

About Health TV with Jeanne Blake
Type I Diabetes
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JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. One hundred and fifty thousand children in the United States have diabetes. That's the body's inability to use or metabolize sugar properly. There are two types of diabetes. On this edition of *About Health TV* we'll focus on type I diabetes, and we'll do so with the help of Dr. Laurie Lafell, the chief of the pediatric and adolescent unit at the Joslin Diabetes Center here in Boston, and Tim, a patient of Dr. Lafell's. Thanks to both of you for coming in to talk with us. We're going to talk about type I. Dr. Lafell, what is going on when somebody has type I or type II diabetes? What's not happening in Tim's body that needs to be happening, that results in his being diabetic?

DR. LAFFEL: In order for the body to use sugar for energy, you need a hormone made in the pancreas which is called insulin. In type I diabetes, the body has destroyed the cells that make insulin. They are very specialized cells called beta cells in the pancreas, and the body's immune system has somehow been triggered to self-destruct those insulin-producing beta cells. This is a gradual process, but over time Tim's body no longer has the insulin-producing cells. So in order for Tim to look as healthy as he does today and to do everything that every other 14-year-old does, he needs to take insulin by injection, because his body no longer makes it.

JEANNE BLAKE: Now, when you say his body no longer makes it, Tim's type I is something that is early onset, or juvenile onset, as it used to be called. The other kind, type II, is adult onset, basically, right?

DR. LAFFEL: Right.

JEANNE BLAKE: Is there any other distinguishing difference?

DR. LAFFEL: Type II previously was called adult onset diabetes because type II would be distinguished by age, but types are not distinguished by age any more. It can happen at any age. The difference with type I and type II diabetes is, in type II diabetes the insulin-producing cells are still present in the body. The body is just not making enough insulin for the body's needs because of something that's called insulin resistance. This resistance occurs in the setting of obesity, in the setting

of sedentary lifestyles, lack of physical activity, and then certain populations are at increased risk for developing insulin resistance.

JEANNE BLAKE: So do we know why Tim's insulin cells decide to not do what they're supposed to do?

DR. LAFFEL: In contrast to type II diabetes, in which we understand a little bit about the body's developing insulin resistance and the obesity or inactivity, in type I diabetes, there was basically nothing that Tim did or nothing that his parents did that caused the diabetes to happen. There is some trigger, some trigger in the environment that lets the immune system self-destruct, doesn't reproduce beta cells.

JEANNE BLAKE: It's something in the environment literally?

DR. LAFFEL: That's something we're not quite sure of. What we know about type I diabetes is, it's a combination of having genetic susceptibility to developing auto-immunity, and autoimmune diseases are things like arthritis, some bowel disease, thyroid disease, and vitiligo. So there are many diseases that people have heard about. I mentioned vitiligo, because Michael Jackson may have vitiligo, and it is an immune disease that causes the skin to lighten, for example.

JEANNE BLAKE: Okay.

DR. LAFFEL: So there's susceptibility to autoimmunity, but there's some external trigger that then tells the immune system to destroy those insulin-producing beta cells.

JEANNE BLAKE: In fact, the Centers for Disease Control has ruled out that childhood vaccinations are a cause of type I diabetes. That was a published report about a year ago, I think.

DR. LAFFEL: Well, the scientific community has been looking to find what is this environmental factor that may be triggering autoimmunity, and it's probably multiple environmental factors. But it's not just one factor. It may be many factors in different people; it may be different factors at different times at different ages. But the important point is that the immune system has been turned on to destroy the insulin-producing beta cells. When I talk about the self-destruction, what I mean is, if my pinkie was cut off by a paper cutter, it would hurt. My body would not be able to grow back another pinkie, because we only have the potential for one digit, because the cells that would make another pinkie don't exist. If

I skinned my knee, the skin on my knee would grow back in a couple days and you would not even know I skinned my knee, because the skin on my knee has the potential to grow back into skin that covers the knee. Unfortunately, those cells in Tim's pancreas are like my pinkie. If they are destroyed by the immune system, there is no potential for them to grow back.

JEANNE BLAKE: Now, we're going to talk with Tim in just a moment about what it's like to live with that reality, but before we turn to Tim ... diabetes when it's, I guess at any age it's more dangerous than a lot of people give it its due. But the complications are potentially pretty awful if you don't take care of yourself. They include ... can you just give us some breadth of what the complications are?

DR. LAFFEL: Well, the complications are frightening, because it involves loss of vision, loss of kidney function, diabetes is the leading cause of amputation, non-traumatic amputation in this country, and blood vessel disease. So you get early heart disease as well, possibly.

JEANNE BLAKE: Can you help us understand the role that insulin plays and why that variety of potential complications is there? I mean, what does insulin do?

DR. LAFFEL: Well, what insulin does is, it helps control the blood sugar level. Everyone has blood sugar levels that sort of rise and fall in response to food. That is normal metabolism. In the setting of diabetes, blood sugars rise too high in response to food. So if diabetes is either untreated or treatment may not be adequate, the sugar levels rise too high. There have been large studies in this country and around the world which have proven without a shadow of a doubt that the higher the blood sugar levels are, the less well-controlled the diabetes is, the greater the chance of developing these complications.

JEANNE BLAKE: But do we know why? Every program I get this why, why, and I'm like a child. I want to know why.

DR. LAFFEL: If a person doesn't have diabetes, they don't get these complications, so these complications are related to the abnormal metabolism. They're related directly to how high the blood sugar is. When the sugar isn't being used normally, the body resorts to using other fuels as well. So when our sugars are high and the body can't utilize normally in the absence of sufficient insulin, lipid levels – cholesterol, triglycerides – also rise, so you have this combination of sugar levels are out of control and then lipid levels go up, and so on. But the point is, these complications are incredibly frightening, but they're also preventable.

JEANNE BLAKE: Right. And we'll be talking about that treatment as we go on. But that's the first time in my life I've understood that. Very good explanation, Doctor. It really does let everything else that creates all these complications get out of whack. All right. Well, Tim, you were diagnosed – you're 14, right?

TIM: I'm 15.

JEANNE BLAKE: You're 15. You were diagnosed with diabetes when you were 11?

TIM: Yes.

JEANNE BLAKE: What was it like? What were you feeling that you knew that something was wrong with your body?

TIM: Well, when it first started, my heart was kind of beating irregularly, like when I would be doing activities and stuff such as mountain biking, skateboarding, and stuff. And I would always be very thirsty and very hungry and I would also have to go to the bathroom a lot.

JEANNE BLAKE: And did you wonder, What's wrong with me?

TIM: Yes, I kind of wondered that, but I just thought it was because of my activity, because I was really active, so it really didn't bother me too much.

JEANNE BLAKE: And then how did you find out? What then went from it not bothering you to your actually going to the doctor and finding out what was wrong?

TIM: Well, it was kind of getting worse, because I was getting more thirsty and I'd be drinking a lot and then I'd just be going to the bathroom just as much. I would also be losing weight, and so we went to the doctor and it was right around Christmas vacation, right around the 18th, I think. We went to the doctor's and they said I had diabetes.

JEANNE BLAKE: And what was your reaction? First of all, did you know what that meant?

TIM: I had no idea. I just thought Hey, something is screwed up.

JEANNE BLAKE: Did the doctor explain it?

TIM: She kind of said a little bit like your pancreas is not working, you should go to Children's Hospital, and that's what we did.

JEANNE BLAKE: And what was your reaction?

TIM: I was just like, oh, I thought, Oh my God. I didn't know what was going on.

JEANNE BLAKE: So it was frightening?

TIM: Yes.

JEANNE BLAKE: And do you remember then when you started to find out more and more about what it was what your reaction was?

TIM: It was just like ... I have really no idea what I was like. I was just kind of like a little bit shocked knowing that I would have to go through this for the rest of my life.

JEANNE BLAKE: It's hard, especially when you're 11 years old thinking of forever. It's a tough concept for a young person.

TIM: Yes, exactly.

JEANNE BLAKE: So you had to start getting insulin injections?

TIM: Yes. When I was diagnosed I took like two shots a day, one in the morning and one at dinner. I was taking very little insulin because my cells in my pancreas were still alive and kicking; they were getting destroyed.

JEANNE BLAKE: I see. And so what was that like, to have to get a shot? Most young people, most people don't like shots. What was that like?

TIM: Well, the needles were a lot smaller than the flu shot or something.

JEANNE BLAKE: Oh, they were?

TIM: It was still a pain, because you had to test your blood sugar four times a day and take a shot. So it was just like ... you just really didn't want to go through it.

JEANNE BLAKE: Were you giving yourself shots at that point or do you now?

TIM: Yes, I give myself.

JEANNE BLAKE: And when did you start giving yourself shots?

TIM: Probably like a month right after I had it.

JEANNE BLAKE: Really?

TIM: Yes, because I kind of wanted to be independent and do it myself.

JEANNE BLAKE: An 11-year-old. Do a lot of 11-year-olds give themselves their shots, Doctor?

DR. LAFFEL: Well, Tim does a great job with his diabetes and he does a great job because his parents are with him all the time. Tim obviously has the understanding to hold a syringe and to drop a dose and to inject the insulin. But he does this because his parents are right there with him and his parents are helping with the dose and they're helping to make the right choice for his meal planning and his exercise. He's right. He has the independence because he can hold the syringe but this is all within ... you know, he has a safety net around him and that's why he's doing so well.

JEANNE BLAKE: It's incredibly important to have that family support to do as well as Tim is doing. Tim, when you had to tell your friends, or I'm assuming that you told your friends ... did you tell your friends?

TIM: Yes, I told many of them.

JEANNE BLAKE: Right away?

TIM: Yes, probably like the next time I saw them I told them.

JEANNE BLAKE: And what was their reaction?

TIM: They were like, "What's that? What's diabetes?" And I had to explain it to them and they were just like, "Oh, that really stinks."

JEANNE BLAKE: And did anybody ever tease you or make comments about it?

TIM: No, no one ever did that.

JEANNE BLAKE: That's good. How did you find that it affected ... I know that you're doing well, I know that you're active in sports, but how did you find that it did affect your life?

TIM: Well, right from the get-go I kind of found that it affected me.

JEANNE BLAKE: How?

TIM: Because, like, before I could just, like, I could just wake up whenever I wanted to. I can do that now, but I just have to incorporate the shots into that. You could eat whenever you wanted to without having to do anything, you wouldn't need to test your blood sugar, so it's almost like you have more freedom. But now you still have the same freedom, but you just have to, like ... it's all a matter of just taking a shot at the right time or testing your blood sugar.

JEANNE BLAKE: Dr. Lafell, when we were out in the lobby before Tim came in, I saw a snapshot of what that's like, because I think that your mom or dad mentioned Where's the testing kit, and it's in the car, and do you need a snack, and should we get a snack, and it seemed to be sort of a microcosm of life with Tim. Right? I mean, that's what the managing of diabetes is like, making sure you're always thinking ahead.

TIM: Yes.

JEANNE BLAKE: Do you think it has a negative effect on your life in any way, or at this point now for a 15-year-old is it pretty routine?

TIM: I think it's really routine, it's just like an everyday thing.

JEANNE BLAKE: So, Doctor, talk with us a bit about Tim's treatment. It's typical, right? Two shots a day are you still taking, Tim?

TIM: I'm taking three now.

JEANNE BLAKE: Three a day. Because your cells ... more have died off, right?

TIM: Yes, pretty much.

DR. LAFFEL: He takes a minimum of three shots a day. Because if he ever has a day where he needs to eat a little bit more or his sugars may be running a little bit higher, which happens all the time, he would actually then get an extra fourth or fifth shot a day. What we try to do is, we try to give insulin to match the child's lifestyle. The treatment programs for children with diabetes, for adults with diabetes, are individualized, because diabetes doesn't go away. It's a 24/7, 365-days-a-year job. You don't go on vacation from diabetes, and in order to keep up with the rigors and the demands of diabetes management, you at least want to make it fit easily into Tim's lifestyle. That Tim could learn as an adolescent how to sleep late with diabetes is wonderful. That's key, and you learn how to do that by changing the timing of some of your insulin injections. And you don't do this in isolation.

JEANNE BLAKE: Give me an example. Changing the timing of your injections, what does that mean? Help me understand.

DR. LAFFEL: Well, right now, Tim, for the most part, takes insulin, and you can tell us when, Tim.

TIM: I take one in the morning when I wake up, I take one at dinner, and I take one when I go to bed.

JEANNE BLAKE: Okay. And so the change is where?

DR. LAFFEL: By taking insulin ... he has to take insulin before breakfast and before supper. You also take different kinds of insulin, because you have insulin that's called short-acting insulin that sort of covers a meal, and then you take long-acting insulin, which covers what is called the basal insulin needs in the body. Even when we are fasting, the body still needs insulin in order to use sugar

for energy. So you take different kinds of insulin and at different times of day to match what the pancreas used to do.

JEANNE BLAKE: I get it.

DR. LAFFEL: And now by moving that supper shot of insulin, Tim still covers his dinner and even a bedtime snack if he wants to, but taking a long-acting before his bedtime allows him coverage overnight and into the morning and lets him sleep late.

JEANNE BLAKE: Terrific. You're involved in sports, yes, Tim?

TIM: I play hockey, I mountain bike, I'm going to be playing on the lacrosse team for my high school.

JEANNE BLAKE: Wow.

TIM: I play paintball.

JEANNE BLAKE: That's not a sport, young man.

TIM: Oh, yes it is.

JEANNE BLAKE: Paintball is a sport?

TIM: It's a professional sport.

JEANNE BLAKE: Oh no. What's happened? Paintball is a sport?

TIM: It is a sport.

JEANNE BLAKE: The look on Tim's face is like, "Boy, you don't know very much."

TIM: No, I mean, my friends and I are in a five-man tournament team now. It's just as competitive as a hockey tournament.

JEANNE BLAKE: I stand corrected. But you don't find ... Doctor, what about Tim putting that stress on his body? I mean, does that require a closer management?

DR. LAFFEL: The exercise isn't stress for his body. The exercise is health for his body.

JEANNE BLAKE: Well, you know what I mean. Demanding, demands on his body.

DR. LAFFEL: It's just like for everybody else. Maybe we don't have to play paintball, but exercise is healthy for all of us.

JEANNE BLAKE: But doesn't that demand on the body change the requirements?

DR. LAFFEL: It means he needs to be more vigilant about his diabetes management, because when you're exercising your muscle cells need more energy, they need more sugar for energy, so you have a chance for your sugar to fall rapidly. So Tim has a bigger job than other people when he exercises, because he needs to check his sugar before exercise, check his sugar after exercise, he needs to provide a snack before exercise. And not only that, even hours after the exercise sometimes, you're at risk for your blood sugar dropping. He needs to be checking his sugars at bedtime and providing an overnight snack to make sure there isn't a lull. I give Tim a lot of credit.

JEANNE BLAKE: This rigorous schedule that you're describing, that takes so much vigilance on Tim's part and on the part of his family. Is there anything in research right now where you could see this becoming a little bit easier?

DR. LAFFEL: There's a huge amount of research going on in this country and elsewhere, trying to learn what causes diabetes, ways to hopefully in the future prevent diabetes, in the future to cure diabetes by replacing those cells that have been destroyed in the body. While we're waiting for these really important scientific advances, every single day there are improvements in technology that is a very important part of Tim's diabetes management. I mean, the way you check blood sugar today can take as little as five seconds. When this technology came out only about 20 to 25 years ago, it would take over two minutes and would not nearly be as accurate. So five seconds isn't a whole lot of Tim's time for checking Tim's blood sugar. There are new insulins around to add to Tim's flexibility. What families tell me is that, besides knowing diabetes doesn't go away and it's frightening to be living with it, the thing they miss the most is the lack of spontaneity, what you heard Tim mention before about how he has to think about diabetes before sports and so forth. New technologies will help bring back some spontaneity. Those include possibly using an insulin pump, using a new kind of insulin that provides

some basal insulin coverage, and then you just take small injections when you're going to eat, and quicker ways to check your blood sugars and more continuous ways to check your sugars.

JEANNE BLAKE: There are pumps on the market now, and I guess, from what I've read, they are in the process of being refined and made more like the natural body process.

DR. LAFFEL: Pumps are one of the choices for treatment, and Tim could elect insulin pump therapy. The thing about a pump now is, pumps still have to be managed. They're what's called open-loop systems; all they do is deliver insulin. Just like a syringe, they just deliver insulin. They still need the programming of the person to decide how much insulin to give.

JEANNE BLAKE: And that has to change all day long, right?

DR. LAFFEL: It needs to change as you eat. The basal amount of insulin can be preprogrammed, but it doesn't help you every time you need your sugar changed.

JEANNE BLAKE: I see. Okay, that makes sense to me. All right. I could keep talking to both of you. Tim, I'm going to say goodbye, because we want to get your mom out here to get her perspective on all this. But I applaud you for coming in to tell your story so that other people can understand what it's like for a 15-year-old to live with diabetes. And we wish you continued good luck and good health.

TIM: Thank you.

JEANNE BLAKE: So we'll be back in just one moment with Kathy, Tim's mom, to learn about what it's like to have a child with diabetes in your family. Stay with us. ...

We continue our discussion now about type I diabetes with Kathy and Skip, Tim's mom and dad.

Thank you for coming in today to talk with us and to shed some light on what it's like for a family to go through this. Skip, when you learned that your 11-year-old athletic son was living with diabetes, what went through your mind?

SKIP: I was pretty scared. I was scared for him because of the infringement that it would have on his activities throughout the rest of his life. Plus, I really didn't know a whole lot about the treatment of it. All you hear about is the fears of the long-term consequences of the disease. And through his stay at Children's, through the education program actually that was set up over at Children's and also at Joslin, we started to learn more and more about it. The part of the whole treatment, I think, which is the key, is

that the whole family gets connected with it. That's the whole learning process, and I think Tim's a really good candidate, he's a good kid to be able to let us help him with it, and we in turn are more than happy to help him.

JEANNE BLAKE: So you really do take the team approach? And Dr. Lafell has said that that is key to managing it as well as his disease is being managed.

SKIP: That's right.

JEANNE BLAKE: What is it like for you, Kathy, to sort of have to monitor that, every day, day in and day out? We're four years into his diabetes so now it's somewhat routine, but it had to have shaken up the routine big time.

KATHY: Oh yes. In the beginning it's overwhelming, and Tim will probably tell you, I think I was counting Cheerios for the first month, because you start with a meal plan and you start counting carbohydrates and it's an entire learning process that we went through. The one thing that we kept telling ourselves, and we've talked about this before, was that it's a lifestyle change, it's not a life sentence. And keeping that in mind, we worked to make the right changes for Tim, and yes, it was difficult, and we luckily had a lot of support from the team at Joslin, and there are parent support groups that we went to. So we saw other people dealing with the same issues.

JEANNE BLAKE: That's what I was going to ask you. What did you take away from that support group?

KATHY: Just the fact that a lot of the things that we were experiencing were common to many people, to many families, and yes, there is stress related to learning about diabetes and to learning how to deal with it. There are joys when you learn to do things right, when you've given your child a shot and you haven't had any seepage, the insulin stays in his body, because sometimes that can seep out onto his skin, when his blood sugar levels seem to be leveling off. There are a lot of successes that we saw too.

JEANNE BLAKE: Dr. Lafell said that we don't know what causes it. I just can't imagine that you didn't go back and wonder what caused it, and I'm wondering if you felt if you had angst over that or felt guilty?

KATHY: Not guilty, because immediately at Children's we were taught that it's no one's fault, it's something that takes place. It's almost ... I can picture it like a puzzle. There are a number of different pieces that if they all fall into place, then if the puzzle is complete with diabetes, then that could be the onset of the illness. But it's not anything that either one of us could have done to prevent it or either one of us could have done that caused it. It was just a series of things, a series of incidents, perhaps, that took place in Tim and then here we are.

JEANNE BLAKE: What do you think, and I'd like either one of you to respond to this, your son seems so very well adjusted with this and as the doctor says, he's doing extremely well. He's sort of the model diabetic patient.

KATHY: I'd like to think that, but he's just a regular kid and he always was. He was a happy fellow before diabetes, and he's going to be a happy fellow throughout his life.

SKIP: We just didn't want anything to basically restrict anything that he wanted to do, and I think through the education he can learn to live with it. The fact of all the activities that he does and different sporting activities, I mean the one thing we're concerned about is him being by himself, like if he's mountain biking or if he's biking around town with his friends, if he gets low, how to be able to be treated. The next fear that we're going to be going through is, two years from now he's going to be driving. The more that he can be adjusted and learn about his body right now, the better off he's going to be.

JEANNE BLAKE: I'm wondering what advice you have for other parents who are just learning about this, about their child living with diabetes, and what advice you have that can help them deal with it as successfully as the doctor thinks that your family is dealing with this.

KATHY: What would I tell people first? I'd say be gentle on yourself and don't beat yourselves up about something that you can't change, that with support between one another, the support you have among family members, with your friends, with loved ones, there are so many ways you can get support to feel more confident about dealing with any issue in life. That's what people need to hear.

SKIP: You're not alone. You're not alone. There are a lot of groups out there and everybody has been through it before. And I think that's probably the whole key. We were so paranoid at the start. I mean, we had scales and this and that and how much is four ounces and this. I think the one other thing, too, with the program is that they had a phone call system, so if you didn't know how to take the shot or you didn't know how to do something, you could make the phone call.

KATHY: Call right into Joslin. They walked us through what we needed to do to adjust Tim's insulin level. It was great.

JEANNE BLAKE: Well, this program does air in other communities and other cities, so we hope that they have programs that can address those needs and give parents that kind of support. That's a good note to end on, that you guys are feeling that it's important to reach out, and hopefully other families that are hearing this will know to do the same. Thank you so much to both of you for coming in. I'll see you next time. I'm Jeanne Blake.

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