing?

Right. That's exactly right. Then I tell them that it only they can only have it for 24 hours and then they'll have to get rid of it because it does tend up to gel up. And then they just get a refill for their kit.

I'll put a link in here for more if you want to look at a chart or some more information because more hospitals are putting out information about mini glucagon shots. Although again, that is an off-label use. I talk to Lily about glucagon almost two years ago now and they wouldn't even address it because they can't.

Right.

We should also touch here that there are some other more stable glucagon methods and brands that are in front of the FDA right now. So maybe this summer will have some alternatives which I think is very exciting. I mean we look at the glucagon that's a total in case of emergency thing. We've never broken it out in 12 years. Thank God. But there's a there is a line of thinking that if we could use glucagon easier, if we had more access to it and it was more stable, that if you were 50 and you didn't feel like eating, you were nauseous or you were ill, you know, take a shot. Not a huge glucagon shot, a mini shot maybe it would be better. So I know that's kind of a different subject but I'm excited for that personally. I don't know if you are.

Yeah. And with my patients, because the the glucagon will expire as well I always tell them, don't throw it away. It's still going to work a little bit. We tell them to put it, you know, put it in your glove box because up here we get lots of snow and if you take your insulin are you have your pump running and you get stuck in the snow storm and you don't have anything at least you could take a little bit of that glucagon. So, you know, it will help you get through that hopefully. So yeah, I mean, there's just kind of little nuances. Of course that's off label, too. But little nuances that you learn along the way.. So yeah if we could have glucagon orally or you know, something a little bit easier that would be great.

I want to ask you about alcohol and low blood sugars because my understanding is that you've got to really change the way you treat them. Can you speak to that?

Alcohol is difficult, or can be very difficult, because some of it will raise blood sugars. But what happens is we worry when somebody's on insulin or medication is the early am lows. Your body when it's busy processing the alcohol because alcohol gets metabolized by your liver, you know, just like some medications will. So when it's busy doing that then it can't, if your blood sugar happens to get low then then it can't give you the sugar that it's storing. So that's how those lows tend to come about because it's too busy working on the alcohol and not being able to do two things at once by giving you the sugar. So then that's when people get low.

So what we recommend, what I always recommend, of course is check your blood sugars. Sensors help a lot too. I mean, they really, really will tell on you if you drink. But you know, I always tell people have something to eat, take a little insulin if you have to but have something to eat with your alcohol. And of course, they'll say well can I have nuts? Well, you can but it's not going to do anything. So I encourage them to have before they go to bed, maybe just a cracker with a little bit of peanut butter on it. Or a cracker with a little bit of cheese. It doesn't take much but you got to have something there in case that alcohol is metabolized.

Yeah. That's something that I do worry about as my son gets older. You know, he's 14 now we've talked about it, but I do think I've talked to a lot of adults with type one who they pay attention. They're careful, but to me,

that's it's such an unknown factor.

Yes. It's very scary. Very, very scary. Especially, when kids get into the college age and their binging and not eating like they should or like Mom and Dad had them eat, or just kind of eating on the run. It can be very, very scary.

So I have a question. I'm not sure I'm going to leave in but I want to ask you anyway. So this is actually not about diabetes, but I have experienced low blood sugar several times and I'm curious. I don't have diabetes, you know, what's going on with me? And I've had it to the point where you know, we have meters all over the place now, and I've checked my blood sugar and one time just at home by myself, I was like 62 which isn't that low. But then I was at "Friends for Life" at that conference and I didn't feel well, of course, I'm surrounded by people with diabetes, so everybody's shoving a meter at me and I was 51. So you know, I ate some gummies and...

Whoa.

Oh now I'm nervous. So what happens to people who are not diabetic who have low blood sugar? I mean, do I just need to be careful and eat more?

Well, wouldn't that be nice? No, it's actually the choice, what we have to add to your diet is protein. So what's happening is called hyperinsulinemia. When you eat carbs, your body is kicking out insulin, but for some reason it's kicking out too much. So you're getting more insulin than your body needs. And then as the as the food is digested and the glucose is used, your insulin is still active and you have too much in your bloodstream and that's causing your low. So one of the things that helps with that is protein. Adding protein to breakfast, lunch, supper, making sure you're having, you know an egg with your slice of toast in the morning and you know a grilled cheese sandwich.

The protein helps. So what that does is it helps keeps the carbs in your blood stream just a little bit longer. So they get digested a little bit slower. And then that insulin is used for that glucose from your food. Having said that you want to get a handle on that because that can lead to type 2 diabetes because when we're born we're only born with as much insulin as we're making to make. And if you're, if we're eating high glycemic foods, you know cereals, juices, regular pops, Gatorades telling our pancreas to work overtime all the time, eventually you're going to you may run out. Okay? I mean you deplete anyway as you get older, it's just the natural progression of getting older, but if you have predisposition for diabetes like a family member with diabetes or you have the hypoglycemia, of course, then what's happening is you're telling that pancreas to kick out even more insulin and then in the back of my mind it says well you're going to run out very quickly and then what's going to happen? Which is a reason we don't use sulfonylureas anymore, which is a medication that you probably I don't know if you're familiar with it, but it's used for type 2, and it tells the pancreas to kick out more insulin. Well that to me is like, why would we do that when we already know they're going to be making less insulin anyway? Why are we telling them to kick out more? So that's a whole another subject. But yeah, the sulfonylureas will do that.

One of the things that we tell our patients is no cereal. I mean, we think even the really healthy cereals like the Special K's and the Honey Bunches of Oats and even you know, if it's not sugary, we think it's real healthy and it's got its very highly glycemic. So we take we take the cereals away if we can. And then change them to toast and peanut butter, or toast and eggs, toast and cheese or you know something that's a little bit less glycemic. Pasta, rice all of those things that you know will really spike up those blood sugars.

So this might be a dumb question, but I've actually never heard that. I thought the pancreas makes insulin or you know, the beta cells make insulin. Not that you're just born with all of the insulin you're ever going to have.

Yep. Yeah. That's what I mean. That's where they're they the insulin comes from is the islet cells in the pancreas. But in the end yeah it, what happens is your pancreas as you get older the the beta cells stops functioning.

I see.

And then and that's the part of the type 2 diabetes as well. It's not it's a little bit easier, I guess to say you just sort of run out of of insulin than telling people all your beta cells don't work. Well, what does that mean? So that's how I get to that.

I know this is not where most people's minds would go, but in my head I'm thinking and I'm sorry parents this now rated PG-13. I'm thinking that does not mean it's like women are born with all of the eggs that they're ever going to be able to fertilize. This is not it's not the same right? That's not really what you mean.

No.

Okay, just checking. That's the first place my mind went. Sorry.

That's Ok.

I was trying to think of a part of the body that does that. Was there anything that I didn't touch on about low blood sugars that you wanted to mention?

The only other thing that I usually teach when I'm doing a hypoglycemia session with a patient is I strongly encourage them to obtain medical ID. A lot of people will say, 'Well I have my pump.' Well, you know, not

everybody knows what an insulin pump is. Or, 'I have an ID card.' Well, when a paramedic finds you unconscious, they're not going to go rummaging through your purse to see an ID card. So I strongly encourage people to get a bracelet or a necklace because that's typically where they're going to look. Just let them know, and it doesn't have to be anything fancy. It doesn't have to have your doctor's name or anything all it has to say is diabetes so that they will at least have some inclination to draw, at least check a blood sugar or give you glucagon or something that they can do. I think something that we as practitioners miss a lot for our patients is to tell him that. But I think it's very, very important especially as a kid.

Then the other thing that I also tell patients is, especially if they're going if they're going on a pump is does somebody around you know you have diabetes? You know and with kids that's a little bit difficult because they don't want people, they don't want to be different and other kids think it's contagious, you know that they're going to catch it those types of things but I strongly encourage that they find somebody or have somebody that they know, knows that they have diabetes. So if they are acting, you know, not themselves they can you know, hopefully quickly act on that.

I think a good support group - I don't mean a formal support group with folding chairs and graham crackers - but you know good friends, good support, that's got to be what you need with something like diabetes. So, that's a great.

Absolutely. Yeah. It's a team effort. That's for sure. Definitely. I mean you really you think of a disease as well, this is my disease. I'll take care of it and do everything, but it really is a team effort. If you have a good team then you'll do fine.

Well Shannon, thank you so much for spending so much time with me today. I'd love to have you back on this was really informative, and it was fun to talk to you. Thank you so much.

Absolutely. Thanks for having me.

All About CGMs

with Gary Scheiner, MS, CDE

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Stacey: Gary, thank you so much for talking to me about this. When I wanted to talk CGM, I thought, “Who do I know who’s worn just about every single one of them, who has patients who’ve worn every single one of them, and really has this expertise?”

Scheiner: Oh, my pleasure, Stacey. I’m a human guinea pig.

I think when you’re talking about these different types of diabetes technologies, if you haven’t worn it, or experienced it, it’s really difficult to understand it. My son’s used a Dexcom since 2013, and I can’t say I understand it as well as he has, certainly, but it’s hard to explain to people who don’t wear them. So let’s just jump right in and kind of set the parameters here. I don’t want to do a comparison of what’s best because it’s very individual, unless you want to jump on it and give us the skinny on the A+ CGM.

I mean the systems each have their share pros and cons. I would say, you know, from an accuracy standpoint, the implantable sensor (brand name Eversense), is probably, has the most best accuracy, but it has to be surgically implanted and it has to be calibrated a couple of times a day. But the Dexcom G6 is very close in terms of accuracy with, you know, no calibrations at all, followed by Libre and Medtronic. I’m still waiting for Medtronic to launch a really state-of-the-art, effective sensor. Hopefully the next generation systems will prove better than the ones they’ve had in the past.

Well, I'll refer people to several articles you've written and we'll link those up comparing them kind of side by side. But I'd really like to focus on whatever you use and maybe we'll go through them type by type. But whatever you use, how to get the most out of it, you know, some tips and tricks so that people can really get the best out of the devices that they're using. Why don't we start with Medtronic? Because, and I don't use that system, I'm not as familiar with it, but take us through what's there, because they have a stand alone CGM, but my understanding could be wrong. My understanding is that for the most part, people use it with a pump.

Yeah, most people who are using the Medtronic sensor and I would say 99.9% using Medtronic sensors are using it with 630G or 670G pumps, that have the kind of a hybrid closed-loop technologies. So yeah, the pump will make some decisions on its own regarding the insulin delivery based on the information that the sensor is feeding into it. Where there is anybody who wants to get better diabetes control and better quality of life out of the sensor, I think the same principles apply, no matter what system you're using. I mean, there's a few subtle differences regarding, you know, calibration and how the sensor's inserted, etc.

There are some basic things I'll start out with. First off you have the three things that CGMs can give us in real time: our numbers, trending information, and high low alerts. So I think it's worth discussing those one at a time, starting with the numbers themselves. And yeah, it's interesting going back a decade or so, we just didn't trust the numbers on CGM the way we do now. In fact, just a couple of years ago, the T1D Exchange did a survey of CGM users and asked them how many of them are using the CGM numbers for determining their insulin doses. And this was long before the FDA approved the systems as a replacement for fingersticks. But even years ago, more than 80% of people were using the CGM for dosing. I think the key is that you're smart about it and know when it's reliable for dosing and when it's not. And there are a lot of scenarios or situations where the CGM is not going to provide you with a reliable data point for determining an insulin dose.

And I'll ask you, Stacey, since you have some experience using them with your son, can you think of a situation where you're going to need to resort to a fingerstick?

Oh, sure. The first one that comes to mind is during a rapid drop. If it's showing me something like that after exercise, perhaps, or just kind of out of the blue, but if it's going very quickly.

Absolutely. And that's, that's attributable to the lag time. When you have a five to ten minute lag time and the blood sugar is changing very rapidly, your sensor, when it's rising, your sensor's going to underestimate your blood sugar almost all the time. And when it's falling, it's going to overestimate your blood sugar almost all the time. So if there are straight up, straight down, or double up/double down arrows on screen, is preferential to do a finger stick to get a more precise number for dosing purposes. Think of any other situations?

I would say, it's funny because switching to the G6, Gary, I don't know if I should tell you this, but we don't fingerstick much at all! So I would say in our previous CGM life, my answer would have been after eating. You know, immediately after eating for an hour or two with Benny, for sure.

With the G6 or any CGM that doesn't require calibration, are there times when it does not give you data?

Sure, when he'll lose signal or with the Share, when I'll lose signal, but there are times when he's swimming, right? He's in the water. Or he's in the shower, or he's laying on the sensor in a funky way. And you don't get those numbers.

Yes. Yeah. And I would add to that, warm-up periods. Which, uh, the warm up periods are a couple of hours with most systems, with the Eversense it's a twelve hour warm up, but during warm-up period, you're still going to need the fingerstick to have any data. And most people find that on day one of a sensor the accuracy is generally not as good as it's going to get. G6 is not too bad. The day one accuracy with G6 is decent; with every other sensor the day one accuracy lags far behind what they're going to get on day two and beyond. So generally, it's a good idea to fingerstick on day one.

Acetaminophen is another thing that affects some systems, not all, you know, the Medtronic, the Dexcom G4, G5, those systems are affected by any kind of Tylenol products. It's amazing how many over-the-counter cough and cold medicines contain acetaminophen. And if you take that acetaminophen, your glucose is going to run higher, it's going to appear higher than it really is on the sensor for a while. So that's another time that finger sticks will be necessary.

You mentioned Medtronic and acetaminophen. I just want to make sure that that doesn't go by too quickly, because I had not heard that. I thought it was only Dexcom.

Medtronic sensors, as well.

If your son has a low blood sugar, after he treated it does the CGM show that his glucose comes up right away?

It does not. It does not.

That's the case with with every CGM. There is an extended lag time when we recover from low blood sugar. So if we trust the sensor, and it keeps reading low, low, low, you're just going to eat, eat, eat and wind up over-treating. And we don't need any help over-treating our lows, we're hungry enough to do that ourselves.

So, perfect example of that perfect storm was just yesterday. Benny had a sensor change, so we had two hours of you know, no blood sugar numbers. And about twenty minutes before the warm up ended. He said, "I feel low." I said, "We've only got twenty minutes." He said, "No, I feel low. I'm going to check." And he checked, and he was 70. And he said, "I feel lower than that. I'm going to treat," and he treated. As soon as the warm-up period ended, of course, it started screaming at us that he was low. Five minutes later, we did another

fingerstick. He was already 84 or 85. Coming up, the Dexcom Share kept screaming LOW. And it's not just in my house, my mom gets those alerts. So I had to text Grandma and say, "It's fine, Dexcom is bananas. It'll catch up, don't worry." It was a long low, he had, Gary, he had like 20 carbs, I think of juice, and it took him about an hour to float up to 120. And then he went to bed. And he was like 90 all night. So it was a crazy one!

Well, be careful how you how you phrase it. It took him probably fifteen minutes to come up to 120. It took the Dexcom longer to recognize the rise. The Dexcom will sometimes take 30 to 60 minutes to capture the rise in blood sugar. And the reason is basically that the sensor is sitting just below the skin. It's not measuring the blood vessels or the bloodstream directly. And it takes quite a while for blood flow to be restored to the skin surface when, when a low blood sugar occurs. You know, our bodies go into a stress response with a low, and it's very little blood flow getting to the skin surface, and hence the sensor's not catching the fact that there's more glucose in the bloodstream. So it's necessary to do finger sticks when you're recovering from a low, to prevent overtreatment.

Also anytime symptoms don't match, like what's happening with your son, if the sensor is saying you're high and you don't feel high, or it says you're low and you don't feel low, certainly it's best to fingerstick and verify what's going on. So finger sticks are still part of the game, even with a non-calibrating system like Dexcom or Libre.

And as far as calibration goes, another thing that's important, to make sure the system operates properly, is that if you do fingerstick and see a discrepancy of more than 20%, it is a good idea to calibrate. Enter that reading as a calibration. Otherwise the CGM is going to continue to underperform. If it's drifted out of range and is running higher or lower than the actual glucose, if you don't calibrate it, it's never going to get back on track; so it is necessary to calibrate when it's not running accurately.

Can you tell us how to calibrate accurately, because I think there is some confusion there, too.

Yeah, well, it's very important to use a meter that's accurate, you know, I, personally, I'm a fan of the Contour Next meter. I feel that that's the most accurate one on the market. You know, make sure your finger's clean when you check, and you enter the reading right away. You can calibrate the Dexcom just by going into settings and entering a calibration. That's pretty simple to do. One of-- I think a downside to the Libre is that it cannot be calibrated. So if it's not performing properly, if it's running higher or lower than your actual blood sugar, there's no way to fix it. At least with Dexcom, with the G6 you can enter a calibration. But as I said it's not necessary to enter calibration, unless you have a reading that's more than 20% off from what the sensor is showing.

Second thing would be the high and low alerts. This, to me, is the major selling point of CGM and is still extremely important for anybody who takes insulin, who's at risk of hypoglycemia. Most people with diabetes do a pretty poor job of guessing what their blood sugar is. And most people don't recognize their lows or their highs until they get to a fairly extreme state. For example, I can't tell them my blood sugar is low until it gets down close to 50. And there are people who can't even tell in the 50s when they're low. And hardly anybody can tell when their glucose is just a little bit high. If you're 180, it doesn't feel any different than 80 does. So the sensors, the CGM is very good at picking up on those subtle highs or subtle lows, so that you can treat them before they become extreme.

So the critical aspects of this, number one, is putting the settings in properly.

And number two, responding properly.

So let's talk about the settings first. Because of the lag time, it's not reasonable to put the low alert at 70. If the sensor thinks you've gone below 70, and your blood sugar is falling, you're probably around 50 already. So it's necessary to put the low alert for most people somewhere between 80 and 90. And just to be able to catch it while it's still treatable and may still be able to prevent the low.

At the high end, take a little different approach. I think it's fine to start with a very high setting, I mean, put it at 300 if you want. I don't want people getting too many nuisance alarms when they start using the system, but eventually pare that high alert down to a point where you're catching it at your highest allowable post-meal blood sugar. So if you don't want to go above, say, 200 after meals, that would be a reasonable place to put your high alert, eventually.

And then the next aspect is response to the alerts. It's sort of like that tree falls in the forest and no one hears that thing. What's the difference? It's the same thing with these alerts. If they, if you get a high or low alert and don't react to it, it's meaningless. And what I have to teach people is that when they get these alerts, they can't think -- they have to just act.

With any high alert, it's a good idea to enter that reading into your pump and bolus, if the pump says to. If you're on injections, calculate a correction dose, but also figure out how much insulin on board you have, and deduct that. But for any high alert, give yourself extra insulin if needed. It's also worthwhile to drink some water, maybe get some extra little bit of physical activity.

And with a low alert, it's very simple. You have to take rapid acting carbs to reverse that downward trend and get your blood sugar back up. If you do that quickly and consistently, I guarantee you'll spend a lot more time within your target blood sugar zone.

There are those times where you hit that high mark, if it's set at 200. And I do have a teenage son, so this might be different for other people. He'll give himself some insulin, and then half an hour later that alarm goes off again.

You want to be careful, obviously, about stacking and over delivery of insulin. But you know, is it a question that if you're always hitting that, to maybe rethink your timing of the first dose of insulin, or you know, simple things like that? I mean, it can really give you an idea of what the heck is going on, if you're always hitting that line.

Of course, it's always better to prevent the high. You know, looking back at some of your data and patterns is helpful, but you know what, anytime a high reading does occur, respond appropriately. And you hit on a very important point, which is to avoid the stacking, and then that means deducting your insulin on board or your active insulin from whatever dose you feel you need.

People who keep dosing over and over again to try to fix it, we call that angry bolusing or rage bolusing, and that almost always leads to serious hypoglycemia. So you know, correct the highs, but do it intelligently. Consider what's still in your system.

And we mentioned the lows being a bit of a lag for especially the Dexcom and CGMs. Is it the same thing with a high, or do the systems seem to react more quickly to a, let's say your real alarm is at 200. Does it seem to reflect that more quickly, or is it another question of blood flow and reflecting the numbers?

Yeah, it should capture. If your glucose is high and you give insulin to reverse it, it should pick that up relatively quickly. The only problem when you're low is your body isn't delivering much blood flow to the skin surface. That doesn't happen when your, your sugar's high, though.

And then the third element of your daily data are the trending arrows, the up and down arrows that you see on screen.

So take an example with your son. If he's going into dinner with a blood sugar of 150 and he's going to eat 60 grams of carbs, you can calculate the dose he needs for that. But what if you knew that his blood sugar was 150 and falling quickly? Would that change the dose that he's likely to need? Absolutely. And the same thing if he's rising quickly, it's going to change the dose that's needed.

And you know, the trend arrows allow us to make better decisions. And we probably make an average of forty decisions a day about things related to our blood sugar, everything from our insulin doses to what we eat, when we eat, physical activity, etc. Just to make our lives better and safer, to help us make better decisions, we should be looking for those trend arrows pretty often.

I teach my patients that for every upward arrow, if their glucose is rising, let's say one to two points per minute, they should probably dose for an extra 25 to 30 points on their blood sugar. So assume their glucose is 25 to 30 points higher than it actually is, and does that.

And with double up arrows, they should figure they're about 50 to 60 points higher than they actually are, and dose for that.

And with down arrows it should assume that glucose is actually lower than it is. If they're dropping one to two points per minute, knock off 25 to 30 points from the actual glucose that they have.

With double down arrows, knock off 50 to 60 points when determining the dose to get. That improves the chances you'll be on target next time you check.

Are the arrow speeds and those calculations consistent brand to brand?

No, they're not! And that is such a frustrating thing. I just finished writing my next edition of Think Like a Pancreas. And I put a section in there on how to make adjustments for trend arrows. And I had to do the research on, you know, the exact nomenclature for every system.

And it is different for every CGM on the market. Some have diagonal arrows, some have single up and down, some have double, some have triple, and they all mean different things. So you have to consider how your system interprets those arrows. That's why I say a one to two point rise, a two to three point rise, and et cetera. Rather than just saying one arrow, two arrows.

If it's a Dexcom, which is probably the most popular and commonly used, I would treat each arrow as 25 points. So if you have a diagonal up arrow, add 25. If you have a straight up arrow, add 50. If you have a double up

arrows add 75 to your current glucose. And if they're down arrows deduct 25, or 50, or 75, but that only applies to Dexcom. Given something else, you gotta look at the manual.

I was just gonna say maybe get out the manual, get out the book for the different brands. But it's frustrating that there's no industry standard in terms of arrows and speed. That would be helpful.

Yeah, the Endocrine Society did come out with a paper that, you know, gave some general recommendations about the arrows, but it wasn't specific, you know, based on which system and which arrows were showing up. But when my book comes out, probably third quarter this year, I've got much more detailed recommendations of how much to adjust based on those.

So the trending arrows, I mean, they're such a help if you're about to go to sleep, if you're about to drive or exercise, or whatever you're doing, knowing what direction your glucose is headed lets you make a better, more effective decision about how to manage your diabetes through that activity. So looking at those trend arrows is very important.

So once you get past your real time data, then you can start to look at downloaded reports. Now with Dexcom, we have the Clarity program that can generate reports. Medtronic has Carelink. Freestyle Libre has their own PC-based software called LibreView. Eversense has an app that's on the phone that can generate reports.

But I'm a fan of something called "spaghetti reports." These are reports that superimpose multiple days of data on the same graph. And that way you can kind of evaluate where you tend to experience most of your highs and lows. You can evaluate what happens before your lows and what happens after, try to troubleshoot. You can see how high your post-meal peaks are, you know what kind of quote unquote spikes you're experiencing after various meal times. You can see if the basal insulin you're taking, whether it's by a pump or injection, you can see if it's holding you steady when it's supposed to be. You know, overnight, and you know, mainly before meals, it should be keeping you fairly level.

You know, there's a lot you can learn from looking at your CGM data to help your own fine tuning process and also for sharing with your healthcare providers.

That spaghetti layout I remember from Dexcom Studio software from several years ago, is it in Clarity? (Gary - Yes.) You can tell that I do a deep dive into Clarity all the time. I usually look at the big picture and then talk to our endo about it. I'll tell you, it's hard to not be a brilliant math person when you're a diabetes parent. It just doesn't compute.

Oh, see, that big picture report, it's also called an ambulatory glucose profile. That's the one that kind of summarizes for you and shows you know, for each phase of the day, what percentage of your time is in range or high or low. And you can learn some things from that.

But you can learn a lot more from the spaghetti graphs because you can dive into more of the details. Unless you're on a very fixed schedule, the summary graphs are going to miss-- can be very misleading. The spaghetti

graphs will reveal a lot more important information than the summary graphs will.

I also like to look at some of the stats. The average glucose on the sensor for the last month should correlate very closely with your A1c. So anybody who has a doctor who does the A1c at the office can actually go in and say, “Hey, Doc, I’ll betcha double or nothing on my copay, I can guess my A1c within 0.2.” And I’ll give you the magic formula for doing that, you can share with your listeners. If you take the average for 30 days on your CGM and add 3% to it, so you multiply by 1.03, that’ll give you a truer average. Because all CGM systems do underestimate glucose a little bit. To that true average, you add 46.7 and then divide by 28.7. And that will give you a free copay.

(Laughter) All right, wait, wait. I have to ask you though, how did you come up with those numbers?

I didn’t come up with them. That’s called an estimated average glucose equation, that was derived from some people much smarter than me. The three percent is my own fudge factor. I’ve just observed that over many years, that the the CGM average tends to underestimate slightly. That’s why I have people add about 3% into their average to get a true average.

All right, folks, I’ll write that out. I’ll put that formula in the show notes so you can cut and paste it.

The A1c and the average are the quantity measures. Most of us now are more interested in the time and range. That’s a much more valuable metric. It really reflects the quality of our control, and if you’re achieving, let’s say, 75% or more time in range, that’s phenomenal. That’s really nice control for most people. If your time in range is under 50%, yeah, you got some work to do. Most people are in the 50-60% range, but getting it up above 75% is highly desirable.

Let me ask you some hardware type question. One of the things that I’ve seen passed around a lot lately is insertion technique. I’ll be honest with you, my son who’s 14, he grabs the G6, he slaps it on his arm, he pushes the button, he’s done. Are there actual insertion techniques with different CGMs that will help you get better outcomes?

Well, the fewer steps that the user has to perform, the less chance for human error, and given you know, with the G6 and Libre they’re extremely easy to do. There’s not a whole lot that we can muck up. So it’s the kind of thing that yeah, a kid can do it. An adult who’s visually impaired can do it. People with bad dexterity or a tremor can do it.

The Medtronic has a lot of steps involved and a lot of things that can potentially go wrong. There’s a lot of extra taping required. So you know, there’s potential for issues with the sensor insertion. So proper training and practice is pretty important.

Sensor sites are less of an issue than you might think. It’s such a big deal with pumps, you know that the infusion sites have to be manage so carefully. We don’t really see too many issues with sensor sites though. The placement is not that critical. As long as that sensor gets into a layer of fat under the skin, it should work pretty

well. It doesn't matter what part of the body, doesn't matter if there's scar tissue or liperhypertrophy there, they still seem to work pretty well.

Is that because it's just reading and not just sending out insulin? Or is it just the wire system?

Yeah, I mean, there's no chemical being infused into the body that has to be absorbed in a certain manner. It's just measuring the glucose concentration in that tissue.

Before we move on, though, let me just ask for the Medtronic users out there, can you give them one or two pieces of advice in terms of the taping? Are there any tricks of the trade that are easy, you know, to share?

The more stable the sensor is, the better. So I hate to say the more tape the better, but yeah, make sure you use the over-bandages to make sure that the sensor's not moving around much.

Another issue we often see is that if the transmitter and sensor sort of bend against each other, then the transmitter may start to lose connection periodically. So place it so that the sensor and transmitter are on a relatively flat linear surface. I know on the human body is not a lot of flat linear surfaces. You know, for example, if it's on your-- if you have it on your arm, put it lengthwise, not sideways on the arm, or even on your-- if it's on your abdomen, put it on a flat area and not a curved area, if at all possible.

We mentioned the G6 with Dexcom being pretty easy, you know, one handed, that sort of thing. But let's talk about the G5 still out there being used. It's a different inserter, it's a little bit more difficult. We used to pinch everything up and really line things up. Any advice on using that inserter?

Yeah, it's again, it's a practice makes perfect type of process. It looks a little bit intimidating, but once the person gets the hang of doing it, it becomes very simple and quick. You don't need to pinch the skin at all. The skin cleanliness is eh-- you don't want to put it on filthy skin, but you don't have to sterilize all that careful, either. We almost never see infections at sensor sites.

I guess one thing to consider is the transmitters going to have to be inserted after the sensor's placed, and with the G5 they have that tail assembly that has to be used. So make sure that you place the sensor in a spot where you can, y'know, easily get that transmitter snapped in.

The G6 transmitter snaps in much more easily. So the actual site's not as critical. You can put it on the back of your body if you want.

So with the G5 and the G4 sensor insertions it just takes a little bit of practice. We have boxes and boxes of old G5 sensors. We give patients a chance to practice it on some fake skin when they come in. So they, you know, let's do it three or four times and really get the hang of the technique. And doing it in one quick motion really is best. People who do it really slowly struggle a little bit. And it can also, it can hurt a little bit. When it's done in one

quick motion it's usually painless. (Note: Dexcom discontinued the G4 and G5 systems after this interview)

Yeah, I wish I had that to practice on. The first time I did it was on Benny, and my husband had been the one to do it. And Benny said, "Just do it quickly!" And I did it SO quickly, I almost yanked it out! I pushed in and I pulled out, and he said, "Stop, stop!" So, you know, you're so nervous you're gonna hurt him. But we get the job done.

Yeah. Reuse of the sensors is another thing people often want to know about. And it really depends on the sensor algorithm. With the G6, the algorithm assumes that there's going to be some change in how the sensor functions every day. There's going to be what's called drift. So by the time you get to day eight, nine and ten, it's interpreting the signal very differently than it did on day one, two, and three. So bottom line is if you try to reuse a Dexcom G6 sensor, there's a good chance the accuracy is going to suffer.

Ironically, we saw the opposite with the G5, G4 sensors. They seem to perform better on the second week, because I guess there was no warm up period, and the sensor was working pretty well right from the get go. There's still that two hour warm up, but the sensor's already been housed under the skin for quite a while. So people are usually able to get a couple of weeks out of those older model sensors.

But with the G6 sensors, it's probably not a good idea to be reusing them beyond the 10 days.

And let me ask you too, anecdotally, I hear a lot--and again, I'm in a lot of mom groups, so I see the younger kids – it seems that that the younger the person and the leaner the person, the more difficulty they seem to be having with the G6 in terms of sensor failures more quickly. Are you seeing that in your practice? And is there anything that can be done?

Yeah, I haven't seen more problems with the G6 than with any other system. But you're right that the leaner a person is, the greater the likelihood for some sensor issues.

And it's related to both hydration as well as the possibility of compression, where, you know, the sensor's pushed right up against muscle wall, or possibly it might be in, partially in the muscle.

So placing a sensor on a fatty area is of paramount importance.

With most lean kids, I recommend the buttocks but with the sensors, it's not one of their quote unquote, approved sites, but it's certainly not approved because they didn't do a full scale study on it used on the buttocks. But people have been using it on the buttocks for, you know, a decade or more. It works perfectly fine there. And there's usually ample fat tissue on the butt to support proper function, whereas there may not be good fat, enough fat on the abdomen or the arm, where they are approved.

You know, we haven't talked much about Eversense, which is really up and coming. And my impression was that for this episode where we're talking about best practices and things that we as individuals can do to make

the CGMs better, I was thinking, well, they implant that into the skin, so there's really not much you can do with it as a user. But there are a few things. Can you touch on those?

Yeah, it's a neat product. And I must admit I'm not, I haven't used it, personally. I'm scheduled to go into a clinic in Philadelphia in a couple of weeks and have mine inserted, so I will get a chance to try it firsthand. I've had a number of patients use it, though, so I've been able to kind of live vicariously through them and see how it functions. And they've all been very happy with it and pretty impressed.

The insertion process, reportedly and from the training I've received, is relatively minor, a pretty quick, simple thing, you barely feel anything when they place it. And once it's in the skin, that that site heals up very quickly. Having it under the skin, it just eliminates issues.

You don't have to worry about changing the sensor on a regular basis.

Transmitter that sticks to the skin can be removed and set aside any time. You know, so for example, if you have to go for an MRI, you don't have to take your sensor out, you just put the transmitter aside. Any kind of physical activity where it can't worn, you can just remove it temporarily.

But a nice thing about the transmitter that works with the Eversense sensor is the transmitter itself can communicate with the user by vibrating. So if there is a low or there's a high, it will vibrate with a certain tone or certain frequency to let the user know there's a potential problem. So you can go out for, let's say, a run without your phone or receiver and the transmitter that's taped to your skin will let you know if there are any issues.

Otherwise, you know, there's an app in your cell phone to present your data for you.

The Eversense does require a couple of calibrations per day. And the current sensor is a three month model. They've already approved a six month version in Europe, and that sensor only requires one calibration per day. And they're looking at versions that require far fewer calibrations than even that. And the FDA seems to take longer than most European safety commissions do, so probably within the next few years, we'll see an Eversense that requires even less work on the patient's part.

I want to move on to a couple of specialty-type questions about CGM. I'm wondering if people who are serious athletes should do things that are different, in terms of either interpreting data or where they wear it, you know, high school athletes, college athletes, people who work out and run several days a week, is there anything different for them?

Well, the adhesion issues are pretty common with athletes, especially if they're, you know, outdoors in the heat or just perspiring a lot with any form of exercise. Extra tape is almost always going to be needed. I know the Dexcom now offers these free over-patches in packs of ten. You just have to call Dexcom and ask for them. And there's a product called GrifGrips that a lot of people use and really like. These are cloth tapes with a cut hole, the adhesive is sort of a gummy adhesive that holds up well, even when you sweat or get it wet. So that can help with the adhesion issues.

Water activities can be a concern, also. The water is not going to ruin the sensor or the transmitter, but the signal doesn't travel through water. So somebody who's using a CGM may not have access to their data while they're in the water. Now luckily, the transmitters will often store a certain amount of data, so as soon as you're in

range of your phone or your receiver, your data will drop in, but to get live data while you're in the water is just not gonna happen.

You always know when someone has gone on vacation for the first time with the CGM in our group, because there's this panic of, "It's not working in the water," and then you realize it's not going to work in the water. Oh, gosh, so many fingersticks outside the pool.

People who sleep in water beds have a problem too. They lay in a water bed, and they're not going to get a signal most of the night.

Wait, for real?!

Yes, yes. Yeah obviously, if they put the transmitter on their abdomen and they sleep on their back, it's not a problem, but the other way around, if they're laying on the sensor, and they have their body on top of it and a water bed under it, there's nowhere for that signal to go.

Good thing the the 70's are over, man! That could be a big problem!

Hey, yeah!

Sheesh. Let me ask you, I don't know if you can answer this. But technically speaking, there are a lot of best practices in terms of remote monitoring and even getting a signal on the user's cell phone. Can you speak to that in terms of the Bluetooth connection and making sure your phone doesn't have twenty other Bluetooth things in it? That sort of thing?

In general, I haven't seen too many problems with people receiving data on a sharing basis. It seems to be pretty reliable and works well. I don't use the sharing data, personally, I guess, my wife has never asked to see my sensor data, and I don't know, I'm just, I don't want to share it with her, she'd know everything I'm eating when I'm out. But yeah, I could not, obviously a parent's going to want to see their child's data. And a lot of partners, do want to see it, you know, especially with their partners traveling, they like, just like to be alerted about lows. I tell you, just try not to be too much of a helicopter parent or helicopter partner. Just get alerted if there's a problem. You don't have to be watching every little thing all throughout the day. That's overkill.

I have done many a show on remote monitoring and parents, and will continue to talk about that because it's

such a great tool. It can give you such peace of mind if you let it is my opinion.

Yeah, or it can drive you insane.

Right. And I'm obviously a perfect parent, so I do it beautifully! And I never bother my son (Laughing) What else have we got? You know, you mentioned a couple of minutes ago, we were talking about leaner folks, and you said that dehydration, but that could be an issue for everybody using CGM. Right?

Yes, okay, yeah. You know, when someone's in a state of dehydration, they're not going to receive good blood flow to that fat layer below the skin. And when there's very poor blood flow to that layer, the sensor is not going to receive accurate glucose levels, it's not going to perform well. So in a state of dehydration, the sensor becomes very unreliable.

And a second issue we see are called compression lows. And you may have seen this on your child's sensor at some point where they're going along just fine, and then all of a sudden, it just drops like a stone for about 15 or 20 minutes, and then pops right back up to where it was previously. That- that's a compression low, and that's just due to physical compression of the sensor under the skin. It can certainly happen overnight if you're lying on it, or if you're sitting on it during the day, or pushing up against it somehow. But that's an artifact. That's something you-- it's not a true low or a true drop that's taking place.

Yeah, you get pretty good at spotting it after it's happened a couple of times.

That's right. Yeah looking at sensor data is an art and a science, and I'd encourage anybody who's using a CGM to work with a good clinician who's able to not only interpret the data effectively, but teach you how to do it. You know, what types of patterns to look for, and how to make appropriate adjustments based on those conclusions that are drawn.

Before I let you go, right before we started talking, I was looking at some articles that you've written and I found one from 2007, when you were giving terrific advice about using CGM and-- but you laugh, because it seems like it's such a different world. Looking back, it is pretty amazing how far we have come and where things are going. Can you share your perspective on that as someone who uses these and has lived with diabetes?

The first CGM I wore was in 2003. And that was a Minimed system called the Minimed CGMS. And it was nothing more than a black box with a wire coming out of it, that attached to your skin, and it had a very large sensor that went into the skin. Now that thing was cumbersome, clunky, it didn't even give you data while you wore it. But it was really cool being able to download it and see what the glucose levels looked like all day and night. It

wasn't terribly accurate, but oh-- seeing what the patterns were like was fascinating.

Now, we can not only see our data live, we can learn cause-and-effect relationships as they happen. We can trust these things. We can use them as a management tool on a minute-to-minute basis if we want. And like I said, if you're, if you're skilled at analyzing the data from them, you can learn so much and fine tune your program.

I wanted to mention if anybody doesn't have a clinician that really understands these reports all that well, they can reach out to my team, because we work with people all over the country and overseas, by phone and by internet, to analyze these types of things.

And Gary, let me just take that one step further. At Integrated Diabetes Services do you work with people of all ages? Kids, adults, seniors?

Yes

It's really important because not everybody does. So I'm just wanting to clarify that. And then let me also ask you to continue the thought about the accuracy of the CGMs, because of course, the next step is the pumps and the closed systems that are going to be using that data. We really are almost there! I mean, it's incredible when you talk about wearing that CGM fifteen years ago, sixteen years ago, we're really on the precipice of multiple systems. I assume you're excited and think they're going to be accurate. I hope.

Yeah, very excited. And personally, I am running this do-it-yourself loop app that takes, you know, an old pump along with the new Dexcom G6, and runs it through an app on my phone, and the app controls my pump's insulin delivery. It's got several little technical glitches now and then, but overall it helps me achieve the best control that I've had in thirty years. And it does, it does start compensating for my own inequities. If make mistakes on things or underdose, overdose, et cetera, it fixes it for me, not immediately, it takes a little time, but it does compensates for things that I don't get exactly right. So it's like having another brain watching over things for me and helping take care.

That's fantastic. Gosh, well, I can't wait, you know, it's a lot of great stuff that's coming. It's a lot of great information here. Gary, thank you so much for spending so much time with us.

Again, all the information about Gary and his amazing team will be at Diabetes-Connections .com, if you want to contact them for a consult, or more information. And of course the book, Think Like a Pancreas, a new edition coming out later this year. Maybe we'll come back on and talk to you about that, or at the very least give the information to my listeners. But Gary, thank you so much.

Stacey, it was my pleasure.

All About New Diet Guidelines

with Hope Warshaw, CDE RD

[EPISODE ORIGINALLY AIRED JUNE 27, 2019]

Hope Warshaw is a dietitian and diabetes educator. She's served as president of The American Association of Diabetes Educators and sits on the Board of the Academy of Nutrition and Dietetics Foundation. Hope's books include *Eat Out, Eat Well – The Guide to Eating Healthy in Any Restaurant* and *Diabetes Meal Planning Made Easy*.

Stacey: Hope, thank you so much for spending some time with me. A lot of ground to cover here. Thanks for jumping in on this.

Warshaw: Delighted to be with you.

All right, let's get started. The first thing I want to talk about are these new consensus updates. The American Diabetes Association published a new guidance report recently about individualizing nutrition goals and diabetes care. And what sticks out to me is that they say there is no single recommended nutrition plan for people with diabetes. So what do we do? Can we just start from that recommendation?

Sure. Let me just take you back with a little bit of history. I've been around a long time. This recommendation is really consistent with what the American Diabetes Association has said for a number of years. So there have been what have been called position statements or, and nutritional recommendations over the years. The ADA, it has moved recently to more doing consensus reports rather than position statements, and these consensus reports are all wrapped into their standards of care, which are published annually in January. And then updates are done in what they are now calling their Living Standards.

So I would say for a number of years at this point, the message from ADA, in terms of nutrition, and really what to eat has been individualized. As you and I know very well, there are 30 million people diagnosed with diabetes in the U.S. It happens that for the first time, these nutrition guidance—this nutrition guidance includes

both people with diabetes and the 84 million people that CDC estimates have pre-diabetes. So it's an awful lot of people.

And the research just doesn't bear out that there is one eating plan that people with pre-diabetes and every person with diabetes, whether it be type 1, type 2, or other types—there are many other types of diabetes—that there's one type of eating plan to follow. So this is nothing new and revolutionary,

I guess it seems revolutionary to me in that this is more, you know, you should eat in a way that results in a deficit of energy, right. So you want to promote weight loss, you want to focus on the things that I know you know, and they're so rote to folks like you in-the-know, more vegetables, minimizing sugars, you know, choosing whole, unprocessed foods.

But a lot of us are looking for a plan. So if I go to my nutritionist or my endocrinologist as a parent of a person with type 1 diabetes, what are some things I should be asking about in terms of eating well, based on these new guidelines? I mean, do I walk in and say, give me a plan that works for me?

Let's step back for a second. I do not believe that given real life today, that people follow, let's just call them diets. Okay? People don't do that. People need, I think much more of a skeleton of what their approach may be, what some goals should be about the way they choose foods and put meals together.

And that's why I think that—I mean, with these kind of consensus reports, it's always based on research. When you dig into the details of this consensus report, they went through, you know, six hundred pieces of research. They have particular exclusion criteria about the research that they consider looking at and that that they did not. There were, I think the number was, fifteen experts in nutrition. A number of them are my longtime friends and colleagues. And this came together, this is all research-based.

So to read through, and I think it's a value to read through, one of the messages is that health care providers should focus on key factors that are common among the healthful eating plans. And those are, and you listed a few of them: Emphasize consumption of non-starchy vegetables. Translated, that means load your plate with raw and cooked non-starchy vegetables.

Number two, minimize consumption of added sugars and refined grains. So refined grains, your white breads, your white pastas, your cookies, your pastries and baked goods that are made with white flour. Added sugars— the biggest contributor of added sugars to the American way of eating is what we consume in beverages.

Number three was choose whole foods over highly-processed foods.

And the fourth one sort of goes along with the second one, but that was replace sugar-sweetened beverages with water as often as possible.

So the point here is that those can be some, some core principles the people work towards. And the reality is that those core principles are no different than for anyone else without diabetes trying to eat healthier today.

So when we look at this—and they talked about individualization, and there's no single recommended plan, and everything you just said, one of the things that comes up time and time again is whether

we should be eating low carb, or, and I've seen more recently, a differentiation between low carb and very low carb. Is there anything in this report that says that low carb or very low carb is better than an everything-in-moderation plan?

I would say, in looking at the research and looking at this consensus report, you really need to split out type 2 diabetes and type 1 diabetes. And let me just give you definitions. Because this, one of my tweets at the ADA meeting was, when we use these terms, low carb, high carb, low protein, high protein, can we please put a number on it? It doesn't do any of us any good to just be thrown around these terms without full understanding. And there's no higher being out there that has ever really said this means this and that means that.

But for the purposes of this review, a low carbohydrate eating pattern was defined as 26-45% of total calories. So that is low carbohydrate. They defined very low carbohydrate as less than 26% of total calories. So I think that's important to understand.

Can I jump in, Hope, and ask you, I don't know if you can translate this. Can you translate that to carbs per day?

I can only do that given a certain number of calories. You can't say grams unless you know the calories. And what people often don't understand, and I don't blame them, because nutrition is a lot, and confusing, but the reality is because foods are, as I call them, "packages of nutrients," either in combinations of carbohydrate, protein, and fat.

And if you are going to eat, say, very low carbohydrate, then to get the calories that you need, you're more than likely going to be eating a good bit of protein and fat. Because you got to get your calories in somewhere.

So I would say that the body of literature is getting stronger for the value of low carbohydrate eating plans for people with type 2 diabetes. Does that mean that is the only way for people with type 2 diabetes to eat? Absolutely not. And the paper does a very nice job of reviewing the literature on eating patterns. Mediterranean eating style is covered, vegetarian or vegan, low fat, low carb, etc.

So there's actually a fabulous table that covers a lot of math and I'm sitting here, reading off of what's all of those numbers.

In the area of type 1 diabetes, there is actually very little, if not no high quality research done around low carbohydrate or very low carbohydrate eating plans.

You're kidding.

No, I'm not kidding. I'm talking about research. Right? Well-conducted research. I mean, we hear so much, Stacey, about nutrition and we hear headlines and, you know, we hear different people's vantage points promoted.

But I'm talking about research. And I'm going to quote because I actually wrote an article for for my dietician colleagues that will be in a magazine called Today's Dietitian. And I'm going to quote my colleague who was on the committee, who's had type 1 diabetes for, my gosh, I think at least forty years. She wrote, and this is, I'm quoting

her in my article, she said, “We always have to remember that research and people with type 2 diabetes cannot be automatically translated to type 1 diabetes. They’re two very different disorders.”

Okay, so let me ask you maybe, then this is a bit of an editorial question. I’ve been in the community for 12 years now. Why do you think there isn’t more research on overall diet and type 1 diabetes, or is it just low carb? It just seems to me that when carb counting was introduced, that they would start following the amount of carbs.

So, well, I mean, I think it’s important to understand that carb counting is a way of meal planning. You can use carb counting to consume a high intake of carbohydrate or a lower intake of carbohydrate. It is not—There’s nothing about the term “carbohydrate counting” that indicates, oh, that means low or very low carbohydrate.

Of course, of course, but well, I mean, my—I guess my question is, why hasn’t it been—I guess my question is, is it just that there are not enough people with type 1 to study the nutrition? I’m curious why, when carb counting as part of how we dose insulin, why there isn’t more study on the amount of carbs, you know, or carb counting routine, and whether it matters.

Unfortunately, there isn’t nearly enough nutrition research in general. Nutrition research is very hard to do. Because it’s humans. And it’s what they eat. And to control for one variable means that you may be having people, you know, eat differently than they tend to eat. And, you know, it’s one thing to put people in a controlled research center, but it’s another thing to have what researchers called free living environment.

And while there certainly has been a decent amount of nutrition research over the years, the number of subjects and studies tend to be relatively small. The duration of the studies tend to be relatively short.

And, you know, I think it’s important to keep in mind that—Compare this to the research that comes out of the pharma industry. I mean, I look at some of those studies, like a number of studies that were reported out of the ADA meeting. They are international studies. There’s thousands of people in these studies, but you look at the price tag on those, they’re millions! So I think we’re bringing up an important point for your listeners to understand.

Absolutely, I’m surprised to hear that there isn’t more research and it makes sense as to why. It’s just frustrating.

It is frustrating. I mean, believe me. Very frustrating. We’d like to have answers, and, you know, unfortunately, I think that, that’s sometimes where, you know, where messages get filled in where there really isn’t research to back that up.

Yeah. All right, so let's talk about some things that you can help with, with what we know right now. You mentioned low fat, high fat, high protein, things like that. Can you talk a little bit about dosing insulin for high fat and high protein?

And I'll tell a quick story. We found—we had not thought about this, at all. We were—When Benny was diagnosed, he was almost two years old. We were dosing based on carbs alone. And then we went to a friend's house. And this was several weeks, maybe months later, and he ate a hot dog. And he was high for like, twelve hours! And we didn't understand why until we asked our endocrinologist and we learned about high fat and high protein. He'd eaten hot dogs before at home, but they were much lower fat.

So can you explain a little bit more about how that affects the body? Or, I guess what I'm asking is how do people with type 1 dose for that high fat, high protein?

Well, I mean, that's, that's a good question. And I would say it's really just in the last five, maybe five to ten years that this conversation has even come up and that there has begun to be some research around this topic, enough so this ADA nutrition consensus report actually contains some advice. Not really numerical advice, but some general advice about insulin dosing and fat and protein.

So, I mean, just to track back for a second, I mean, we know that the carbohydrate in food— in fact, it really bugs me when people call food “carbs,” because food isn't carbs, food contains carbohydrates. So that was an editorial comment, as well. So, I mean, we know that generally speaking, all sources of carbohydrate raise blood glucose relatively fast, yet— So protein really, by itself—but again, when do you really eat protein by itself?— because I go back to my message about food comes in packages of nutrients. So even when you're eating, you know, a piece of boiled chicken, you are eating—I'm talking even skinless boiled chicken— you still eat a combination of protein and fat. But sure. There are differences from, you know, a piece of broiled tilapia to a piece of ribeye. And the amount of protein and fat in those two, sort of sources of protein, if you will.

So, fat really is the nutrient that is slower to impact glucose, than carbohydrate is. So the thinking today is that there's enough research to be able to say that there's consensus that the amount of fat and protein in a meal can impact the level and timing of postprandial glucose.

It's sort of underlying the level and timing. So level, meaning how much glucose rise you may get from that meal, but more importantly—and I think to your story about hot dogs—is the timing of that rise. So the timing with potentially lower carbohydrate, higher protein and fat meal, relatively speaking, is that you may see a slower rise and a later rise.

It depends what tools people are using to measure their glucose, to take insulin. Are they using a pump where they can extend a bolus over a number of hours? Or if they're taking multiple daily injections, are they willing to say, Okay, I'm going to take, you know—say they're eating pizza, you know, the sort of an enigma food, as I call it—Can they take X amount a few minutes before they start eating, and then take sort of the rest of that bolus dose, maybe and I'm making this up, but an hour into the meal, to try to, you know, minimize the rise of glucose, say an hour or two or three or four later?

There's no recipe book at present. People need to use their glucose monitoring, and/or CGM data to really learn about themselves.

Before we go any further, Hope, this is a dumb question, but I always got tripped up on this—

Oh there's no dumb question!

Well, you know, stick around, you'll be surprised!—But postprandial just means after meals, right?

Exactly. We could say “post meal,” just as easy, but prandial is “meal”, you're correct.

It's so much to talk about. I know I could keep you here for hours and hours, but I'm gonna kind of zip through a few topics if I could.

Sure.

One topic that comes up quite often, and there's a lot of confusion here is net carb. And net carbs come about, in my opinion, because there's a lot of advertising on packaged products. And I know this is more geared for people with type 2, but a lot of people in the type 1 community eat these products and look at these in the store and wonder about it and how to dose insulin. It'll say there's 20 carbs, but only 2 are digestible. So what does that mean? And if we're using insulin, what should we be doing to count or discount it?

So firstly, it's worth noting that FDA over the years has written some letters saying they're not going to make the decision about net carbs. And that they're not going to come after companies that use that wording in their advertising. Notice that that is not on the nutrition facts panel. And I think if, if entities did that, that might get in the FDA's craw. If there's a significant amount of quote unquote net carbs, I think you could maybe subtract maybe half of the—half of that amount from the total grams of carbohydrate in the serving. But for the most part, when we're talking about fiber, really since 2014, ADA nutrition—and they were called the recommendations at that point—The recommendation was made to not worry about subtracting fiber.

We've never done that. We've never dose that way, and I asked our endocrinologist about it early on, and he suggested, just as you say, you see what happens, but generally speaking, don't. I mean, but it does come up.

Yeah. The reality is that, and I think health care professional suggests the notion that carb counting is some easy thing to do. And the reality is that it absolutely is not. Really accurate carbohydrate counting is one tough job. And now looking—

Especially if you're cooking, and trying to make healthy food! Sorry, go ahead.

Right. I mean, you know, now we're starting to talk about well, count the protein and count the fat, and I mean, that's a lot of work. And then figuring out, you know, your bolus doses based on that. So with that concept in mind, the reality is, and even me as a dietitian, counting carbs is only so accurate.

And the average American is, at best, eating 14 grams of fiber a day. The bottom line there is we need to eat more fiber. We eat really fiber-deficient diets. And then if you go restricting some of the best sources of fiber, which are foods that contain carbohydrate: legumes, and fruits, and vegetables, and some starchy vegetables, then you're really not typically getting the fiber that you need.

I would encourage people to really focus on the big picture when it comes to nutrition. You put those principles of healthy eating into action, focus on weight management, focus on carb counting from the perspective of really knowing and looking up the foods that one eats day in, day out.

My premise for years, around carbohydrate counting, has been develop your own personal food nutrient database. When people stop and think, you realize that we really tend, as human beings, to eat a pretty narrow list of foods on a day in, day out basis. So my premise is if you have the carb count, maybe some of the protein and fat, on the foods that you eat 80% of the time, then you're going to be way far ahead than if you're just sort of winging it when it comes to carb counts. Does that makes some sense?

Oh, absolutely. So let me ask you what I think is going to be a frustrating question for you, and you feel free to throw your hands up at me. I'm going to go back to the low carb and very low carb discussion we had earlier. It's so popular right now. And people have so many questions. I personally, when I hear those, I think—and I just I'm curious if this is ballpark at all—when I think of very low carb, I think of fewer than 30 carbs a day. And when I think of low carb, I think of fewer than, you know, 70 to 90. Low carb for me, the second one, is something like fewer than 30 carbs per meal, and very low carb is 30 carbs per day. Well, I guess my question is, you know, for people with type 1 diabetes—

I know. I mean, let's just look at your son.

Ha ha ha! I'm laughing, because he's not low carb!

Yeah, hellooo! I mean, he's probably at or near the peak of his energy needs. Ever.

For context, for context, if you're a new listener, he is fourteen years old, he's about 5'10" right now—He's a big dude.

Exactly. And I'm 4'10" and like to keep my weight where it is. So, you can't talk grams. You have to talk in relative

terms to that person and to the amount of calories we need.

I mean, you're reminding me of a story that I tell often that, I was giving a talk, I think it was in Maryland. And I just said, I'm four foot ten, and there was an endocrinologist who happened—who was standing next to me when I was asked the question of, How much carbohydrate should I eat, by someone in the audience. And so here's this endo, who's like six foot five, standing next to me, and I just said to the person, do you think that Dr. (I forget his name), but and I need to eat the same amount of carbohydrate? It's just not logical. We need to think more about what we're asking.

But I guess this gets to the frustration that we as lay people have, in that it is so much easier for me to count carbs and limit to a certain amount a day, than it is to say, all right, well, how many calories do I think I need? And then, I'm going to divide that and figure out what percentage of carb I should be having during the day. And I'm not trying to make light. But you do understand that. That's why I think a lot of this gets very popular, because it seems more simple.

I think that certain ways of eating almost have their magical properties to them. Do you know what I mean? And for people with diabetes, we're also talking about glucose control. And I'm a fan of having people obviously work with a dietitian. I mean, you shouldn't have to be figuring this stuff out on your own. You should be having some sense of what's optimal for you, based on how you talk about the way that you want to eat.

If someone comes to a dietitian and says, I am vegan, or, I want to move towards eating more vegetarian, that is something that they should work out, some kind of plan. They should have a sense of, well, how much carbohydrate to shoot for at meals based on their calorie needs.

So, I'm not saying people need to figure it out for themselves. I'm concerned with the current situation with the sort of general population popularity of the keto diet and people with diabetes in general having the notion that they need to eat very low carbohydrate.

All right, well, let's get into it. I'm glad you brought that up and the keto people are gonna yell at me, no matter what we say. So that's okay. I'm good.

We're used to being yelled at.

But I have to say, the people that I know who quote "do keto," and post about it, seem to be doing so well with their type 1 diabetes, it really has seemed to help them—

And when you're saying "well," you mean, solely glucose control.

Right. I'm jealous of their graphs, I think their weight loss is amazing, they seem really fit and happy. So what's the problem? What are we not seeing?

Well, I mean, I'm a little confused about the profile of the person that you're describing. Because I think when I think of someone with type 1, I understand the glucose profile. I'm not quite clear on the weight picture. I'm concerned that we're getting too glucose-centric. And I— you know, while I think CGMs are phenomenal, it's a lot of data.

And, I have some concerns about the way all that data may be encouraging people to eat and what foods they may be eliminating as a means to almost have these straight lines in terms of glucose control. And the reality of the matter is, I mean, you know—I don't have diabetes. My post-meal glycemia, it goes up and down. Maybe it's a baby roller coaster, compared to what some people may look at as a giant roller coaster.

But what—one of the concerns I have is—I have a few concerns. One is healthiness of—and I, and I don't think I'm talking about “low carb” as I defined it, but perhaps more, very restrictive. You know, almost eating no carbohydrate. And what food choices are people making? If their calories are coming from avocado and nuts and white fish... but if they're coming from ribeye and bacon and sausage, is that necessarily a healthy thing? And are we making people unnecessarily rigid? And are we potentially removing the enjoyment of food?

I mean, to me, at its base, food should be enjoyed. Food in our lives and in our world is social, and ever more so than it's ever been. So those are some of my concerns.

Yeah, I share those concerns. And I think you've hit on an amazing point that we're just starting to really scratch the surface of, which is the constant monitoring. And I am a huge fan of CGM. I really think it's helped my son immensely.

But I do think we're at this point now, where it's almost like when you are so focused on the scale, and I do this throughout my life, I've done this back and forth. We're so concerned about the number on the scale that we're forgetting about the enjoyment of food, the social of food, you know, the eating well, and being healthy. And I feel like sometimes we, and especially as parents, we get so worried about that number on the glucose meter (or the continuous glucose meter) that we forget that our kids need to grow up with good eating habits, not just be focused on “time in range.” But can you speak to that? Can you just kind of reassure us that if my kid is not at 80 his entire life...?

I think your question is how do you balance this with raising, raising a kid with healthy eating habits within a disease that—managing a disease, type 1 diabetes, that is so food-focused, and I think it's a challenge. But what I know of psychology and eating and eating disorders, I think this very rigid, very low carb, so you're 80 all day long—and I know that's a total exaggeration—I just don't see how it can be healthy from an emotional well-being—and from a—standpoint, and from a developing—And I know that some of that data is from well-known T1D exchange.

Now, is that surprising? No, because it reflects the general population. Does that concern me? Big time.

I think I come back, Stacey, and maybe this is a good final note—to taking a bigger picture viewpoint. And you know, if you go back to like the DCCT data from the Diabetes Control and Complications Trial, I mean, I think a big message from that was really, it—Keeping those glucose levels, you know, between 70 and 150 on a day-in-day out, having A1c's of that 7%, or, you know, little higher, little lower—Taking that over time vantage point, then that seems to help delay complications.

I think that message of—Let's keep our eye on the bigger picture.

I think that's great advice. And I try to do that every day, and I try and fail, but maybe next time.

Am I saying that's easy? No, I have not walked in the shoes of a parent of a child with type one diabetes. I haven't attempted, because I haven't had to manage type 1 diabetes. I have huge respect and admiration for so many parents, for so many people that I know who manage this incredibly challenging disease. But with that said, I think, from what I see, I think— and given all the research, I think keeping the—your eyes on the bigger picture is some sage advice.

Yeah. Well, I really appreciate your time here. You know, I thought maybe we go really specific and nitty gritty into labels and research and the numbers, but this was a terrific conversation, I think, really helpful. I know it helped me. Hope, thank you so much for spending so much time with me today.

It's always a pleasure.

All About Researching T1D Prevention

with Dr. Michael Haller, MD

[EPISODE ORIGINALLY AIRED AUGUST 1, 2019]

Dr. Michael Haller is the Chief of Pediatric Endocrinology at the University of Florida. He is the principal investigator or co-investigator on numerous JDRF, NIH, and Helmsley trust funded studies.

Update: The teplizumab study referred to in this interview is on-going. As of summer 2020 it showed a third year of success. More at trialnet.org

Stacey: Dr. Haller. Thanks so much for joining me, exciting times. I'm really excited to talk to you today.

Dr. Haller: My pleasure to be here.

Before we get into the prevention studies that came out and other things that are going on, let's really kind of dial back and start at the beginning. Can you tell me a little bit about what TrialNet is and what you're trying to do?

Sure. TrialNet is an NIH funded consortium of the top type 1 diabetes centers across the US and Canada and even Europe and Australia. And our goal is to try and develop therapies to ultimately prevent and reverse diabetes. And to achieve that goal, we have to identify patients who are either newly diagnosed with type 1 so we can encourage them to participate in research studies, trying new drugs to see if we can protect the remaining beta cells extend their honeymoon phase and hopefully eventually get to reverse their disease. And then the bigger chunk of what that does is actually tries to identify folks who are at high risk for developing type 1 diabetes by screening family members of people who are already affected with type 1 to see they have markers of autoimmunity, and then either follow them to see if they progress to being higher risk, or put them in prevention trials aimed at trying to delay

their disease.

That's really the main emphasis of TrialNet that it's a huge operation. As you can imagine, trying to identify people who are at risk for type one is not easy, because people don't walk around with a name tag on that says, "Hi, my name is Mike, I'm at risk for type one." We have to draw the blood and identify markers in their blood and we have to talk people through why they would want to do that. So it's an exciting time for all those efforts. But it's certainly a big challenge.

I'm going to skip around here a little bit. So forgive me if, as you listen, this sounds out of order, but I have to jump ahead because the news came really recently that we had the first study to show that any drug can delay type 1 diabetes, the diagnosis. Can you talk to us about this?

It's called teplizumab. It's a mouthful. Teplizumab is a monoclonal antibody designed to track the parts of the immune system to knock out or kill cells that have a marker on them called CD3. And CD3 is sort of like a name tag for these kinds of cells that are going out and attacking the pancreas. Now, unfortunately, it's not so specific that it only attacks those cells that might be targeted at the pancreas. You know, there's some collateral damage that it gets rid of other cells that are part of the immune system, but that's the big challenge in in type one is trying to find drugs that can get rid of the silos that we want to get rid of and not and not the ones we want to keep.

But the results of this study are really, truly exciting and paradigm shifting for the field. As you mentioned, this is the first time in the history of type one that we've been able to show that anything can really durably delay or prevent the disease from progressing. So what that study did was take patients like I mentioned, who are high risk for developing type one, so family members of somebody who has type one who had markers in their bloodstream that told us they were going to progress to clinical disease where they need to take insulin in the next several years. And they were treated with this, this drugs immunomodulatory drug teplizumab. And what the data have now shown, the paper was recently published in the New England Journal of Medicine, was that in fact, the drug did delay onset of type one, which means there was actual prevention and some of the patients on average for at least two years, and so while it's certainly not a home run, we can't guarantee that we're preventing the disease forever and the patients who received the active drug versus who received the placebo agent. It's a huge win for the field of type one, it establishes the proof of concept that we really can effectively change the natural history of the disease. And I hope that it accelerates our efforts to do more and more studies with other drugs like teplizumab and adding additional agents to try to get an even better effect for our patients so that we can ultimately say, hey, it makes sense to screen everybody for their risk for type one, sort of a public health initiative and treat them with these drugs to prevent them from getting the disease.

Something I've always wondered. And I don't know if you can answer this. Why is it so difficult to prevent or treat autoimmune conditions? It's not just type one, right? I mean, nobody's cured or really prevented an autoimmune disease, have they?

Yeah, it is a challenging beast. You know, the immune system is really smart, even when it's confused about what supposed to do. And so once the immune system has decided it wants to attack cells tissues, which is what we mean by auto immune disease, and then type one, we just are specifically looking at the immune system attacking beta cells. It figures out all kinds of different pathways to get to that end, and cleverly changes the way it does it. And so it's probably not surprising that it's been so challenging, just given the way autoimmune diseases in general come about and specifically help type one happens.

And in the type one space, we're further challenged by the fact, and so it's a good challenge in the sense that we've gotten better, better caring for diabetes. So you know, people reasonably would say, I don't want to take a therapy that's a risky agent or drug to prevent or reverse the disease because I can potentially take care of diabetes with insulin and pumps and continuous glucose monitors.

Now, I don't live with diabetes personally, but you know, I have a personal connection to it. My grandfather had type one and I take care of patients every day. And while I understand that argument, but the majority of my patients I talked to say and I had currently understand that living with type one is incredibly challenging and hard and, and more patients than not are actually willing to accept a little bit of risk for the potential benefit of delaying that disease. And certainly a two year delay for most families who've now lived through this is would be tremendous. And most folks who have gone through that would say, "Man, if I could have just gotten my kid from six to eight, or eight to 10, or 10, to 12, or any amount of time, Some even say a day would be worth it." That'd be totally fine.

Personally, my son was diagnosed right before he turned two. And I got to tell you from almost two to almost four, I would take that in a heartbeat because he could not even say diabetes when he was diagnosed. Yeah, I mean, the communication was not there. I mean, it's unbelievable at that tiny little age to get them to tell you what's going on. But let me ask you about the people in the study. Do you mind sharing a little bit about but how does it work? My hat is off to anybody who takes part in any kind of clinical trial, whether it's technology or drugs or medications, these, these are pioneers and people who are sacrificing even if they may say otherwise. You know, they're taking time, they're taking risks. So my hat is way off. But can you tell us a little bit about what kind of goes on during something like this?

Sure. And thank you for bringing it up yet to patients who participate in these studies are absolutely the diabetes heroes. Sadly, not enough patients are able to participate in studies just because of the time commitments and logistics and maybe being risk averse like you mentioned. So if you know somebody who participated in a study, please give them a hug and a high five and a hearty thank you. Because without those folks, we can't find these things that might work and move the field forward.

Let's start with the study. Say I'm a mom, I've got a six year old or whatever the age of the person is here. I don't know how much detail you can share or what might be interesting, but I've never participated in something like this. So I show up at TrialNet. Then what do I do?

The trial starts with a screening study. We just draw some blood from somebody who's got a first degree relative or a secondary relative with Type 1 diabetes. And if the markers in their blood show they have the antibodies that we associate with risk for type one, then we asked them to come back for additional testing. And the frequency of that testing is dependent on what we learn about their risk from the next set of tests. And so for patients who are particularly high risk, which is the kind of patient who was enrolled in the lab study, if they were old enough to be in the study, and they had the right risk markers, which included completing an oral glucose tolerance test that was already abnormal, but not quite at the diabetes diagnostic level. So these were patients who are really unfortunately, high risk really on the verge of getting diabetes within the next few years. They were offered the opportunity to participate in this trial.

And when you when you mentioned that it's a big commitment, teplizumab is not an easy drug to receive. It required a 14 day infusion of the drug as an IV. So every single day for two weeks, patients had to come in and get poked and get an infusion which was technically a half hour infusion. But by the time you come and get your IV placed and get the drug and follow up, we're talking about several hours every day for two weeks. So huge commitment. But nevertheless, if I told you that those two weeks was going to buy you a two year window or potentially longer of diabetes free time, I don't know many patients or families that wouldn't say sign me up. I think it is a paradigm shifting thing. We just, we hadn't had something that did this before. And now that we do, I hope that it will encourage more and more families to participate in the research process to sign up for screening to hopefully find other therapies like teplizumab to find out how we can improve on teplizumab's findings and so that we can ultimately tell patients one day that you know, we're screening your kid, not just for research, but because we know we can do something about it.

What's next for teplizumab. Is this study kind of done? Do you now start something new to see if you can prevent it longer? What happens next?

Yeah, a little bit of both. We obviously met the study's primary endpoint and published those data. But now there are lots of questions to ask and answer, which is how long does it benefit last and those who got treated? And what happens if we retreat? Some of those patients who got drug appear to be responders and still haven't developed type one? Can we extend the benefit even longer if we give them another course of the drug? And so TrialNet is actively looking at those options right now. I think one of the challenges for teplizumab and specifically is it's a, not an FDA approved drug for anything at this point. It's still been even though had a long history of being developed for this purpose and being tested in the type one space multiple times in new onsets and now in this prevention space, it's never been licensed. So despite the excitement about it, you can't just go out and get this today from your endocrinologist or anybody else. The only way to get it would be through a study so the company that owns it is trying to do new and additional studies both in newly diagnosed patients. In fact, they just opened up a study. That's not part of trial that but it's by the company, and then TrialNet is going to be doing some version of the either a retreatment study for treatment with teplizumab plus other agents is likely to come down the road because we all still believe given to early question about the complexity of autoimmunity, that we're going to have to do more than just a single drug to kind of get us over the end zone, we're probably going to require combination therapies or what we call induction and

maintenance therapy. So first treating with teplizumab and then some other drug to keep the effect going.

Another recently completed study, my understanding is, ATG-GCSF, can you talk us through a little bit of what that one is?

Sure. So the study of thymoglobulin (ATG) and GCSF which stands for granulocyte colony stimulating factor – I apologize for all the letters and names - has been a labor of love and a passion of mine personally for the last decade or so. The work that came out of that really is a beautiful example of the importance of translational science that came out of my institution of the University of Florida.

The story is really interesting. There was a transplant immunologist, who was using fairly aggressive what's called non- myeloablative transplant approaches for people with really severe bad autoimmune diseases like end stage rheumatoid arthritis and multiple sclerosis. And he was having really impressive outcomes. But his approach was really quite aggressive. It would be akin to almost doing chemo therapeutic treatment for these patients. And so he started to talk about the potential of using that approach in type 1 diabetes. And honestly, the US type one community just wasn't willing to think about that because the risk level was was so much higher and we hadn't really had any successes yet. So we ultimately took that approach to a group in Brazil and and did new Patients with this approach to their and today is still probably the most potent way to provide a short term reversal of Type 1 diabetes that we've seen in newly diagnosed patients. And so our group was really interested in that.

But before we really have to dissect this, take it apart, deconstruct it and try to put it back together in a way that would make sense for treating kids and a US audience because of the risk there was just too high. And so we went from the bedside, essentially back to the bench and we started doing animal studies in the mouse model type one, and found that two of the drugs that they use in this sort of very complicated approach really gave us the most bang for a buck and those two drugs were ATG and GCSF. And so once we had demonstrated that repeatedly in the animals, we decided we would do a pilot study in humans.

And the first thing we did was actually study this and folks who had what we call established type 1 diabetes, people who had diabetes for at least four months, but as long as two years because that population often largely has been ignored in the timeline. intervention space, even though we now know that many of those patients have lots of beta cell function still around. And what we were able to show was that the combination provided for almost a 40% preservation of their ability to make beta cells and start to make insulin alpha two years after a two day treatment of a anti thymocyte globulin and a 12 week course of the GCs F. So that was really exciting. But we wanted to then continue to move it sort of earlier in the disease process to new onset and ultimately, into the prevention space. So at that point, we convinced the TrialNet and the NIH to fund a large confirmatory study, similar to this episode we just talked about, but a new onsets to see if the low dose of ATG with or without the GCSF, could provide protection for beta cell function and improve A1C. And we've now published one year and more recently, two year data. And in fact, we we didn't show that so the most interesting finding was perhaps that the the low dose of ATG by itself was able to provide for the most robust preservation of beta cell function and reduction of hemoglobin agency and newly diagnosed patients.

Why I'm really excited about this approach is it sort of related to what we just talked about before with

teplizumab in that entire time aside, globulin is been around for 25 years. It's a commonly used medicine in hospitals every day. It's primarily used for pre treatment of folks getting kidney transplants, but in that indication, they use it at a 10 times higher dose. So we're using it as a very minimal dose of this drug. And we still need to do more studies to confirm our observations, but the pathway to taking it into the clinical care of patients is perhaps a little bit more direct, because it's been around and already has a label.

Now, of course, we'd have to do additional studies to get a label for the type one space. And you know, that's being considered right now, but, but I'm excited about the opportunity to continue to study ATG, I think it's very similar to pull them out in many ways. It has some advantages and that only requires a two day infusion. Instead of a 14 day one. And so the next step is for trial maps to start a prevention study and that study is being planned as we speak. That would be very similar to the teplizumab study that we talked about taking high risk patients, giving them a low dose of HCG. And following them to see, in fact, that can prevent them from progressing to clinical diabetes where they need insulin.

So exciting. And you mentioned people with type one who are not newly diagnosed. Let's just talk about that for a moment. Because I agree, I think there's a feeling that well, these prevention studies are fabulous. And you know, one day, we'll make sure that, you know, no one develops type one, but what about the people who do have it? Were you surprised? Or I guess I should ask you put that in perspective for us that discovery that they're still producing beta cells that something can still be done here.

Yeah, a lot of people don't realize that. But I think one of the best ways to think about it was analogy that previous director of the JDRF made, which was, if you think about an hour of the clock as being the amount of time somebody lives with Type 1 diabetes, the new onset phase, which is the first hundred days, where we've normally done these studies, is like less than a minute. And so we ignore the whole rest of the population who live with type one, many of whom fund our research through, you know, being donors or advocates, we sort of leave them out of the opportunity to participate. So one that's wrong morally and two it's wrong, because we now have better science that demonstrates that people with type one, especially those who were diagnosed a little older, unfortunately, not kids, like your son who were diagnosed so young. But people who are diagnosed as teens or even young adults, often have functional beta cell mass for years, even five to 10 years is not uncommon, and it's quite variable, but we can measure that and know and those patients are potentially huge population who might benefit from some of these immunotherapies that we're talking about. So I think you're starting to see the pharmaceutical companies And the scientists who work with these drugs, designed trials to sort of re-infranchise that population that's long been left out. So we felt that that was very exciting and important finding from our study, our first study of ATG and GCSF. And now we are seeing other studies like it coming along.

Alright, so let's just go backwards for a moment and talk about people diagnosed very young, like my son who was diagnosed at 23 months. I hate to hear something like that. But I have to ask, Can you elaborate on what you meant by that? Nature has no real cut offs, but you know, what, what ages are you talking about there?

Yeah, so unfortunately, kids who are diagnosed under four to five years of age tend to have a more rapid and severe disease in that their beta cell mass is, is less when they're diagnosed, and they just may retain less over a shorter period of time. And it's a little bit obvious that you know, somebody who made it to 30 or 40 or 50 years of age before they developed type one, obviously had a slower progression of disease. So in some sense, it's not too surprising that their progression after the day they need insulin is going to be slower than in somebody who unfortunately, developed type one at 23 months. But as you can imagine, it's incredibly variable.

It's one of the challenges of type one, there's so many flavors of type ones. And every individual patient is different, you know, I haven't done this now for 20 years, I still every time I walk into a patient's room, you know, their diabetes is different than the patient I saw before and will be different the patient I see next. And that's probably true for some of the biology of what's going on with the immune attack. And so it's probably not a one size fits all, won't be a one size fits all approach. And we have to get better at personalized medicine. So know what wait what may work as a therapy to prevent diabetes in a 10 or 15 year old, or even a 30 or 40 year old is going to be different ultimately, then what will likely work for somebody who's you know, a year or two old and really high risk.

It's really interesting. I mean, I as a mom, you know, I just pointed I don't want to hear things like that. But for the purpose of the interview here the information, it's really interesting and it kind of explains Benny my son had basically no honeymoon once he was diagnosed and we were very fortunate he wasn't in DKA. It was not an emergency situation that day, but boom that was it. We never looking back we never had a honeymoon period.

Yeah, that's a pretty common experience. Unfortunately for kids diagnosed that young. They just, you know, they just trashed their beta cell mass so quickly that they don't get a honeymoon. Yeah.

That's a great way to put it. My son will be thrilled to know that he totally leveled it.

He killed it. He knocked it out of the park, not the game you want to win unfortunately, but you mentioned something else. So that's really a key factor which is that he fortunately didn't develop DKA but still even in the US 30 to 40% of new onsets come in in DKA. And sadly, that number continues to go up, not down. It's another really critical reason to do screening programs. You know, while we can't yet justify general global screening for the purposes of preventing DKA, people who have a family history of type one certainly should get screened in TrialNet and be followed because we know, very good data that folks who are followed in these studies have a marked reduction in the likelihood of DKA for a subsequent family member who unfortunately, might be developing type one. And so while you know, economically, it doesn't make sense, you know, obviously, no parent who's gone through this would say that they wouldn't do something to prevent DKA and another child who might have to deal with it. And we're talking about a reduction from, you know, 30 to 40%, which we're seeing in the general community down to the 5% or less. So that's a huge secondary benefit of participating in these trials.

You know, one thing that has come up recently, though, unfortunately, and as you say, you want to do more screening, but TrialNet seems to have had the funding cut back. Can you talk a little bit about the changes that have come? Because I did get when I told people we were going to be talking about prevention, and I was speaking to TrialNet I heard from a few people who said ask them how long the changes are going to go on.

I appreciate you asking that question. And for all your listeners, we appreciate your ongoing advocacy. Keep, keep speaking up being loud about the value you find in these programs and talk to, you know, your congressmen and senators. Ultimately, that's where the money comes from town that is funded by the National Institutes of Health. And we get a bit of a special allocation of my own money called this special diabetes project. SDP monies, unfortunately, looks like it's going to move forward with some some newer funding. But yes, we did recently face some budgetary cuts because of decisions that had to be made at the at the NIH level. And because of that, we had to strategically talk about how much screening we could do to still identify the highest risk patients that we need to put in these prevention trials. And part of that calculus resulted in us having to cut back on the frequency with which we had previously been doing repeat screenings, but I completely agree with all the you know, upset families out there part of that huge value of being part of our family was Being able to come back in for rescreening every year. And either knowing that your kid wasn't that increased risk this year, or finding out that unfortunately, they were but knowing that, therefore, that that meant you would get a closer follow up and intentionally be in a prevention trial. So I remain hopeful that that decision will be overturned, to be short lived. But at the end of the day, it's a purely economic one. And so, if any of your listeners have influence or everybody can, you know, don't be shy about giving that feedback to your TrialNet center if you're already in TrialNet or talking to your legislators about why you think this is important.

We have international listeners as because TrialNet is not just in the US are these are these funding issues in like the UK as well?

Thanks for bringing that up too. So TrialNet it is mostly funded by the NIH but we also get some funding in kind from the JDRF and the direct funding has largely been used in the past. To help us maintain the international centers. And so, you know, they as a group, given that we use the funding all the same, are affected in the same way as it relates to this current screening change, because we can't have a different program in different countries. But again, hopefully as funds will come back to the network, we will be having the ability to increase our screening programs. And I should say, some of the screening things need to be changed anyway, because the network is evolving, and we're learning more and we have better more precise ways of doing things. But you know, some of some of the changes that were made were, were certainly a little bit more draconian than we had hoped.

Let's talk if we could about some other prevention theories. As you can imagine, with the podcast, I get a lot of interesting guest pitches and emails. And when I'm very careful, you know, I have a no snake oil policy, and we try to do a lot of research before we let things through. But one of the things that comes up time and time

again, our stories about people who are diagnosed with Type 1 diabetes, but prevent the onset or extend the honeymoon by diet. Is that possible?

The short answer is, it doesn't appear that that's possible. We don't have any evidence that supports that assertion. The longer answer is certainly if you, you know, restrict carbohydrates, which obviously was the way we treated diabetes before we had insulin, you essentially went on a starvation diet, and that will no doubt reduce the severity of the hyperglycemia. But it doesn't ultimately change the beta self destructive process. And unfortunately, before insulin was discovered, you know, this was a uniformly fatal diagnosis. So there are a lot of people who are very interested in excited by using diet as part of the therapy for type one and I absolutely agree that is an important part of what we do eat everything has a huge effect on glycemic load. But diet and of itself is unlikely to be able to change the immunology and the natural history of the beta cell loss. And there really isn't any data to support that of yet.

Anything else with prevention. I mean, Verapamil is not a prevention drug, right? It's not with those trials, or is it?

It hasn't gone into prevention trials yet. But sure, there's tons of things on the list that we'd like to continue to try out. And honestly, the main limitation, to do all those things is an adequate number of people identified and willing to participate in the studies in a trial that screens 20 to 25,000 people a year, but when even if you're screening, first degree relatives, only one in 20 are going to have antibodies. And so you know, as opposed to one in 300 in the general population who are at risk for type one, so it takes a lot of work to identify a high risk patient and then, you know, they may not want to participate in the study again, The particular agent's risk profile or the logistics or any number of reasons. So again, we really need people to participate in screening because we have lots of drugs that we'd like to try.

Verapamil is a very interesting drug that is an old blood pressure medication. And a recent publication demonstrated it may have the capacity to preserve beta cell function as well in new onsets .It's a relatively small trial in adults that needs to be repeated in children and adults. And then if those results are confirmed, it would absolutely make a lot of sense to us in prevention or combined with another agent. So again, we talked about, you know, maybe teplizumab plus other drugs or ATG plus other drugs, Verapamil would certainly be on the list, but I should mention that TrialNet is already planning additional prevention studies as well. So we have we have an open trial that's a mechanistic based study. So it's really not designed to answer the question of whether or not a drug this particular drug can prevent disease, but it's designed to give us some scientific answers to questions that if they look good would would lead to a larger trial.

And that's using actually an old, more anti malarial drug called hydroxychloroquine. And then there's another drug that's being evaluated for a trial as well. That's a really interesting story. It's called methyldopa. Methyldopa is a really old blood pressure medication, and through some really beautiful science. And that drug was found to bind to a particular area that really is critical in the way our immune system sees insulin and might develop an immune response to it. So this is sort of a backwards way of discovering an old drug in a new way, by screening entire libraries of agents to try to find things that fit into particular areas of a part of the immune system.

And so that's that is also being planned. So we have a lot of things in the pipeline. There's a whole number of other autoimmune drugs that are used for treating things like you know, arthritis and psoriasis, and the list goes on and on that we'd love to repurpose to see if they might work well in type one. But to do those things we need patients, families willing to pay it. And of course, we need funding.

You mentioned that your grandfather had type 1 diabetes. What do you remember about that? Would you mind sharing his story a bit?

Sure. Yeah, so I'm not terribly old. I guess it's all relative. I'm in my 40s. But I remember even as a young kid, when we essentially had to influence and that's what grandpa took. And I remember very vividly when the first blood glucose meters came out. And I have sort of some memories of when he was still using clean test tabs for any of your old timers out there. When we were before we had the glucose testing. You sort of did a chemistry experiment in the bathroom with your urine to see what your blood glucose might have been four hours ago, to think of that where we were and again, thinking I'm not all that old of the guy to where we are now. It's just miraculous how much type one care has improved. I mean, you know, to think that continuous glucose monitor Essentially standard of care now that we have multiple insulin analogs, and you know that we have insulin pumps that are now talking to those CGM and the potential for sending closed loop systems is almost realized, is just amazing and miraculous. And my grandfather lived into his 80s. Even with old school influence, and all those things, because he lived a incredibly regimented life, he was really good at exercising every day and eat his very similar meals. And he was essentially a good patient, and did the best you could do with what the technology was. And so I use his experiences with living with type one to hopefully motivate my patients, remind them, essentially, that diabetes is always going to be a terrible disease until we can prevent and reverse it, but but if you had to choose a time to living with it, you know, now it's not so bad compared to what it used to be like. And now the pace of improvement is just accelerating so nicely that even a year goes by and we we discover and improve things better than the last 10 years. So I think the future looks very bright.

I'm always astonished to hear if people who lived well, at a time before you mentioned all these great technological advances, but who lived before home glucose meters, the idea of not being able to check your blood sugar even two times a day? Or, you know, did you have to, as you said, the tabs and you know, the urine kits, and it's amazing to me, that must have been such a sea change for people like your grandfather, with his diagnosis, does that mean that you can participate in trial that can be considered enough.

So I would be a second degree relative as a grandchild. And now I'm unfortunately above the age limit, you have to be 21 and a second degree relative to be screened. But I've been involved in the TrialNet and before that was the diabetes prevention trial that I did get screened back when I was very first starting out in this because I've been fortunate enough to work with Dr. Desmond Schatz, who's a world renowned pediatric endocrinologist was a previous president of the American Diabetes Association, but I've worked with him since I was a teenager Actually,

that's my first experience and really working in type one was working in his lab back on the first trial designed to see if we could prevent type one using oral insulin. And that was called the diabetes prevention trial type one. So back then I did get screened. Unfortunately, I didn't have antibodies and I was old enough at that point, even though I was still a kid to not really need to be re screened.

That's fascinating. So in high school, you knew this was going to be your life was that because of your grandfather? What made you want to go into endocrinology?

Yeah, I I totally knew I was pre med. And I had that experience of seeing my grandfather. But honestly, it was it was more of a mentoring opportunity than anything else. That's just such a wonderful person to work with. really got me passionate interested about the field. And then I went off, I left. I grew up here in Gainesville, Florida, where the interest in Florida is, but I actually went to Duke University for undergraduate school. But when I graduated, and it was time to make my decision for medical school, Dr. Schatz was again, extremely influential, and he really is what convinced me to come back to Gainesville, do medical school here and then residency in pediatrics, and then along The way I started participating in diabetes camps. And that was really what did it the combination of being able to work in a field where I could do some really interesting science, take care of patients long term. And frankly, going to diabetes camp, which was just such an amazing experience, made it very clear to me that I should be a pediatric endocrinologist.

Do you still see patients?

Oh, yeah, no, I do. I'm a little bit of a strange breed in that. I always have seen myself as a clinician who happens to do research. And so while I don't get to do clinic every day, cuz I have so much research and administrative responsibility now, I would never give that up. And, you know, most of the research I do is really patient oriented research. And in fact, I get the pleasure of being able to spend more time with my research patients just because it's not under the same guys as a clinic where you have to see a patient every 40 minutes or hour. So everything I do is really patient base, but I work with an incredible team of scientists, and so I get to work with Mark Atkinson and Todd brosko and Clive waterfall and clay Matthews and an up and coming scientists who, who do a lot of the work in the lab, and then bring us these great ideas to try to test and patients so that we have a really unique team here at the University of Florida that allows us to do those things.

Is it difficult to see patients who are kids, I mean, my son has a great relationship, his endocrinologist, we've been able to see the same one. Luckily, from ages two to now he's 14. And I wonder, Is it difficult to know that you're researching, you're, you know, you're trying to do prevention and, you know, which hopefully even someday cure, but you're, the research is slow. I mean, and and we understand why it's not a criticism, but the research is slow, and the patients are growing up, is it difficult and any kind of emotional level to look at your

patients and feel like, gosh, I really want to help these people more. Uh, but you know, the research just isn't as fast as we would like it to be.

It's so incredibly frustrating. It frankly it pisses me off, but part of why I get up every morning. come to work and I'm excited to move things forward. I mean, the pace of research is glacially slow. And I'm not a patient guy. So I've lost my cool more than one time trying to promote what I think is important research so that we can get these things to our patients faster. And that's why I mentioned I think, like a clinical guy just happened to the research, because at the end of the day, that's what pulled me into research, I realized that was what we had to do to get the patients better care. So yeah, I find the process, you know, it's necessary. It's what we have to do, we have to do good science, and that takes time. But sometimes the administrative burdens or the funding lags those things can just be so mind numbingly frustrating that, you know, really good people, unfortunately, sometimes leave the field. And so we I would encourage people not to do that, of course, we need people to stay passionate about type one and do the hard work of the research and the clinical care. But yeah, I have to go to clinic and look people in the eye and say, Sorry, I don't have anything that's good enough for you yet. And I emphasize it yet. But that's a hard conversation to have with people day in day out.

I'm glad I asked. I wasn't sure that that question was going to go anywhere. Yes, sometimes people look at me like, I'm crazy when I asked things like that.

No, it's not crazy at all. And it's just part of why I'm excited about the anti thymocyte globulin, and ultimately, CD3 and all these other things. Because, you know, we're getting so much closer to the point where I can really say to somebody who's been newly diagnosed, I have something I can actually do for you. And this may no longer be just a research question. And they'll always be research questions, because we can improve on things, but I may have a real therapy besides but we've been doing now for close to 100 years, which is just just give you insulin. Obviously we're better at doing that too. But it sure would be nice to do something besides that.

Sure, would you you did mention the oral insulin study. My ears perked up on that. Is that complete? What happened with that?

Yeah. That's a good example of this challenge we have between risk and benefit. So for a long time, we've wanted therapies in the type one space that would be entirely without risk in oral insulin. It was one of those a pill that you take by mouth, obviously orally, but doesn't affect your blood glucose. And it's essentially an immune tolerating therapy, at least that's the idea to convince the immune system to recognize insulin that gets sort of chewed up in your stomach as a as as being you and therefore not not attack it. And the reason the rationale for this studies were that when you give oral insulin to a particular type of mouse that gets diabetes, it's very effective at preventing them from getting diabetes. And so everybody was really excited about it. And so one of the first large scale multicenter trials designed around the attempt to prevent type one was the diabetes prevention trial I

mentioned and that was the precursor to what became TrialNet. And that trial, unfortunately, didn't demonstrate a benefit, although there were some signals that were, you know, suggested that there might have been benefit in certain subpopulations. And so TrialNet subsequently did a, again, a large trial of oral insulin in that particular population that looked like it might benefit and sadly that to fails. Demonstrate benefit. And so, you know, I think what that demonstrates is type one's really hard to fix. And to that animal models don't always tell us the whole story. In fact, they often tell us the wrong story, but we're stuck using what we got to get some idea of proof of concept. And then lastly, that we are going to likely need to use things that have more potency, that are a little bit more, you know, side effect profile associated to be able to really change the needle on where diabetes is going. That's not to say that oral insulin may not still have some potential for benefit. In fact, we've never tested it when we've given it after something like thymoglobulin or teplizumab or in combination with other immunomodulatory modulatory therapy. So there may still be life for oral insulin or other antigens specific therapies. And there are many others that are that are sort of in line for testing as well. But that story is, you know, almost 15 years or more of effort, and just again, exemplified how long it takes to find out the real answer. We all want answers quickly. But if we don't do the science the right way, we continue to promote bad ideas and in hearsay, and that's just not how we're gonna get get real therapy that benefits patients.

You know, Mike, we've talked a lot about, you know, exciting studies and some setbacks and how long things take and the frustration, are you still jumping out of bed excited to do this research?

Now more than ever, I mean, it's a really exciting time to be here, because we now have stuff that looks like it actually works. I mean, the feeling in the room in the last decade when we kept going to meetings and reporting negative events, was certainly weighing on everybody heavily. And so to be able to come to the American Diabetes Association and report these data nationally, internationally in the last couple years with the outcomes like thymoglobulin and and CD3, really has been a huge boost everybody's morale and I think puts us in a really great space because we can continue to argue that people should be getting screen we should be doing these studies. Because we are effectively changing the Natural History of the disease. So I'm really excited about where we're going. And I just hope we can get there faster.

Wow. Well, Mike, thank you so much for joining me. We'll put all the information about TrialNet in the show notes so that people can learn more and find out how to get screened on but I really appreciate that. Thank you so much for joining me today.

That's been my absolute pleasure.

All About Women and Type 1 Diabetes

with Elizabeth Forrest, Nicole Johnson, DrPH, MPH, MA, and Risa Katz:

[EPISODE ORIGINALLY AIRED AUGUST 29, 2019; TAPED AS A PANEL DISCUSSION AT THE TOUCHED BY TYPE ONE CONFERENCE IN MAY 2019]

Elizabeth Forrest, diagnosed at age 10, she is the founder of Dancing for Diabetes and Touched by Type One which creates programming and support for the type 1 diabetes community.

Nicole Johnson, DrPH, MPH, MA, Miss America 1999 diagnosed with type 1 as a college student. She is an author, speaker, and the National Director of Express Feedback for Good at HundredX.

Risa Katz was diagnosed with type 1 three months before her wedding, and her daughter also lives with type 1. At law school, she focused on discrimination in the workplace and in schools under federal laws, including the Americans with Disabilities Act. She is on the Board of Touched by Type One.

Stacey: Thank you all so much for being here! This is a wonderful panel with a lot of experience. My first question is will go down the line you may know and be familiar with the movie *Steel Magnolias*. *Steel Magnolias* is sometimes people's first point of contact with Type One Diabetes. They rereleased the movie after 30 years. It has a 30 year anniversary release this weekend. So I thought we just start real quickly by going down the line. Risa, we'll start with you *Steel Magnolias* love it or hate it yay or nay.

Risa Katz: Actually, I've never seen it. (laughter)

I hadn't seen it before I was diagnosed. And then once I was diagnosed with type one, my mother, who had already seen it told me don't ever watch this movie. And since then I've kind of learned a little of what it's about. And I have to say, I really don't want to watch it because I want to keep a very positive outlook. And I've been

through three pregnancies successfully. And I want to look at it that way rather than focus on the negative aspects.

Elizabeth Forrest: Well, as I'm 30 I was that around when the movie was released, and I actually only heard about it a few years ago at one of these diabetes events, and I've heard of the movie, but I never knew there was a connection with type one diabetes. And I heard someone speaking about the movie. And of course, in the connection to type one diabetes, and I just haven't gotten around to seeing it. So I don't know. Yes, I'm in the middle.

Nicole Johnson: I'm the only one that's seen it. I've probably seen it like 10 times. You never know. I mean, it's on on the weekends, on cable, right? You know what, I'm going to be a very different opinion than you would expect. I'm going to say love it. And here's why. We don't have enough movies or scripts or plays coming out of Hollywood that have a type one element. And they get it wrong a lot, but they get parts of it right. And it gets us talking and that has incredible value. I met the young man that was the son of the woman that the movie was inspired by many years ago. He's not young anymore. I met him many years ago and he was incredibly proud that his mother's story was portrayed in the way that it was. I found that very inspiring.

Stacey: That's great. And I love it too, because I saw it. I'm a little older than you. I saw it a long time ago before I had children. And I loved it. I think it's a great movie, but it you know, it is a true story, but it is of its time. So, to your point, I wish we had more current movies that dealt with type one in some kind of realistic way. But thank you, ladies.

Okay, I have a list of questions for Diabetes Connections, my podcast, I have a Facebook group. And I told them, we were going to be having this panel and they inundated me with questions about women's health and type one diabetes. And I know that you're prepared for some frank talk, right? That's why we're here. So I think we're going to just go ahead and rip the band aid off and go ahead and start talking about periods and that kind of thing, because that was the thing that really came up a lot.

I think it's well known, maybe it's not, that your cycle can affect your blood sugars. The question came up: how do you figure that out? Do you chart it? Do you? Do you track it? How can you best manage knowing that you're going to have blood sugar swings all through your cycle?

Risa Katz: That's a great question. And I can speak to it in two different perspectives: for myself and then for my daughter who's just going through puberty right now. With myself, it was an expectation of every month, two weeks of regular blood sugars and two weeks of just absolutely crazy blood sugars. And I would try to chart it every month to predict and I would actually have a higher basal rate on my insulin pump, turn that on about two or three days before I was expecting to get it to just stay ahead of it. And that would work some months and some months it wouldn't work, but for the most part, it really helped me to stay as in control as possible.

Now with my daughter, she's 12 years old, she's had her period for a little over a year now. We haven't reached that point yet. Her blood sugars are just incredibly all over the place. And I have been a little frustrated and having to talk to her about the importance of charting it, because we really need to figure out what that pattern is

so I know when to increase your basal rates. And we're in just the learning curve now. Because you know, it's an embarrassing thing for a 12 year old, she doesn't want to talk about her period, which is something even I don't want to think about it. But we're working on it and I think at some point, we'll get there, and it's always going to be a struggle. You know, there's no quick, easy answer to it. But as long as you continue working at it, I think you can be successful in navigating it.

Elizabeth Forrest: So does anyone still use a log book to keep track of blood sugars? I don't. But when I was a teenager, my mom was still very big on us using the log book to track everything. For me. I never noticed the difference when I was on my period if my blood sugars would be a little bit higher during that time. I have always been having less of an appetite during that period, though. And so then I would eat less take less insulin. So I noticed that pattern, but I've never found that it rises, like I hear a lot of others go through. But at the same time, we were tracking it so precisely with a log book and still being a young girl doing that. But to this day, I don't I don't see that often. Every now and then you see it, but you know, that's diabetes. I haven't seen anything other than that.

Nicole Johnson: Okay, so moms who has a daughter in the room with type one? A couple and then who are type one adult women? Okay. birth control pills are probably a part of your reality. And if not yet, they will be soon I would hope because preconception management is very important. So with period, we have the discussion of making sure that we're not getting pregnant. So the birth control pill packs, that I have used for 30 years, when I get to the color pills that denotes my week of my period. I know my blood sugars are going to drop. And that's how I know. So that's played a really big role in my 26 years with type one is that I know when I get to that week of brown colored pills to expect to have low blood sugars on the first two days of my period, and that's about all the tracking I ever did on this because it made it easy and we've got to normalize as much as possible.

I would give you a word of guidance for your young women, or for those of you who have type one, to not overburden yourself with things that you don't have to if you can figure out a way to combine tasks. do that because it lessens the emotional burden and trauma that you experience.

Stacey: And let me just ask you a follow up if I could, Nicole because that is a conversation I think a lot of women with type one are having. I'm not even sure how to ask this question, so I'll just kind of blurt it out. With birth control, is that something that your endocrinologist needs to be involved in in terms of what kind of what brand or anything like that? Or do you just ask your OB/GYN or whatever our insurance covers. Is that an endo level question?

Nicole Johnson: I've never gone through my endo for birth control pills.

But here's a caveat that I'll add to it. So the OB GYN is the one that really figures that out, and there are varying levels of estrogen and hormones. And, and so you have to figure that out with your OB, I had to figure out that I was allergic to generic forms of birth control pills, and that would break me out into hives and make my blood sugars go to 500. And so that was a no go for us. But that was the discussion between me in the OB the

one word of caution with the OB GYN. They are used to diabetes during pregnancy. And so their mindset is that A1C should be 5%. And they're not really attuned to the normal mindset of what your A1C is when you're not in a pregnancy state. So guard your heart or the woman that you loves heart a little bit about that, because I've had a couple of instances where I had to do a fair amount of educating with the OB to say, you know, my endocrinologist is going to manage my diabetes, not you. And here we're going to deal with reproductive health and draw the barriers.

Stacey: Risa, let me ask it a little bit about that with your daughter. I know you're probably not at that particular level, but that's a hard separation all around to be able to, I mean, we're educating as parents of kids with type one when you go to the dentist or the doctor half the time I can't imagine. Do you have that experience for yourself when you were getting pregnant with your OB?

Risa Katz: Yes, I did. It's interesting that you bring that up, because when I've gone through three pregnancies and the pregnancy especially with my daughter, I was 37 years old, and I was dealing with a new high risk doctor. And every time I would come in because I had multiple ultrasounds because of the high risk, he would talk to me about how my A1C level is too high. And I think I was at like 6.3, something like that for a pregnancy with twins, which my endocrinologist was thrilled about, but every time I would come in, I almost dreaded the appointments. I'm like, Yes, I wanted to see the ultrasound of the baby. But I want another lecture and I would try to explain to him, my endocrinologist is handling this. I've been going to her for the past 20 years. She has been with me through my other pregnancies. We got it handled, but it never really got through to him. So it was just a decision. You know, on my part to just I knew I was being taken care of just get through the appointment. Listen to him, enjoy the ultrasounds know that she was healthy and developing. Just move on from there. But I agree you do have to have that discussion. And you will encounter that from the doctors. And I think it's a lot also because they deal with a lot of type twos. And with type two diabetes, it's just a completely different ballgame. And you can get your A1C down a lot lower a lot easier. But when you're type one is we all know it's a huge struggle, and especially with all the hormones and everything, so I would say, Don't stress it about, you know, your OB your specialist, follow your endocrinologist advice, because they're the ones that know you. They're the ones that really understand it.

Nicole Johnson: Just because of this topic. We should jump to A1C recommendations during pregnancy, because I don't want anybody to have a misperception because you've just heard some numbers thrown out there. So the American Medical Association and the American College of Obstetrics and Gynecology and all of the diabetes medical associations the recommendation is that your A1C is below seven. Alright, so that's when you get pregnant. While you're pregnant, baby helps you a little bit. It doesn't mean baby's taking your insulin or taking things from mom. But because you're growing a human, you're doing some extra work. And so your A1C drops a lot. And it's not as horribly hard as it sounds like it is. And so throughout my pregnancy, I was at about a 6% A1C, baby helped me a lot. Now I worked! I really did a lot of hard work too, but I wanted to make sure that we laid that out there.

If you're health care professionals, you should engage with the women that you love, should engage with

them prior to becoming pregnant. This needs to be an ongoing conversation from now until pregnancy time because we need to keep opening the door, understanding why we need to practice safe sex, if we're engaging in sexual activity and why planning a pregnancy is incredibly important. We know adverse consequences happen during pregnancy, if your A1C is higher, and the literature shows that A1Cs above 8%, can lead to some devastating consequences. It doesn't always, but that's where the literature feels comfortable showing it. So the recommendation is below seven, and some organizations will go even further down into the six range.

Stacey: Thank you. That's a great clarification. Let's ask you, because we've heard from two women who are, I would say, pretty self-confident, well educated women who felt a little annoyed by their health care providers. You're not someone to be pushed around, you know, have you encountered that and what is your advice? It's difficult because you have to choose, is this the day that I fight this? Is this the day that I don't? I mean, how important is it? have you encountered that and what do you do?

Elizabeth Forrest: Sure, I think that everyone has had a fight at some point and some more than others and some days are harder than others. But I know that with my endocrinologist in particular, I have a really good relationship. I've been seeing him for many years at this point. And early on, we had a very open conversation where he asked me why are your blood sugar so high? And I said, I have type one diabetes, what can you do for me? And that's how it is. That's how it opened, really in the very beginning and we've been very honest with each other and he's very hands on and so it works well.

But to go back to the OB, when I went to her I went on birth control much later in my early mid 20s. And I went to her asking you, I have type one diabetes, what should I learn about what do I need to do? And she referred me to my endo and he said Go for it, pick whichever you want. So I think it's just communicating with your doctors. And sometimes you have to have the conversation of, I have type one diabetes, remember when you're seeing the non-endos and there's always fights to have, unfortunately. But I think the biggest key is just to express yourself and go in and think about the questions in advance and think about what comes after that. So you can be efficient with their time when you have them for the 15, 20, 30 minutes that you have them.

Stacey: I'm going to continue with menstrual cycles for just another question if I can, because I had a very specific question and if there's no answer to this, and that's fine, but I did want to try to at least answer this woman's question. She has been having trouble finding scientific research on how much the average women's insulin needs increase during PMS. Now knowing that no one here is an endocrinologist. I'm not expecting you to answer this with any kind of numbers. But I thought this was interesting. She says she's seen research on healthy women, that carb sensitivity decreases during PMS, but two endos and many of the online forums only suggest increasing basal not changing your insulin to carb ratio. So my anecdotal question is, does any of that work for you? You mentioned chasing basal rates. Do you ever look at your insulin to carb ratios? Does your body's reaction to food change during that time?

Risa Katz: Yes. And I've noticed that with Ashley too, because the doctors recommend to change the basal rate, increase it and that should do the job, but with her, it is just not working. So I definitely increase the amount of insulin she takes for her boluses on top of increasing her basal rates, and we're trying to find the right balance now. And I think as the months go by, we're getting closer and closer to that balance. It's really a trial and error, so to speak, but absolutely. Now I've heard other women and don't have that problem. I wasn't a child when I had diabetes, but in my 20s and 30s. I had the same type of issues, and she's definitely going to have those issues during her life.

Stacey: Anybody want to add anything on insulin to carb?

Nicole Johnson: I don't have that. Now, when you get to menopause....

Stacey: Wait! That's my next question! Alright, so I got a bunch of questions on this because and I think this goes to, frankly, the the age of our community because look how great it is that people are living so long with diabetes. I mean, I'm not even 50, I'm so young and vibrant (laughs). But the question was, diabetes and menopause. I'm not there yet, but I want to know what to expect. And then like six people said, Yes, agreed. There's no information on this topic. What's going to happen? What do I need to know? Does the hormone roller coaster ever change? And can I expect relief during menopause? So here you go.

Nicole Johnson: Well, that's funny. And I am going through menopause. Now. It has started here recently. What I heard From some health care professionals, but it's not in the literature. There is nothing in the literature said women with Type One Diabetes tend to start menopause a little earlier. I've heard that. Okay, so so that's hearsay. If you expect relief, you're not going to get it (laughs.)

About five years ago about when I turned 40, my healthcare team, my diabetes team told me that I was becoming resistant to carbohydrates. So I have worked so hard and I'm still not there. But in limiting carbohydrates, because my body's tired, I guess I don't know what it is.

Stacey: I think that's turning 40 and I don't have diabetes.

Nicole Johnson: Darn it. Now, you guys, I've told you how old I am. And all of this piece of information that stinks. But your blood sugar's, the other thing that I've been told, and again, it's hearsay, it's girlfriends with type one talking to each other, which is kind of cool, is that your blood sugars are going back to puberty again. It's that hard. And I would concur. But our technology today makes it a whole lot easier. And so my solutions is I'm using adjunctive therapy. I used insulin but I also now I'm using Trulicity. I used to use Victoza I've tried Metformin. So all of these type two drugs have a benefit for type ones, sometimes. And what I found, as my body's changing and getting older is that they have benefit for a two year period. And then you have to switch and do a new one because

you get used to it and you need to keep changing things up.

Elizabeth Forrest: I was just going to say that that's a really good point. I went to my endo a few years ago and I asked if there's anything else because I felt like I was very active. I had a personal trainer at the time. I was working out all the time, and I couldn't lose any weight. And I was I'm also celiac so carbs are there's very limited carbs in my diet naturally. And I was doing everything I could and it just wasn't I wasn't seeing any change and so he put me on a type two drug supplement as well to go with insulin and my daily lifestyle and it made a huge difference and for the first time in my whole life with Type One Diabetes, I finally felt like I was seeing changes I wanted to see and that conversation came from doing some research but then asking the doctor what's out there, can we think outside the box? What can you offer me? And he came up with that idea. It was great.

Risa Katz: I had the same experience. I went on an injectable that helped level out my blood sugars. And one of the nice side effects of it was weight loss. Actually, I brought it home and my husband's like, can I go on this. And I'm like, no, it's all mine. But that really helps.

But as we're getting older and I think I'm the oldest here. I have noticed the same thing, carb resistance, things are getting more difficult. I felt like in my 20s and 30s, things were pretty steady, and I hit my 40s. And now I'm approaching 50. And I'm struggling more, I'm getting more of those ups and downs, you know, instead of the straight line, and it's just becoming more and more challenging to keep control. And I don't know if that's because I'm premenopausal or what, or it's just a sign of age. I did speak to my endocrinologist about it. And she did give me the wonderful news that the older you get, the more difficult it does get. I think similar to the point about going through puberty, it's similar to going through puberty again. So that's the good news. But like you said, the technology out today just helps so much having different basal rates on your pump, having the CGM and the predictive lows and eventually there, you know, the other end is coming with the predictive highs I think is all going to help And hopefully that's coming out in the near future.

Stacey: I have a dumb question, a follow up, because that's what I do. But Nicole, you mentioned menopause and how it doesn't slow down the roller coasters. It's like puberty. Many women have that perimenopause period, and then full menopause. And then you're really done. You can have kind of come out the other side. It's probably not how they would phrase it. But at that age, then when really you are in menopause, women are living, you know, 30 years past that. Is it a roller coaster the whole time? Do you know, I know. There's not a lot of literature out there. But I would assume it's like puberty during and then after?

Nicole Johnson: Right, right. Thank you for clarifying that. That that's what I've heard but I don't know. I'm not on the other side. I've heard that it's really a nightmare as you're going through it. Yeah. And then when you come out on the other side, Oh, look at that. You don't have to fan anymore (laughs) cause it's a little confusing. Are you low? Are you hot? I mean, I wake up now at night a lot. I'm really hot and sweating. And I think I'm low and I'm not low. So those are some of the pieces that get a little confusing for women when we go through this special time.

Hey, some exciting news is that I know a couple of organizations are really thinking about this topic, and are

beginning to put together some survey instruments to gather some data so that we can have something. At least my grand plan is to have something to take to the NIH Office of Women's Health and say, look, we need to find some research on this topic. So if that grand plan happens is another topic of discussion altogether. But, you know, we first have got to gather all of this anecdotal information and pull it together in a systematic way.

Stacey: That's great. So this is more holistic health, let's call it or just big picture stuff. I don't know a lot of women with a lot of free time and you three seem like you're exceptionally busy. Let's just talk for a moment when we talk about self-care for people without type one diabetes, right? That's really important. I know that I'm supposed to stop taking care of my family first and take care of me and blah, blah, blah, blah. I hear that all the time. And we try to do it, but we're not that great at it. But you really have to do that. The question is, how do you do that? Because I know that the three of you work long hours at home or at work, you're very busy. You're taking care of things you're traveling. I guess I've just asked you to step back for a minute and see if you have any advice for I don't think anybody has it all or balances it perfectly. I don't want to put you on the spot that way. But any advice? I mean, Risa, you have kids of all different ages and I assume you manage diabetes pretty well, because you're doing great

Risa Katz: It's difficult, and it's a struggle. And one of the first things I learned was, don't be so hard on yourself. Diabetes is hard. And you don't have to be perfect. As you all know, you can do the same exact thing one day and get great blood sugars and the next day be all over the place. And it took me a long time to accept the fact that I don't have to be perfect. And you probably heard the speaker this morning talking about how you know a number shouldn't define you. And I think it that is so important to keep in mind you are not a bad person because your blood sugars aren't in control, or your child's blood sugars aren't in control, you're doing the best that you can. And also, I think it's important to try to find an outlet. I have found exercising is my outlet, which is kind of a double edged sword because it makes it more difficult to control my diabetes. But the benefit that I get from it just outweighs those struggles. It gives me that stress release, and I think that everyone needs to find something like that for yourselves.

Elizabeth Forrest: This is year 20 for me with type one. And I think if I take a step back and think about all of it so far, it's to look at the big picture. Don't get started. like Chris said, this morning in the moment, you know, a blood sugar is going to be low, and it's going to be high at different points. And you probably have nothing to do with it. That's just your body. And so to taking a step back and looking at the big picture at all times is really important. So you don't beat yourself down. And then you can try really hard when you do have the time and you have the energy and you have the focus to look at your diabetes. But every once in a while you get distracted, and that's fine. But as long as you're keeping it as a top priority, majority of the time, you can breathe a little and know that you're doing your best and that's all we can do our best every day.

Stacey: Do you ever ask for help?

Nicole Johnson: No

Stacey: and it's not a character flaw. I just set up how hard it is to ask for help.

Nicole Johnson: It is very difficult to ask for help because then you get follow up questions that are frustrating, right? And for me, it's the why and the what and the things that actually turn the helpers into the diabetes police, because they're trying to get you to a solution and to help manage through it. But the perception is one of judgment. And so that's really difficult to deal with. So that it makes it hard. I've got one or two people in my world that I can trust to ask for help. And I don't think actually we ever really wind up with that many core people. And so it's identifying who they are, and then setting some boundaries around the kinds of conversation when we're asking for the help. I'm not low, it's just it's not connecting to my phone. Just so you know, I didn't need to ask for help. On the balancing I am a type a personality. I have a hard time with stress. Because I self-stress. I'm always engaged in something and I'm always planning the next thing. And so my solution for myself is that I always have a vacation or a getaway that's planned. See, that's part of like my planning gene. But if I always have that, I can always see it on the horizon. And I can look at it or look to it when I need to decompress and chart okay, how long is it going to be until I get there? So that's just something unusual that I do with my family. And it's little things or big things, you know, next weekend, we're going to Graceland. That's, that's our target, right? We're all working toward Friday when we're meeting at Graceland.

The other thing that I do three times a day at varying times, but usually it's in the morning, the middle of the day in the evening is I walk and I don't often listen to music, I often just walk and listen to birds and sounds. And I look around and I consciously start counting the things that I'm grateful for. I'm grateful for that green grass, that bird is beautiful, this music of nature. I'm grateful that I have a few minutes to walk around. And then I start when I get through gratitude, I start planning. Because it clears my mind and it lets me think of, Okay, here's what I need to do next. And here's how I can be effective at it. And so it's really a moment away for me. And I have to do it three times so that I can get that clarity of process to move forward.

Elizabeth Forrest: I think being a planner just comes naturally for people to type one because there's so much that we have to control and sort of try to put into place and that is actually one of the therapy I use is okay, I'm going to figure out what the problem is. What do I need to do to fix, what are the options? And that helps me not get so overwhelmed and stressed about things. And then there's a lot of times where I'll just pull out a sheet of paper and start writing lists down. Okay, what do I need to get out of my head?

One other piece that I have come to find it that makes it all come together, is to really put together that support network, whether it's one other person or 10 other people and I know that locally through Dancing for Diabetes and Touched by Type One. We've created a little small network of people that get together and are putting this together. And a lot of times our meetings start focused on the event, and then it leads to talking to each other. Oh, what do you do with this? What do you do with that? And so we have these friendships that have come out of it and we can call and text whenever we need to. And I'm lucky enough that I have a really amazing spouse that has never once questioned any diabetes thought I've ever had. Just simply says, What do you need? Do you need

a Gatorade? Do you need this? This morning here in the hotel room, I woke up instead of asking for anything, I called to the front desk to see how quickly they could bring an orange juice up. My husband got out of the bed and said, I'm going to go to the vending machine right now, don't worry. And so we should ask for help. But it's nice that there are people in my life that just know that they can handle it too. And so think about who's close to you, or who can be close to you with a little bit of work and rely on them because we're you all Everyone needs least someone they can count on for sure.

Nicole Johnson: She just gave you, by the way, moms who have younger daughters maybe who aren't married - it's like the test for the future guys that come into your life, right? Diabetes is the ultimate resource to use to discard the bad apple boyfriend test. Will you give me orange juice? (laughs)

Stacey: **One of the things that I think I hear a lot about younger girls with type one from their parents is how do I help her with body image? It's not just that there are food issues and insulin issues. It's the technology and it's wearing of gear and bruises on your body, perhaps. And I know we're not going to solve that in the next 10 minutes here. But I was just wondering if you could address that a little bit because we as women have issues, me too these days, we all have body image issues. Anyway. If anybody wants to jump in, you want to start Risa?**

Risa Katz: Well, yes, and I can say when I was diagnosed in my early 20s, I had issues with wearing a pump and with people seeing that I was wearing this medical device, and that carried with me for quite a long time. Insulin pumps weren't that common back then. And you get a lot of strange looks about them. And then I had a daughter and she was diagnosed and I made the decision that I don't want her to feel that way. I want her to be proud of who she is. And if she is a person that has diabetes and needs to be on an insulin pump or a continuous glucose monitor, then she should be proud and wear it out. Right? So whereas we used to go on cruises and take the pictures, and I would make sure my pump was hidden and not seen in the pictures. Now I wear it just like my CGM right here, right out there because I want her to see that I want her to see it's nothing to be embarrassed about. In fact, you should be proud because how much more difficult is getting through life when you have type one diabetes? And if you can be successful and when I say be successful, I don't mean have perfect blood sugars, but I mean, just have a good quality life, then, you know, you have succeeded more than anyone else without it, without that type of challenge. And I think that has helped her a lot in terms of body image you know, because you're right, there's so many pressures out there on girls to look perfect and be perfect and meet this image. And if we could get them to just be so proud of who they are and what they're accomplishing and how they're surviving. I think that will go so far as they get older and turn into young women.

Elizabeth Forrest: I was terrified to put my Dexcom on my arm when I first started using it. Part of that is living in Florida. It's hot. Okay, so now when I wear a tank top someone's going to see it and ask me questions and they're going to look at me funny and those are things going on in my head right? But being around some of the kids they would wear it and if they can do it, I can do it. And what led me to start doing that was I was putting everything on

my stomach, my pump, my Dexcom. Well at some point it you've got to give your body a little bit of a break and so I thought, all right, well, I guess I'll try it this one time, and I put it on my arm and nothing happened. No one asked me anything. No one said it was weird. No one looked at me funny. So okay, I'll keep doing this.

And what I found over time is people were actually coming up to me and asking me questions and saying, what is that? Is that a diabetes thing? And so we would have a good conversation out of it. And then when I was now confident about it, I would then think, Okay, this is now a tool. Now I'm going to wear it proudly, when I go shopping, or I'm at the grocery store, and I hope people come up to me, I'm ready to tell them about it. And so it's definitely been a process, but I was terrified when I first got the Dexcom and it actually sat on my counter for months before I even took it out of the box and put it on because I was just too nervous about it.

Nicole Johnson: I think this is a very significant issue and if left unchecked, it can spiral into many other negative issues. I've learned recently from the psychology researcher, Brene Brown, you've heard of her right? She's all over pop culture right now. She has this technique which has really been effective for me, and in raising my daughter. It says start your conversations with the story I'm telling myself, to identify if it's real or not real, right? We did this as a family last night. It was my mother, my daughter and I shopping. And of course, we all found things that we thought we looked bad in, right? The story I'm telling myself is this makes me look too heavy. And then they chime in and say, No, are you crazy? That's not the real story. And but then another one did it right. Oh, I don't like this. I need to lose 20 pounds. And we go, that's not the real story. So it's teamwork, and having the support but then also recognizing when you are on the verge of that temptation of the negative self-talk, because that's really super powerful. Body image is always going to be there as a challenge, especially for women because our devices are ever present. And I was diagnosed before we had these devices. So it's only becoming a little bit more and more, the more we can do to show our young people, examples, role models like Elizabeth, others that look at them, they're doing it, it's okay, look at this creative technique that they figured out, the better. In fact, my friend from Tandem carries around a picture of me from January wearing my pump. And I'll tell you truthfully, the dress was just a little tighter than I expected it to be. So I could not put the pump where I wanted it. So I clipped it to my boots. And he took a picture and he goes, Yeah, and I went, Well, I'll do that again. So just like getting creative as a community is going to help a lot.

Stacey: And I would just add to that if your daughters are saying, I don't know anybody who wears this, I don't see anybody who looks beautiful. If you allow them to go on Instagram or show them your account, there are so many wonderful young people, I say as this as an old lady, who are wearing their devices and making them front and center. So I would highly recommend that.

Nicole Johnson And there's a couple of companies that have just come out featuring people with health conditions.

Stacey: I'm glad we had the time to answer that. Because, you know, and you're hearing from a Miss America who I always do you think we think you're perfect. And it's so wonderful to know that you are not!

(laughter)

Stacey: You laugh, but doesn't that help? It helps me. I don't look like I looked when I was 20. Thank you all for being such a great audience. I hope it helped you. Thank you all so much.

Evidence-Based Hope

with Dr. Bill Polonsky & Dr. Steve Edelman

[EPISODE ORIGINALLY AIRED SEPT 24, 2019]

Dr. Bill Polonsky is the President and founder of the Behavioral Diabetes Institute, the world's first organization wholly dedicated to studying and addressing the unmet psychological needs of people with diabetes. He is also Associate Clinical Professor in Psychiatry at the University of California, San Diego.

Dr. Steve Edelman is an endocrinologist who lives with type 1. He is the founder and Director of TCOYD, Take Control Of Your Diabetes which educates, motivates, empowers and inspires people with diabetes by providing conferences & educational programs.

Stacey: A little bit of backstory before we jump in. You're going to hear me talk about these two slides right at the start, two photos. I posted them in the Diabetes Connections Facebook group, but it's really important to the conversation that picks right up that I tell you exactly what's on those slides. The first one is from the Diabetes Control and Complications Trial. The numbers are from 1978 of people living with type 1 for at least 30 years at the time. So, in 1978, they had lived with type 1 already for 30 years. The rates of complications are high, 30% have severe vision loss, about 15% have had an amputation and almost 40% have kidney problems. It is a very sobering slide.

The second slide is from something called the EDIC Trial and you'll hear Dr. Polonsky talk more about that. Again, people living with type 1 Diabetes for at least 30 years, but this time, it's 2009. And the difference is striking; less than 1%, severe vision loss, less than 1%, amputations, and about 6% with kidney issues. This is in 2009, still 10 years ago. So, things may have changed since as well. Well, as you will hear, I spotted these two slides on social media years ago. I've been looking for context ever since, you know, what does it mean? Are things continuing to get better? What changed? What are the people in the study doing that they, they had so many fewer complications? You know, I've just really wanted to know. Well, Dr. Polonsky and Dr. Edelman clear it up for me.

Gentlemen, thank you so much for joining me. I'm excited to see where this conversation goes. You're both such wonderful speakers, and it's always fun to hear you talk. So, thanks for spending some time with us today.

Dr Edelman: Sure, you're welcome.

All right. Let me start by telling the story that sparked me wanting to have you on the show. There are many reasons why but this one really piqued my interest. For many years, I have had these little pictures on my cell phone of graphs showing how much better living with diabetes has become. I will explain within those graphs in just a moment. But I pull these out, and I pulled them off Twitter, somebody else's presentation or something, pictures maybe from TCOYD years ago. And every time I'm in a parenting group, where people are so worried, and they're terrified, and they're worried about complications one-year in. I throw these pictures and everybody says, 'How come I don't know this? This is amazing.' And then I was at the TCOYD conference in Raleigh, earlier this year. And there's Dr. William Polonsky, who I realized is the man in the slides that I've had all along, presenting them.

So, let me start there. Bill, in did your presentation tell me first what are we looking at here? This is a study about, you know, unfortunately, the complications that used to come with type 1 and how these complications have gone way down.

Dr. Polonsky: Sure, glad to Stacey. I get it Everything that you're referring to, and I've been working on, and with Steve as well, what we call evidence-based hope. We've done such good job over the past few decades trying to scare the bejeezus out of people with diabetes. We haven't done a good job talking about what is in fact, the good news.

And that we now know, is really evident that with good, good effort and care, odds are now pretty good, you can live a long and healthy life with diabetes. And Steve and I have been shouting that from the rafters for a long time. And I hope that it's finally starting to get clear. But when we talk about that, especially when I talk about a psychologist, people just say, oh, you're just giving me this happy talk and all that positive stuff. And I go, no, no, there's real honest to god data and good data. So what you're referring to is when I present just a little bit of that data, where I talked about from an old study back in the 70s, about the percentage of people with type 1 who are receiving pretty good care that ended up running into those scary complications, amputations and blindness and more than what a very high percentage of those people that did that versus what it's like nowadays. And we look at what's called the EDIC Study where they look at long term outcomes. So, there's no guarantees. But the good news that we see now in the studies is going to happen to you, Mr. X, or you Mrs. Y. We want people to know, this is now what's possible. Again, this idea of evidence-based hope.

Can you talk a little bit in specifics, when we're talking about evidence based here? I kind of got excited and talked about the slides. Can you briefly explain the difference between what we saw in those two between

being diagnosed long ago and being diagnosed more recently?

Dr. Polonsky: Oh, my God, I could bore you with enormous amounts of details, but go for it Steve.

Dr Edelman: I have suffered through this presentation like 10 times. You know what kills me, Bill and I have a private joke. Bill speaks right after me in the morning, and we want to finish on time. Bill's an awesome speaker and he gets to these two slides. And the first slide just shows the rate of complications in a group of people with type 1 collected over the previous 30 years. And the complications are high, 30 to 40 to 50%, eye, kidney and nerve disease. And then he says, did you notice something about the slide because it said 1978, and 1978 is when the data was published 30 years prior. And then he goes on and on, he probably spent six or seven minutes talking about the slide. And then finally goes to the next study, which the clinical action that was completed in 2009. Now, even that's 10 years old, and the rates of complications of eye, kidney and nerves issues has gone dramatically down. I mean, like, you can barely see the little bars in the bottom of the slide. And basically, what he's trying to tell to people is that listen, this is not just me, the touchy-feely guy saying that, oh, you'll be fine. There's hardcore data, that all the different advances are improving people's lives reducing complications. And that was 10 years ago, before CGM. Even you know, so I'd love to see some more recent data.

Well, the speaking critique aside, and I saw him get those digs in there on timing. But to be specific, the second study ended in 2009. But the people who were in it were diagnosed as I read it, and please correct me, the people in it were diagnosed 30 years prior.

Dr Edelman: Correct

Okay. Does it follow? Is it logical, then that people who were diagnosed less than 30 years ago would expect to see even fewer complications, I don't want to make a jump.

Dr Polonsky: This is not what's expected. This is what's possible. Like the 2009 data that we present is from people who are in what's called the EDIC Trial. This is like really good care, and good follow up care all of these years. This may not be typical within the US, but this is what's possible now because of all the amazing resources. The technology that Steve was just talking about. This is what's possible.

So, what makes it different? What kind of care are these people getting? Is it as simple as they actually see an endocrinologist? Or do they have technology? Can you tell us a little bit about what the EDIC Study provides or asks them to do?

Dr Polonsky: Let me just get to sort of the major differences between those two slides. how things have changed is in the first data from 1978 or we show it this high risk of complication, those people never heard of any A1C test, they never heard of glucose monitoring. It didn't exist. They didn't have analogue insulins like we have now, didn't exist. So, all the things that we just think of now is common, no big deal, we're there. There are so many other way

cooler things we can talk about that have happened since that, but it's just fundamentally that's how limited things were back then. Steve, you lived it, you know about some of this.

Dr Edelman: Yeah, yeah, I survived it. I think I want to emphasize what Bill said, it's what's possible. You know, as an endocrinologist myself, I see people with horrible complications in 2019, because they didn't have access to good care. Or there were other emotional behavioral barriers. You know, I mean, I hang out with my friends like Jeremy Pettis and other type 1's. Aaron Kowalski. We're all looping. You know, we all doing so much better now. But there's a lot of people that really do not have access to this technology. So that's one of the things that Behavioral Diabetes Institute and TCOYD does is trying to raise awareness and education so people can go out and get the things they need to stay healthy.

Steve, you know, in that EDIC Trial, or that EDIC Study, what kind of care? Is it just checking in with the physicians? Can you talk a little bit specifically what excellent care means?

Dr Edelman: Yeah, excellent care. Well, should say that one of the largest studies in the type 1 area is called the DCT. You probably talked about it with other guests, the diabetes control and complications trial. What it means is the participants to go to a specific diabetes center, they have set appointments that are probably spaced out no more than three months. In addition, based on their needs, they will see a dietitian and certified diabetes educator, they'll even have an exercise physiologist that helps them with all the different aspects, kind of the Dream Team. So, they have a specialist that addresses many of the issues of diabetes, and they have social groups. They have access to the best technology like pumps, CGM, pens, and the best medication, the longer acting basal insulin and inhaled insulin. So, it's not only just access to devices and medications that are up to date, but experts within different subdivisions of where people with diabetes may need help. It's a true diabetes collaboration clinic and people do extremely well.

How do I get my kid in that?

Dr Edelman: Well unfortunately those types of clinics are not common. Now how old is the kid?

He's 14

Dr Edelman: Yeah, the thing is, you know, in San Diego, you know, we have the UCSD children's clinic, Rady Children's clinic. And it's amazing that when kids are young, and they grow diabetes center like the Barbara Davis center in Denver. They go there and they have social workers, dietitians, exercise people, excellent endocrinologists, and they have 10 resources. And then what happens is, they become an adult, and they get nothing. They go to an office, like an UCSD, whatever, and they sit in the waiting room, and there's people,

hundreds of people, you know, 18, and there's no support services at all. They get 15-20 minutes with a doctor and see you later and you know, come back four to six months. So yeah, that's why you people have to really learn this stuff on their own.

Yeah, well, we're fortunate. My audience is obviously very well educated, very interested, very engaged. So let me just ask for people who are listening who can take control of their diabetes, who do have access to at least a general practitioner who could write a prescription, or at least know to ask about looping or know to ask about Afrezza. What can they take from something like this? They're not going to have an exercise physiologist and a social worker. Bill, let me ask you, what can somebody who's you know, in their 20s or 30s, who is paying attention to their diabetes, what can they take from the EDIC study that they can change in their own day to day care to improve?

Dr Polonsky: Oh, that's a tough question. I guess I my mind went somewhere else. I need a backup for a minute. So I feel like I didn't answer a previous question. Just so you know, in that 1978 study, just to get very specific, the percentage of people after 30 years of diabetes who had severe vision loss or going blind was about one third of them about 30%. In the EDIC trial published in 2009, after again after 30 years of type 1 diabetes, percentage of those who had vision loss or gone loss who were in this was called the intensive part of the study, what 30%. It was 1%. As far as we know, actually, no one's gone blind. And just to be clear about how the remarkable extraordinary heroic efforts they've taken, they won't that heroic or extraordinary. These are people who for four to five, six-year period back in the late 80s, and 90s, managed to achieve the remarkable A1C goal of 7%. And when that study formally eased off and ended back in 1983, on average, their blood sugar A1Cs flared up to where they are now, which is about 8%.

So, we're seeing these remarkable results, because these people have decent glycemic control. And because it had ongoing care, because all we can talk about what an individual can do at home. And as Stephen said, so clearly, it's really nice when you've got touch points out there, when you've got TCOYD to go to, when you've got a regular health care provider to see on a regular basis. As opposed to how often it seems like as adults, people are abandoned with their diabetes. And it doesn't touch points as I can tell you what to do, which is to be your cheerleader and to help you stick with it you know, some of the tough and annoying things you got to do every day, like take insulin and do it at the right time and things like that.

So, Steve, to follow up, and I don't want to leave that point too much of adults. I want to go back to that too. But I am fascinated that these people had excellent control in their, you know, they were seven, which was amazing at that time, and then floated up to eight, and they're still doing okay. You know, I think in the diabetes online community, many people feel that if they are not under six or under 6.5, that they are failing. Steve, can you address that? Because gosh, that puts a lot of pressure on people.

Dr Edelman: You know what, that is such an excellent question because I see patients all the time. You know,

the problem is, through the years people are so afraid of complications. And many doctors that really are not knowledgeable. They scare people and people think that they even think that if they get a blood sugar over 200, you know, they're going to start developing complications. People with diabetes do not need to be that low. In fact, it's dangerous. And the incidence of hypoglycemia goes up dramatically, and people still pass away from hypoglycemia in 2019. I'm hoping at a much lower rate, because of CGM and things like that. But we know from clinical research that if you can get your A1C to less than 7.5 that's a great first start. I mean, like awesome, like, if I had to give someone a grade, I'd say that's an A minus, you know, And obviously, if you can get to around 7, and we're a little bit below 7 without excess of hypoglycemia, then you're golden.

Now if you look at the national statistics from the T1D Exchange where they looked at the average A1C and 35,000 type 1's that go to, you know, premier Type 1 Diabetes Centers that only about 25% of those people with type 1 have an A1C less than 7. What does that tell you? It's tough. You have a kid that's 14; oh my god, that's a totally different species of human. And we know when you look, when you look at the average A1C of teenagers, it skyrockets because they don't want to wear a pump, they don't want to wear a CGM, they don't want take their shots, they don't want to prick their finger. You know what, just give them support and eventually they'll come around, but it's tough when you're a type 1 to get an A1C less than seven. Now the other thing I'll say really quickly, and you guys should watch a video on the TCOYD website. It's entitled, 'Why the A1C sucks, and Why Time in Range is So Much Better.' Because, you know, does anybody walked out I think on a daily basis feeling different depending on their A1C, they want to know what percent of their numbers are between 70 and 180. And that's the real big issue. You could have a golden A1C, but you could be going from 40 to 400 and still have an A1C that's around 7. So A1C is one thing, time in range, glycemic variability, all the ups and downs, everybody with type 1 knows exactly what I'm talking about, that's more important.

And can I just follow up Steve on the teen question because we have a lot of parents who listen, and there is so much fear and stress when A1Cs go up. And when time and range go up. I have to tell you, when my son hit puberty, and I've shared the story before I don't share his A1C, I don't think it's anybody's information but ours. But when he hit puberty a little early and his A1C shot to a number we'd never seen, I burst into tears like a dummy because I don't like to show him you know that it upsets me, burst into tears. And our endocrinologist who was great laughed at me and said to my son, relax, she's going to be fine. And adjusted the pump, but we found that it was just too much insulin for his pump to really handle. So, he takes long acting with the pump. And it's been a life changer for him. It's been wonderful.

But my question I'm sorry to get off on a tangent. We have a lot of parents who listen, can you be reassuring with that evidence-based hope that just because you may have a couple of years of higher A1Cs, that your relationship with your child is just as important, that maybe there are ways to not necessarily let it go. But finding that balance, right? I mean, I know you work with adults, Steve, but can you talk about that for just a minute.

Dr Edelman: Now I'll say a quick comment and let Bill jump in. In general, the duration and severity of hyperglycemia dictates that people are going to get these eyes, kidney nerve disease. So we have some patients

who have horrible control, never get complications and other patients that really have pretty good control that get complications, but those are the fringes But most people and I think for the teenage years, you know, you need at least five years to develop any early signs of diabetic retinopathy. And that's why they don't even recommend eye screening for five years until after the diagnosis. So, I would just say to parents that they can't freak out because that freaked out attitudes can overflow to their, you know, their kids. And the other thing is, you know, on the other end of the spectrum, a lot of parents worry about hypo, you know, severe hypoglycemia, and I heard Bruce Buckingham at Stanford, pediatric endo, say to a group of parents, just when your kids get to high school and they go to college, make sure they sleep with someone every night, and that was for safety. That's supposed to be a joke, Stacey.

I'm stunned into silence, because Bruce Buckingham, who has a great sense of humor. I'm trying to vision, I mean, we've had him on the show before what he's like an elder statesman and to have him say something like that (laughs)

Dr Edelman: You know, he's an ageless individual. So people have your kids sleep with someone every night. So, Bill, what advice is better than that?

That's wonderful, thank you. Like I said, I have a 14-year-old boy. Over to you, Bill.

Dr Polonsky: I am stunned into silence just thinking about that (laughs).

Oh, no, how can I top that one, that was great. Well, and again, it's just also just reflecting but we kind of see this whole issue of how does any parent, we see with adults, but it's even more dramatic of parents. How do you ever decide with your kid or your kid's doctor that the ratio we like to call a quote unquote, healthy good enough? Like, what is that? Does your kid have to have A+'s all the time or he will be a failure in life? What does that mean?

And what we see is rather than come to some agreement about what that number might be with your physician, what we often see parents doing is almost competing with each other right? My kids A1Cs is better than your kids A1C. Well, so what, it often doesn't isn't related to evidence. And as Steve said, to get lower, there is no good evidence, getting that low is necessary are going to give you much extra bonus at all. And parents of kids that have type 1 diabetes, my experience, Stacey I am sure you can talk about this, are probably the most anxious people I've ever met in my life. Because just like you said, if there's a high blood sugar, oops, my kid died and it's my fault. That's divorced from reality, just not true. But we know parents struggle with this and simply because no one's really like Steve sat down with them and said, let me tell you how this really works.

I think too, that social media does not help. We were very fortunate, you know, in a way that Benny was diagnosed before social media. I think Facebook, I talked about this a lot on the show. It's such a wonderful thing for support, but it's horrible because all of these people are just sharing their worst stories and their fears.

Dr Polonsky: So it can be the opposite of the bragging, but I always wanted to start a website called ‘my diabetes is better than yours.’ To just sort of have a lot of fake things about, to make you feel as bad as possible because that’s what we see this going on. This isn’t just horror stories, its stories about how well I’m doing well, here’s a picture of my time in range. What’s wrong with your kid? You know that it’s just as destructive.

I personally think it’s human nature. Right? Once we can measure something, then we can compete on it. You know, CGM are wonderful. The information is fantastic. But when you’re looking whether you’re a parent of a child with type 1 or an adult with type 1, I think it’s very difficult to not assign a value to those numbers. And to that time in range as Steve mentioned. Bill, any advice for you know, if I’m looking at that Dexcom all day long, and my son pops up to 250 after lunch, and I feel guilty and sad. What do I do with that?

Dr Edelman: Don’t tell anybody else that.

Dr Polonsky: You know, back in the world’s before CGM, we used to hand out little stickers, and we’ve encouraged people to put on their meters. And the stickers just said, ‘Remember, this number is just a number.’ It’s not a statement of your self-esteem or your kid’s self-esteem. It is a number. And we spent a lot of time trying to help grownups with diabetes and parents and teenagers just to realize that these are not statements of being good or bad, that they are numbers. Steve does a lot of that with his talks at TCOYD talking about how the values that people put in these numbers and just how ludicrous it is. But I think Steve does a great job because he says the best job, I know of making fun of it all.

Yes, you’re very funny. Steve. I want to ask you before you talk about how you help other people; did you have to go through this yourself? Did you have to get to a point or do you are you still at a point where you sometimes you look at a number and think what did I do wrong?

Dr Edelman: I’m much better than you know, you could talk about it all day, but it’s so frustrating. And also, you know, it’s a whole issue of letting others know I mean, when I have a good blood sugar on my CGM monitor my phone. Yeah, I’m the first one to stick it up and says who cares about cyber security I want everybody in the world to see the number. When it’s bad. I don’t care what I don’t care how many lectures I’ve been to or given or listen to Bill, it’s still embarrassing. If you have a blood sugar over 200 you feel like you have to give an explanation. Oh, I you know, I forgot to do the pre bolus or whatever.

So, it’s a constant battle. And I think the more people are comfortable on how to deal with the numbers, the less anxious they get, you know, so learning how to deal with highs, doing good correction boluses, using Afrezza, using CGM, utilizing the trend arrows to do the best guess. I think that does help because you know that if you’re if you’re going up and you’re out of range, which everyone goes once a day at least you know how to deal with it and you reduce the once again the duration severity of blood sugars in the elevated rates.

Stacey one current example of how this is still a problem for so many people, is if you look at those

grown-ups who have type one diabetes and have a Dexcom G6, the enormous numbers, probably the majority, who made the choice of not sharing their data with anybody else. And again, it's fundamentally the sense of people are going to not understand, they're going to offer annoying advice or it's going to be intrusive in some way. And fundamentally, is this terrible thing in terms of how we've all grown up with blood sugars that they're not often recognized enough is what they are. They're just pieces of information. And the very first thing anybody or a parent should do when they see an out of range number, your first thought should be, that's interesting. I wonder if we need to do anything about it, as opposed to how did I or you screw up now.

My mother was used to help me with my son when he was a toddler, and would come visit a lot. She would always gasp if the number was out of range. She didn't even know she was doing it. But she would say 'Oh,' and it got to the point where I think my son was about six or seven, and he took me aside, he says, I can't hang out with Grandma, if she's going to do that all the time, and they're very close. So, I had to have a big conversation with her. But she didn't even know she was doing it. It's so innate in us.

Alright Steve, so I'll get nosy and you don't have to answer this. Do you share your CGM data? Is that something that you are doing?

Dr Edelman: Yeah, I share with five people including Bill.

Today I got low, it only beeps if I get below 55. So those typically the first guy to say 'juice buddy', or my girlfriend, and then Jeremy my good buddy endocrinologist says, 'Hey, Steve, get your crap together and do something' - really encouraging little messages. Sometimes I get low on purpose just to see who texts me first, I want to see who loves me the most.

I'm not gonna tell my son that he would probably be on my case. That's really funny. It's a good point because I don't want to get too much into my personal stuff. I don't mind, but it's not about me.

Dr Polonsky: Stacey, I'm a psychologist, you can talk to me.

Well, I try. But you know, it's been, it's been a long, 12 years, my friend, my son still talks to me. So, what can I say? Oh, he's bananas. We're talking about evidence-based hope. Is there other evidence? I mean, we focused on one or two studies. I don't want to; I'm putting you on the spot here. So, it's okay, if you can't pull stuff up. But I don't want to let you go without asking. Are there other studies or other key words that you'd have people kind of follow up to look at that are good news?

Dr Polonsky: I think the most important thing to look at and this is I think, where that source of confusion is. I mean, there is sometimes there's studies that show that but really, if you look at studies and Steve and I talked about this all the time, they'll say things like, you know, we examine the big population of folks with diabetes, and we

found out that people with diabetes are higher risk for running into kidney problems or heart problems, period. And that's it. Oh my god, that's horrible.

I don't think that's reasonable. I don't really care if people with diabetes are extra risk for these problems. Let's divide that into groups, those people with diabetes, who for whatever good reasons, have managed to get their numbers in a safe place; A1C, blood pressure, lipids, hopefully, they also are not smoking or not wearing seat belts. And let's compare that to people who blown it off, which is an awful lot of people with diabetes, or don't have the care they need and have sky high A1c and blood pressures. Let's look at those people separately. And that's when you start to see the good news.

The good news isn't that everybody's doing better. The good news is that with good care and effort, everyone, most everyone can do well, and that's a big difference. So when you're looking at studies, make sure we're not talking about how people with diabetes are doing, but how people with diabetes who are in you know good cardio, metabolic and good glycemic control will do. That's the really interesting stuff. Does that seem fair to you Steve?

Dr Edelman: It seems extremely fair. And I totally agree. I mean, it makes perfect sense.

Let me ask you to weigh in to Steve on another question, I always wonder to is there enough study on people with type 1 diabetes? I guess as a layperson, I'm asking, do they look at it enough? Because I look at things like is a low carb diet good for some with type 1? And there really isn't enough study out there yet. You know, things like that.

Dr Edelman: Well, well, you know, what, it's interesting you say that, you know, I think things have improved a lot. I think that the health care professionals research of the world that you know, you can't just lump type 1 and type 2 together, completely different animal. So, I say I'm encouraged that many of the studies I see today are specifically in type 1 and type 2. And let me tell you, if they try to submit a manuscript to a journal, that's like I'm reviewing or Bill's reviewing and they don't separate out and they need to separate out. Oh, automatic rejection. I feel so powerful, gosh.

That's fascinating because it's amazing to me that someone would try.

Dr Edelman: It's flawed study design, and we see it all the time. So, it's truly true. You know, you see that these guys are losers.

Bill, let me ask you this. I have been accused in the past and I know I do this. I do have a bit of rose-colored glasses on when it comes to type 1 diabetes, if it's possible to have them. I'm not a Pollyanna. But I am very aware that my son has excellent care. We have excellent access. He's a happy kid, I got lucky. He's doing what

he needs to do. We are far from perfect. And I don't tell people you know how to eat or how to dose, that's not my deal. But I find that when other people see the studies like we've talked about today, and talk to health care professionals who are more optimistic, they kind of feel like it's worth trying more. Does that make sense? I mean it to me what the message that you all have of this evidence-based hope gives people the hope to try again. Am I being too much of a Pollyanna, Bill?

Dr Polonsky: No, I think that's exactly right. Again, we have good evidence about a very high percentage of people living with diabetes. And I'm going to say type 1, and type 2, who really feel hopeless. And anything we can do that provides people with the truth, which is that they are not necessarily hopeless. And to remind them of the fact, based on lots of evidence, that was good care and effort odds are pretty good, you can live a long and healthy life with diabetes, we're doing a good thing. So that doesn't take away from what Steve said, which is that we're still seeing lots of people running into horrible complications. And that's absolutely heartbreaking. And sometimes that has to do with genetic factors that we don't understand or other factors. And sometimes it has to do with the fact these people have never been able to access the care they need. Sometimes that's do with ways in which they sort of disconnected from their own diabetes care. But the good news is we know that it doesn't have to happen, at least for most folks. So yeah, it's a careful message we're trying to say. I hope that's clear.

I appreciate you making the distinction because I'm not trying to put the rose-colored glasses on everybody. Steve, let me ask you, we have a little bit of time left here. Talk to me about TCOYD. I went to the conference for the first time in Raleigh. I absolutely loved it. But tell the listeners if you could, what makes this conference different?

Dr Edelman: Yeah, well, you know, first of all, in a way, it's very unique because you don't see too many conferences for people with diabetes. It's primarily a conference where people can learn. And a minor part of it is the healthcare but an important part of it whereas I've seen other type of events where it's mostly a health fair and one or two lectures, so primarily education.

The other thing is, Bill has gone to probably 98% of them or more, and it's getting good people to speak. A lot of our speakers have type 1 diabetes, and we want our speakers to be not speaking down to people with diabetes, but speaking to them. And so, we try to get motivation, motivational but educational. And we encourage humor and humor leads to information retention.

And, you know, we also have the type 1 and type 2 tracks so people can get their individual areas covered specific to their type of diabetes. And we have general lectures where people, you know, the rooms too big to ask questions, but that's why we have all the workshops and the hands-on sessions, and where people can get their individual questions answered. So, it's really trying to address, to educate, and motivate people using humor to have them put diabetes higher on their priority list.

The other big thing, I will let Bill jump in, who's as much TCOYD as I am, is that we put a lot of time and effort into educating the type 3, the significant other and the caretaker on diabetes. Most people, they're forgotten, and they need to be educated and motivated just as much as the person living with diabetes. Bill calls them the

diabetes police, and, you know, patients, people with diabetes or diabetes criminals, and you know what, there's a whole way to communicate your love for someone that you're living with diabetes. And you know, as a mom, it's tough when you're kids a teenager, but husbands, wives, you know, they just don't realize it, and they say, you can eat that piece of chocolate cake. And my response is 'oh, yeah, watch this.' So, you know, it's just communication.

So, I think if I can summarize that was really some of the unique features of our conferences. People love them, they come back to them, and there's just not your boring diabetes education class. Bill knows a lot about diabetes education class he just reviewed several for a hospital.

Well, and I'll jump in before you can answer because I did want to ask you, Bill, I sat in on what was billed as your burnout session with people with type 1 diabetes with their spouses and partners. There was a couple of us parents in there and then kids, but it turned into this awesome bitch session. You know, you encourage that, tell me about your complaints, tell me about what's wrong? And it was not just complaining because you know, obviously you are a talented health professional who turned us around and taught us to kind of help each other without knowing it. But I thought that was absolutely fascinating. Do you do that often?

Dr Polonsky: I think I do it every program I ever do with TCOYD or anywhere else in the world.

Dr Edelman: That's why Bill has been married three times he's tried that approach? No, I'm kidding.

Dr Polonsky: I think what the magic is that happens at TCOYD. You know, Steve says people leave with new information, new ideas about what to do. But to me the most important thing and the reason why people keep coming back and these events are successful, because the majority people leave with a new perspective on diabetes. They leave feeling hopeful. They leave feeling like I know what I can do now as opposed to feeling kind of powerless in the face of this disease. And they leave feeling not so isolated anymore. They can make connections with their type threes or diabetes policemen and they meet other people. who are going through exactly the sort of thing that they're going through.

And so quite one of the parts I get to play, as you mentioned, Stacey we get to do these sessions often, I get to ask people tell me one thing about diabetes that's driving you crazy. And the most powerful thing that you saw Stacey, when we do this isn't necessarily having to fix all of those things. Because that takes can take some time, but it's for everyone in that room to know that everyone else goes through aggravations with this disease too, that's normal. And as a group together, we can hang out and figure this out. But you're not alone. That's what's important.

One quick statement Stacey, are things have changed so much that in the last 25 years since we started TCOYD. In the olden days, we were on the defense of you're just sitting there you're waiting for to develop complications. And now we're on the offensive. We can go out and attack diabetes and do with it with a such a positive feeling that you do have control.

What I want to ask you Steve is you do have such a great sense of humor and I and Bill you too obviously. I'll

link up a lot of the videos, and I hope people watch them. But I'm curious, when did you figure out or was it always a part of you that humor really is such a great tool for diabetes? And how do you maintain that humor when you are a person who lives with type 1, which is not an easy life? And you are a person who sees those complications, as you said, from patients, how do you do that? And why is it so important to do it?

Dr Edelman: Well, you know, first it's important for your listeners to know that I have complications myself, and you know, I have high issues I've had retinopathy, I've had macular edema, I had injections of medicines in my eye, I get kidney issues, but I guess the first thing is that I have a sense of humor, and I was born with that.

So I wish I could say there's a way to go to class and if you're not, if you don't have a sense of humor where you can get one, but I think you know people you know being knowledgeable and taking away fear and anxiety is a way to bring out someone sense of humor and get them to laugh at something that they normally wouldn't laugh at. And, you know, self-deprecating, you know, it's always, it's always healthy. And so, I think, you know, you have to judge your audience, even though TCOYD, it's a group audience, and even if someone's not laughing at what I'm saying, they hear everyone else laughing and then they might laugh at the next thing I say. So, I think just putting things into perspective and taking, you know, taking someone's fear of dialysis away, even though they may have kidney problems, we have ways to prevent it and to prevent the progression. The basic part of it is knowledge and knowledge is key. And that does help with a lot of the emotional behavior issues that Bill deals with a lot of his patients.

Dr Polonsky: And just to highlight that, I think that lies at the heart of being finding a sense of humor about diabetes, and everything I see Steve do. It's about talking about real life with diabetes, and how you can make diabetes doable but also treated the way it really is in real life. I think a better question for Steve is how could you not be funny about diabetes. Especially when it's in your nature, but it's real life. It's all about real life. That's the heart of it.

Wow. Well, I'll leave it there. Thank you so much, both of you for joining me. I'm thrilled to hear from both of you on such an important topic. Thanks for spending so much time with me.

Dr Edelman: It's been my pleasure to hang out with you and Bill.

Dr Polonsky: Absolutely.

Type 1 Diabetes and Mental Health

with Allison Nimlos

{ EPISODE ORIGINALLY AIRED OCTOBER 31, 2019 }

Allison Nimlos, MA, LAMFT, is a licensed association marriage and family therapist specializing in chronic illness, anxiety, and relationship issues. She is the founder of Greater Than Counseling and Coaching and has lived with type 1 for more than 25 years.

Stacey: Allison, thanks for being with me. I'm really interested to kind of see where this conversation goes. Thanks for making the time.

Allison: I am so happy to be here.

This is a very broad topic, and I want to get to your diabetes story as well. But what made you want to go into this field, why become a therapist to focus on mental health?

That's a great question. When I was kind of going through my quarter life crisis back in my mid-20s, I was trying to figure out what I really wanted to be when I grew up. I thought I wanted to be a diabetes educator. It was something that I had actually thought about on off for many, many years actually even remember telling my dad when I was 12, that I wanted to be a diabetes educator. And it sort of waxed and waned in my interest over the years, and I had been writing for DiabetesMine for a couple of years, and I have really enjoyed being able to teach people about diabetes. I thought I wanted to be an educator and work with people on a one-on-one basis, not just write an article and hope it made an impact to somebody because you just sort of put things up and you hope somebody resonates with it.

You don't really know where it's going to go. I wanted to have more of that personal interaction with people and so I had started pursuing prerequisites for, you know, nursing or dietetics, kind of that normal kind of the traditional normal path to becoming a diabetes educator. And as I was doing it, I realized it wasn't really speaking to why I wanted to be a diabetes educator. Just helping people learn to check their blood sugar, helping people eat healthy. I wanted to help people really live and cope and thrive with diabetes, which I think motivates a lot of

people who are in kind of the advocacy field anyways, which I had been doing for quite a while just wanting to really inspire people and move people to have hope and feel like they can do anything.

And so, taking a look at kind of my core reasons - why I wanted to be an educator, I started asking around with some other therapists that I knew who also worked with people with diabetes. And I said, this is kind of what I'm thinking about doing. And this is kind of why I want to do it. And they were really supportive. They thought, yeah, that that could really make a big impact. And it was right around the time where there were a lot of studies coming out about the psychosocial impact of diabetes and the mental health side of diabetes. It was just becoming more and more of the conversation and a lot of the large conferences and research studies were coming out and so it really just seemed like everybody was just starting to get it.

It had always been a thing and it's always been an issue. I mean, mental health and diabetes has always been linked but it was finally becoming a real big part of the conversation and I thought I think this is where I'm needed and now especially being a practicing therapist. So many people do say that how much they wish they had a therapist with diabetes, how much that life with diabetes, the shot, you know, shots or wearing an insulin pump or the 24/7 of diabetes, the real impact on relationships, how much it really shaped who they are and how they wish they had somebody that they could talk to about that. I'm just seeing more and more evidence that the specialization is really needed. And I'm, I'm really excited to be a part of that. I wish there were more of me, you know, there's like 12 of us, right? I mean, there's, there's more than 12. But you know, there are not a lot of therapists with diabetes. And there's not a lot of therapists who really specialize also in diabetes, they may have it but it might not be something that they're super vocal about working with as a real specialty.

I'm still pursuing my CDE, I'm just going to very long route. I'm going to the unique qualifications pathway, which is much longer, but I do also want to be an educator. I want to do both because I really think that that's what people need. They need education and they need the mental health support and you can't separate them. They're inextricably linked in the life of someone with diabetes.

Sure. Well, let's talk about that. Because I think that the biggest topic that seems to come up the most obvious one, for people who talk about trying to find a therapist or needing help with diabetes, it seems to be what everybody kind of refers to as burnout. Is it really burnout? I mean, where does somebody start if they think I just don't want to do this another day?

Well, nobody really wants to do it another day. So, it's really quite prevalent. Bill Polonsky and Larry Fisher, they're out in California, have really spearheaded the research in this area. And so, I've read a lot of their research and have met with them and talk to them about this.

And from my perspective, I kind of take, I don't know maybe a unique or kind of, sort of put my own stamp on the topic. I really see two things show up for people or maybe even like a spectrum of things that show up for people in both the clients that I have worked with, and also when I do speaking, and just meet with people out in the community - there are two words that get thrown around and that's diabetes distress and diabetes burnout.

And if you read the research, if you read articles online, you'll see them use somewhat interchangeably that they kind of mean the same thing, and it goes everywhere from having just this frustration, or anger or fatigue

with living with diabetes all the way to not actually managing diabetes anymore. And that can look like a lot of things to me. And that can be anywhere from not taking insulin as needed or not to have testing blood sugar and not wearing CGM or ignoring the alarms. I mean, it looks like a lot. I mean, there is such a spectrum of health as shows up for people. So it's very individual and I think that's one thing that I think people need to keep in mind is just like your other mental health issues anxiety and depression, those things can show up differently for different people, what symptoms people have, the root cause of anxiety is going to be different for everyone.

I think the same idea can apply to those dealing with diabetes burnout, or diabetes distress. And so, I sort of put things into two buckets. When I give my talk, I talked about diabetes distress and diabetes burnout as kind of being their own things.

Distress, being more of the day to day emotional burden of living with diabetes, just being really frustrated, with the roller coaster, maybe feeling angry that you are having to take time away from family or a social event, maybe feeling guilty or shame over the blood sugar reading that you're getting. And then if that persists, it can really lead to people really pushing away from their care because it becomes so distressing that you have to say 'I don't want to do this anymore.' And so, I'm not going to and people don't necessarily think that like, consciously that they're like, I'm just not going to take care of myself. Most of the time, it's a very subconscious reaction to what's going on and they just delay, they kind of bomb on both later. And I'm just going to, I'll take it a little bit like, I just want to do this right now.

And so, it starts showing up in their health behaviors, it starts showing up in are they pre-bolusing? Are they testing? Are they doing all these things? Then at the end of the day, three, six months later, they go in for their A1C, and it's elevated from where it had been, and everyone's going, what happened? And it's really been this slow progression that is really kind of insidious that you may not even know it because it just builds so gradually, that you get to this point. And I think a lot of people, I mean, it is normal, I mean, just diabetes, the stress affects like half of the people with diabetes at any given point, like it affects everybody, basically. But a lot of times I think people think that there's just nothing that you can do about it like this is just diabetes and so there can be kind of a hopelessness with resolving it in any meaningful way.

Well, I guess my question would be then, what do you do, right? How do you even recognize it's happening? And then once you see it, if it was easy as Oh, I just need to get back on track. Right, everybody would do it.

First of all, there needs to be a greater awareness among I think our health care providers for recognizing the stress and burnout. I think that is a big conversation topic that is missing when we go in for our appointments. I can't recall a time when I've had an endocrinologist or a nurse practitioner ask me how am I doing mentally with just balancing life and diabetes? I mean, sometimes it can be validating, as far as my A1C goes up a little bit, oh, well, you're a new mom and that sort of thing. Like they can sometimes just sort of recognize that this is a transition point in my life, but as far as actually doing any kind of assessment, or really having that conversation of educating people that the stress and burnout are real things that people with diabetes experience.

I think if more people had the language to describe what they're going through and to know kind of ahead of time, this is something that could happen, this is something that's likely to happen because of the nature of the

disease, I think people will be much more readily able to reflect on their experience and then say, 'Hey, I think that is what I'm going through, I need to reach out to either my health care provider, or I need to reach out to a therapist or a psychologist, because this is something that needs to be taken care of, so that it doesn't negatively impact my emotional well-being and my physical well-being,

You know, one thing that interests me as a parent of a child with type 1 is that I often have gotten comments from very well meaning friends who say things like, 'Well, you know, it's great that he's so used to it, you know, always just be part of his life. He's fine. You know, he'll grow up and he'll, you know, he'll be used to it.' And I worry a lot about well about Benny certainly whose 14 now, but about adults with type 1 who've lived with it either since childhood or were diagnosed as adults. And there just seems to be this perception that, oh, they're over it, they got it. But that's not the case, right? I mean, you could have diabetes distress and burnout at any age.

Yeah, absolutely. Yeah. And it doesn't just go away. If it's not taken care of, if it's not addressed, it's not really going to just go away. Research shows how persistent it can be if it's not really tackled head on. I think it can kind of wax and wane a little bit, but it's pretty persistent as far as what they're seeing through, you know, interviewing people. And yeah, I think going back to what you're saying about growing up with type 1 diabetes, I think that there is this idea that it becomes normal or it's not a big deal anymore.

And the truth is that diabetes changes; going through puberty, it changes, physiologically there's changes, but then relationally when you get older going into college like your entire social structure changes. Your parents aren't there anymore and you're on your own for everything. So not only are you having to worry about paying rent and paying the bills, but you're also having to remember to go to the pharmacy and learn how to check your insurance benefits and all these things. This is more kind of To Do's and then you have a whole new set of people that you're introducing your diabetes to.

If you've grown up, then you might almost forget that you have to introduce it to people because you've gone through elementary and middle and high school that at least that's what I was for me. Everyone knew by the time I graduated from high school that I had diabetes; I didn't even have to introduce it anymore. But then you go to college. When I graduated from college, I moved across the country. So again, the whole transition and the whole kind of upheaval of your life happens, especially in your 20s fairly regularly as you're kind of establishing yourself and establishing like your own circle, you know, new friends in your work and romantic relationships and your own children. And so, it keeps going. And so, diabetes continues to evolve, not so much in that the disease is changing, but the way that it kind of shows up and impact your life changes. And those things can be just points for people. And if you're not getting support to go through all of that, it's really hard. It can sometimes feel like you're being diagnosed all over again because you're going through the changes.

I know one of your specialties is that path to independence, that transitional time, from teenage to college to you know, living on your own. Can we talk about that for a minute?

Yeah, I love it. I love talking to parents, whether I'm coaching them or, you know, doing family counseling. I think it's such an important topic because again, I think up until recently, there were not a lot of structures in place to help teenagers and parents navigate that very unique transition because taking ownership of diabetes is much different than taking ownership of your homework. There are different consequences to that; starting to do your own laundry is different than ordering your own diabetes supplies, or learning how to change your own basal rates and things like that.

So, I think families need a lot of support and education as far as like what to look for, because this is not something that is going to show up in like Parent magazine. Like how to guide your kids, the independent management is not going to be an article in Good Housekeeping.

So, let's just jump in and answer some of those questions, if you don't mind. What are some things that parents should be doing and can do to help out with this transition?

I think that's such a big question. I think there's two things that immediately come to mind as far as the questions that I get most often is when to start and what to allow kids to start doing. And so I kind of say, you know, start early and go slowly that you can start asking and kind of gauging interest and maturity level as early as like 10, 11, 12 years old, But you need to obviously give over full control much, much slower than you would other tasks just because of the seriousness of the tasks that you're giving over.

And I think that's where a lot of parents can, you know, they don't do it intentionally. But I think that's where parents and teens can find themselves getting into a lot of that kind of the DKA scares and things like that. And that teen girls 12-13-year-old, maybe want to because they want their parents to stop asking them about their diabetes. They're like, yeah, I'll just do it. I know how to do this. I've been doing this since I was six. This is easy. And then they do it and then they kind of go through their own burnout distress because there's a lot going on when you're a teenager and they can have a hard time with the management and kind of the forethought and the reactivity that diabetes requires, when they're also balancing peer pressure and liking a guy or girl, you know, whatever.

You know, there's a lot of distractions when you know when you're a teen, wanting to impress somebody focusing on your sports. And it's not that they won't ever be able to do it, but their brain development just isn't there yet to be able to kind of cope with everything. That's why you see kids who struggle with remembering to bring their homework or remembering to bring their lunch or their instrument -kids are always forgetting things. When you forget things related to diabetes, though, that that's a lot more serious than forgetting your English essay.

So it's not that parents should completely hold on to everything and say, 'No, you're not allowed you I'm ready to do everything' because that also sets the kid up for not developing the skills at all, but it's this real dance of giving a little watching and communicating and assessing your kid because your kid is going to be very different than someone else's kid. As far as their readiness, their maturity, their brain development, even the devices that they're using are going to require different skills, different management. Start early introducing kids to concepts and demonstrating and showing them this is how you call the pharmacy. This is what you say - I'm not expecting you right now to go and do this on your own but I just I want you to be watching. I'm going to demonstrate other things that they have to learn. You demonstrate first and then you let them try it out while you're watching. And

then eventually you watch a little bit less as time goes on until they're now either 18 or 20 or 22.

I don't think there's necessarily like a complete cutoff. In fact, I actually advocate against that, I think that part of burnout is that abandonment that adults feel like, I have to do absolutely everything for diabetes completely on my own. And I am tired of it. I'm not necessarily in favor of a complete cutoff. Especially not all in one 'let go' though. I think it needs to be done really carefully, really slowly. And it needs to be done kind of on the terms of the individual with diabetes, and they may want more or less support than someone else. And I think that's great. I think that flexibility is really needed to match the personality of each person.

How hard is it for an adult to reach out and ask for help? Somebody you know, like yourself, very capable. You're a mom of a toddler. You're working, you're busy. I imagine you're not running around saying I really need more help. Even if you might, I mean, it's hard to ask for help without diabetes. How do you talk to people about you know, saying, you know, you can't do this all on your own? It's okay to share the burden. It's got to be difficult.

Yeah, it is. It is. That's a piece of self-talk that I work with a lot of my counseling and coaching clients all together is this idea of being a burden is a prevalent narrative. I think as you grow up is, you're a lot of work. I think, because we see it, it's like, we think it's a lot of work. And why would anybody want to do this or I don't want to give this over to somebody else. I've met so many young adults who are worried about getting into a romantic relationship because they're worried about the burden of diabetes.

For me I don't know if there was necessarily a moment in time where it became like a revelation or I don't I don't think it was like a light bulb moment. But I think just evolving to the point where you could see how reaching out to those who are particularly close to you. So, you don't necessarily need to feel like I'm going to just ask strangers or anything like that. I think starting with those who are closest to you, because those are relationships where, as humans, we want to help ease the burden of those that we love. I often ask my clients and think of it in reverse, like if your spouse or your best friend or your brother was going through diabetes or just going through something really hard where they felt burden would you want to help them? And of course, the answer is like course I would want to help. I love them. And it's like, that's what love is, love is wanting to help ease the burden that somebody is experiencing. And so, if you are secure and confident in that relationship, then that is an interaction that you can really invest in.

And I think being able to see how the sharing of burden really can actually enhance the intimacy and closeness of a relationship, it makes me more open to, you know, inviting my husband to get me to use facts or to tell him what my A1C is because I know if I'm excited about something, you should be excited about it. I know he wants to be in on it so that he understands what my experience is and can be emotionally supportive, or vice versa. If once he goes the other direction, and I'm sad about it, he wants to be able to comfort me because that's why he's there, right? Like, that's why you get in these relationships is to be able to be supportive. And so, understanding that diabetes is just like that. That for me is something that has helped as a mom and as a wife and friend and daughter having that relationship and knowing that that's why they're there. That's the purpose of those relationships is not just to have a good time, but it's really to be able to be a support for each other and this is one of the areas. Where we most need support? And there is our experience will show that I mean, there's research to show it but you don't need research to know that you need support with ideas.

Right. Let's back up. We're well into this interview, Allison, but I didn't ask you about your own diagnosis story. You were diagnosed as a kid; we've mentioned that you live with type 1. How old were you? What do you remember about it?

I was eight years old. So, I did like the whole teenage years. I remember what that was like. And, you know did college with diabetes. And I got married just before I turned 26. And now I have a two-year-old so I've done a number of the life stages. Now I'm going on 26 years with type 1 diabetes. Yeah, it's been definitely been, you know, interesting. And like I said, each stage you know, diabetes just looks a little bit different. So, my own, the stress and burnout have come and they've gone and they've come and they've gone again.

You're in a very different place now as a parent with type 1 of a child who doesn't have type 1. And that's a very different experience. And I know this isn't a whole episode about that. But has anything kind of surprised you in the last two years, we focus a lot about pregnancy. But we don't talk too much about being a mom.

I know. It's like once you have the baby, everything is supposed to be easy. And it's not actually. I would say that's right when the burnout, that's my I guess when my last kind of burnout happened right after I had him because I was in such a period of such intense care. And then there was this huge transition of becoming a parent, not sleeping as much. He didn't have health issues, but we had trouble nursing and he had a tongue tie, so feeding so there was so much attention on him that I didn't even notice. Oh, and I started a job. I had a baby and started a job within eight weeks.

So, I didn't notice that it was just like I talked about. It was like, I don't have time for this. This is so much work. I just I'll do it later. I'll correct later. It's not that bad. You know, 220 was kind of like, well, I'm not 300. Your whole narrative about it kind of changes and adjusts. And for me, it wasn't so much that I just suddenly said, like, I hated diabetes, I'm gonna stop doing it. But it stopped being such a priority. It was so much work and I had so much other work going on. I had to just kind of push it a little bit. And I hear that from a lot of people, they're like, it doesn't have that sense of urgency of keeping the baby alive.

So, I got my A1C done and it jumped like a percent and a half and I was like, okay, yeah, I think I'm in it. And so, yeah, having to regroup was a big turning point. And just needing to really vocalize my needs as far as this is what I think we need to start buying as far as food goes, just you know making some shifts in nutrition not eating as many processed carbs, it's super easy because you just want to throw everything into the microwave. It was just like we needed to kind of regroup here and kind of think about how we want to do things differently.

I'm curious, too, when you have a moment like that in your life, which is a prime example of how difficult diabetes can be. Was it difficult for you to not be angry with yourself to kind of forgive yourself and say, I needed that time, I needed to get through that time? It's okay, that my A1C, went up, my baby was the priority. And I'm getting back into it. Was it hard for you to do that for yourself though?

Yeah, I think just like anyone, I think there's always that moment, kind of cringe that like, oh, man, like, that's not so good. It's easier now. I think I've had a lot more practice. This being sort of mindfully detached from the numbers, that when I either see a blood sugar reading or I get an A1C to know this is a moment in time, this isn't forever. And to know that an A1C that we know at that level is not going to make or break my long-term health, it's important to respond. But it is also equally important not to be too reactive, like emotionally.

I've done a lot of my own work around being able to see numbers as just data. And it's hard sometimes especially when you are putting a lot of effort into it. There are those times of being frustrated and I think that's normal. I think there's also an encouragement I want to leave people with to one not over pathologize your own emotional reaction, that's also normal. You know, not everything has to be rainbows and butterflies and unicorns, and you are upset with a 272, you can be upset that you're 272. Like, that's fine. Like there's nothing wrong with being upset about a number.

But it's where is that going to go? Are you going to stay upset? Are you going to let that number you know, ruin your whole day or your whole week? Are you going to sort of throw an adult temper tantrum and just say like, I'm going to skip the party and I'm not going to go out with my friends because that's just going to make me more miserable? That just snowballs the emotion that doesn't resolve the emotion. It's okay to be unhappy or dissatisfied with a result. But it's also equally important to say like, okay, now what am I going to do that's going to help me rather than just either giving up and just saying, like, well, I'm just such a screw up. I'm not, you know, I'm not going to get this right or it's not worth it, or I keep trying. It's like, why even bother? I mean, because those fuel the wrong behaviors. They're not going to improve things. They're not going to get you where you want to go. So, it's important to be really mindful of the story you're telling yourself when you're seeing these numbers. It's okay to have those emotions. But where are those emotions taking you?

So a question that I wonder about, and you think you're a good person to ask because you've had diabetes since before a lot of the technology that is around now, and many people, really people outside the community is 'oh, the technology must make your life so much easier. Or, you know, Wow, this is so great. Now you can do that.' And it certainly has improved lives in many ways. But I'm curious, I sense that CGM data in particular, stresses people out. And I don't even mean the people with diabetes. I mean, the caregivers, the partners. Can you talk just a little bit about how do you navigate seeing all of the information? And I guess we'll break it up into two parts here for the person with diabetes because it's so helpful for so many people, but at the same time, it causes a lot of stress in people who kind of get anxious, so let's start there if we could.

Yeah, a little-known secret of me is when I was pregnant, I just stopped using my CGM because of that, which most people would be like, that's the time to use it. Right? And it was it was counterproductive for my mental health. And I had a hard time not being reactive to the numbers. It forced me to really slow down. It was a lot of extra work because I mean, I tested probably 10-12 times a day. It was a it was a lot of test strips, but I would test every two hours and I would only respond to the blood sugar that was there every two hours because what I was doing was I was rage bolusing, when I would see like a 160 and that I hit 30 like five times in my first trimester. And I was just like, this is kind of driving me a little bit nuts. I need to step back.

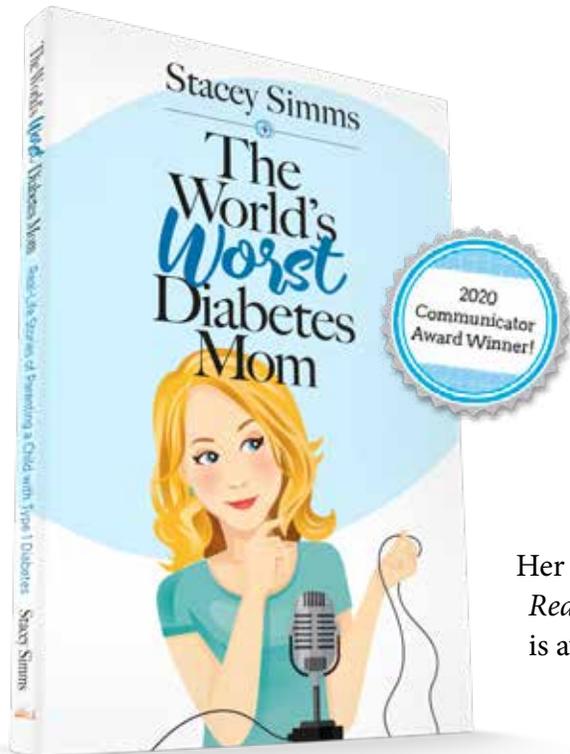
And so yeah, to your point, I think taking breaks from technology, taking breaks from our own expectations of what kind of time in range or blood sugar average we need to have all the time can actually really help. Bill Polonsky calls them diabetes vacations. You just take very short, very purposeful, intentional and planned breaks from whatever it is that you normally do, just to kind of release some of that anxiety and not that you stop taking insulin or the kinds of things that you really need to do stay healthy. So, if you're going to take a break from your CGM, you might want to test your blood sugar a couple extra times just to kind of balance that out. But then there's not that alarm fatigue or anxiety about what the arrows are telling you.

So, there's different ways to kind of manage that. And it's very individual and for what's going to be most successful. For some people is more helpful just to turn the alarm off, you can still have the CGM data, or you can switch to from a Dexcom to a Libre so that you're still getting aspects that you find really beneficial, but you're sort of changing up some of what is irritating you and stressing you out. That's something that I recommend to people to be at least self-reflective about. And then I think with caregivers and adults alike, I think part of the anxiety too is a lot of what we have been told about the numbers. There's just a conversation about what these numbers mean, what they're going to do to you, there's a lot of scare tactics that healthcare providers will give to parents so that parents will give to kids and let kids grow up with and then they hold on to the act of like, this is what that number means. You know, there can be feeling of failing, of shame of inadequacy in everyone parents and the T1's themselves. And so that's something to really pay attention to, and I hope that something that our health care providers will start paying attention to as well because they have such an influence and how we see diabetes and how we interact with it. They are our first teachers with this disease, and they really need to lead by example, and their conversations with us. And then so on and so forth, you know, parents with their children, adults with their spouse or their friends, these conversations spread, and they are the education and they're the story of what an existence what diabetes is like. And so, we have to really pay attention to what that story is because it carries on.

Well Allison, thank you so much for sharing your time with us for this really valuable information. I really enjoyed talking with you. And before I let you go, just really quick, tell me a little bit about your little boy, his name is Henrik. And is he learning more about your devices and anything diabetes related?

He is all "juice boxes are Mama's juice box." That's why we bought you know, we were at the grocery store yesterday and he thought you know, Mama's juice box. So, they're mine and you know, he knows PDM, Mama's PDM although sometimes thinks it's a phone. He'll also say Mama's phone because it looks like a phone so he's getting kinda into some of the language but he doesn't you know as far as identifying objects but he doesn't really know diabetes quite yet. Just that Mama drink juice boxes sometimes. And then he'll drink them when they're not like empty, he'll pretend to drink. Pretty funny.

Well, thanks so much for spending so much time with me. I appreciate it.



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Her award-winning book *The World's Worst Diabetes Mom: Real Life Stories of Parenting a Child With Type 1 Diabetes* is available on [Amazon](https://www.amazon.com) and at diabetes-connections.com.

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