

About Health TV with Jeanne Blake
Diabetes
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JEANNE BLAKE: Welcome to *About Health TV*, I'm Jeanne Blake. On this edition of *About Health TV* the topic is Diabetes. We'll have an interview with the author of this book, *Cheating Destiny, Living with Diabetes*. As author James Hirsch, who lives with the illness says in this thoroughly researched and beautifully written book, diabetes is the only major disease whose death rate is rising up 22% since 1980. We welcome James Hirsch. Congratulations on this well-done book.

JAMES HIRSCH: Thanks Jeanne. It's good to be here.

JEANNE BLAKE: My first question after reading this book and re-reading parts of it is a very basic one. Why did you write it?

JAMES HIRSCH: I've had diabetes for 30 years now so obviously the subject is very personal to me. I have an older brother who also has diabetes.

JEANNE BLAKE: He is a prominent physician in the field?

JAMES HIRSCH: Correct. My brother, Dr. Irl Hirsch is one of the leading diabetologists in the country. Initially I really wanted to write a book about diabetes that explained what the disease tells us about: larger shortcomings in the healthcare system, the medical research field and modern lifestyles. Also what I hoped to do was really explain what I call the human drama of diabetes. Drawing upon not so much of my own experience, but I was able to reach out and contact many people around the country who have the disease or whose children have it. I really wanted to explain from their perspective what the daily challenges and struggles are with this epidemic.

JEANNE BLAKE: You certainly did that well. You've written three books prior to this and you are currently working on the first authorized biography of Willie Mays so there's a wide range of topics that you've covered. With every author when you decide to write a book there's that seminal moment when you say I'm going to do this. What was it for you? You didn't just one day get up and say I want to tell, was there something that clicked?

JAMES HIRSCH: Actually in this case, that moment occurred when my mother passed away some five years ago. She did not have diabetes but she had devoted a lot of her adult life to raising money for the cause and spreading information and education because she had two sons with diabetes. When she did pass away, the Rabbi at her funeral made reference to her work and the work that my father has done and my brother has done and he said when they find a cure for diabetes, our family would have made a significant contribution toward that cause. At that point I thought what have I really done for that cause and really I hadn't done anything except survive. There isn't that many things I do know how to do but I do know how to write, so at that moment I thought I was going to write a book about diabetes. I had no idea what it was going to say but I thought really this book was our family's contribution to the cause.

JEANNE BLAKE: That's so interesting. I never would have thought that it would have arisen out of guilt which you talk a lot about guilt in the book which we'll get to. Indeed, you've made your contribution so now you can move on. I think many people always appreciate that we start these programs that are focused on an illness with a bit of a primer and you certainly are an expert. Do you mind giving us a primer on diabetes? What's going on in the body when one has diabetes?

JAMES HIRSCH: Sure. I think the best way to think about diabetes is that it occurs when your body is incapable of performing its most essential function. In order for you to live you have to eat food. When you eat food your body then converts that food into energy. The way it does this is that

your pancreas produces this hormone called insulin and insulin basically allows the food to enter the cells of your body. In a diabetic body that process breaks down and when the process breaks down the food instead of entering the cells of your body it builds up in your bloodstream in the form of sugar. Sugar in the bloodstream becomes toxic and it endangers every organ in your body. The whole goal in diabetic treatment and diabetic therapy is to maintain normal blood sugar so that the toxicity is not there. Where the disease is confusing is that there are actually three or four different types of diabetes. The most common is what we call Type II diabetes in which your body typically is still producing insulin but your body is resisting that insulin typically because the person is overweight or lives a sedentary lifestyle or doesn't eat the proper foods.

JEANNE BLAKE: It was previously known as adult onset and now because so many young people are getting it they no longer use that.

JAMES HIRSCH: Correct. The reason that so many young people are getting it is because we have a real problem with childhood obesity in America. The type of diabetes that I have is called Type I diabetes and that is a problem with the immune system. Your immune system destroys the beta cells in your pancreas that produce the insulin and when that happens the only way to survive is by taking insulin typically through injections or through an insulin pump. That allows you to maintain normal blood sugars. But there is also gestational diabetes that occurs to many women that are pregnant.

JEANNE BLAKE: Sure.

JAMES HIRSCH: And there are two or three other types of kind of new diabetes that we're just beginning to understand.

JEANNE BLAKE: The big numbers are with Type II diabetes and Type I?

JAMES HIRSCH: Correct. In both cases they are really rising at epidemic levels even though Type II diabetes accounts for about 90% of all patients. We are also seeing huge increases in Type I for reasons that we don't really understand. There's some sort of environmental trigger going on out there that is causing these significant increases particularly in very young children.

JEANNE BLAKE: As a medical reporter, obviously I had reported for years on diabetes, I remember maybe with the last 5 or 10 years very possibly on this program, getting a greater sense of how life threatening the illness is. Your book, I have to say, brought it home at a new level. I think, Jim, it was because you became with the reader in sharing so much about how it's affected your life and that was obviously intentional?

JAMES HIRSCH: Yes.

JEANNE BLAKE: And it worked let me tell you.

JAMES HIRSCH: Thank you.

JEANNE BLAKE: Help the viewer understand? They can read your book and I hope that they will. What it's like to really to live with the illness and I hope that perhaps that you'll share it too the car accident?

JAMES HIRSCH: Sure. In Type I diabetes one of the risks that we have is not just extended periods of high blood sugar which can affect your organs and your heart and your eyes and your kidneys, etc. If your blood sugar goes too low you can have what's called a hypoglycemic

experience or low blood sugar in which you experience various types of symptoms. Typically you'll become confused, you'll begin to perspire, you'll become shaky. The longer that that occurs and without treating it by drinking some juice or having carbohydrates you can lose awareness. It typically does not happen often but because you're trying to maintain normal blood sugars invariably you're going to miss and you're going to end up having too much insulin in your body or not enough food.

JEANNE BLAKE: I just have to say, I have to interject here, I just never knew until I read your book how difficult it was for a person living with diabetes to maintain that level. I never got that.

JAMES HIRSCH: It's difficult Jeanne because there's so many variables involved. It's not just what affects your blood sugar is the food you eat, but every food is absorbed differently in your body.

JEANNE BLAKE: Right.

JAMES HIRSCH: Its impact on blood sugar is constantly varying. If you take insulin, that's great but the way insulin is absorbed in your body varies depending upon where it's injected in your body or the types of insulin you take. Exercise has a huge impact on blood sugar levels. Exercise affects your body differently depending upon what type of exercise and how long after you exercise. Then finally, things like stress have a huge impact on your blood sugar levels and who can go through life without stress? If you have a job interview, you're studying for an exam there are all these variables independent of each other that can cause your blood sugar levels to fluctuate.

JEANNE BLAKE: I love the line that you said having diabetes is like having a constant conversation with your body. You've just described what that must be like all day long for someone who's really managing their illness to be constantly aware.

JAMES HIRSCH: Right. Because you're constantly trying to figure out where am I? One man with diabetes said to me, well I just didn't know how I felt. When you unravel that sentence it says so much about diabetes because on one level that's the easiest thing for us to do. Well, how do you feel? I feel fine. A diabetic person really doesn't know how he feels or she feels because you're constantly trying to tease out what your blood sugar might be at any given moment. No of course what we do is we test our blood sugar with home glucose monitoring so that gives us a number in a particular point in time. What that number is right now will be different five minutes for now so it does require a great deal of vigilance.

JEANNE BLAKE: You were, I think, on the way to telling us about your car crash because of the hypoglycemic seizure.

JAMES HIRSCH: Right. What happened, this was in 2004, I was with my son who was three years old at the time and I was driving him home from a soccer practice. I did have a bad low blood sugar experience where I basically lost awareness while I was driving. I was in the Boston area and I was on a highway when it occurred. What's frightening about diabetes is that when you have low blood sugar the organ in your body that it affects is your brain. Your brain consumes glucose 24 hours a day and so when it stops getting that glucose it begins to shut down. In this instance, I was on the highway and I lost awareness and fortunately, there was a happy ending. The car drove off the road and it actually flipped over in this ravine and fortunately both my son and I had our seatbelts on. As soon as it flipped over I regained awareness and both of us walked away from it without a scratch.

JEANNE BLAKE: The police officer said that it was amazing that you did because your car was demolished.

JAMES HIRSCH: The car was demolished and it was a miracle that no one was hurt.

JEANNE BLAKE: I have to ask a question. You got a ticket for that and you appealed it and the Judge after hearing what you said wrote "N.R." on it? "Not Responsible." I read the paragraph three times and I couldn't figure out whether you had to pay it or not - that you hadn't been responsible therefore you weren't at fault? Or you weren't responsible so you didn't have to pay it?

JAMES HIRSCH: I got a ticket from a police officer who ticketed me for driving outside the white line.

JEANNE BLAKE: Right.

JAMES HIRSCH: Which is manifestly clear. I was outside the white line.

JEANNE BLAKE: In the ravine.

JAMES HIRSCH: Yes, when you're in the ravine you're definitely outside the white line. Actually, the police officer, I remember this so vividly because he just volunteered the fact that his mother had died from diabetes at age 50. Which was really not information I particularly needed at that moment about his mom.

JEANNE BLAKE: Exactly.

JAMES HIRSCH: But anyway, he gave me this ticket and it was going to cost me \$500. At first I was just grateful that no one was hurt and I was gladly going to pay it and then I thought about it. Really in our criminal justice system you're not held responsible for something if you're medically

incapacitated for some reason. In this case I was medically incapacitated. I drove outside of the white line because of my hypoglycemic experience. I appealed the ticket and I went to this courthouse and I stood before this Judge and he was a very brusque guy. Instead of asking me about what happened for the ticket he was really berating me for having diabetes and not keeping it in control like I should. At the end of the day he determined “N.R.” – “Not Responsible.” I was not responsible for driving outside the white line. Therefore, I did not have to pay the ticket. I won the appeal but it was a rather degrading experience because he was basically humiliating in the courtroom with all these other people who were appealing their tickets. I described that experience in the book.

JEANNE BLAKE: All of the things that you talk about, all of the challenges of living with diabetes help me understand so clearly why when your five-year old son Garrett was diagnosed you and your wife Cheryl found it to be so devastating. It’s just not something that you want your child to live with and then there are so many things that you worry about that can go wrong.

JAMES HIRSCH: Right.

JEANNE BLAKE: When you learned that, you have an older daughter who didn’t have diabetes at the time, does she now?

JAMES HIRSCH: No.

JEANNE BLAKE: No, she didn’t. I know that there was a moment where you tested her and she didn’t. Tell us what that was like for you to find out that Garrett would be living with this illness as well.

JAMES HIRSCH: Right. It was certainly heartbreaking. He was actually three years old at the time he was just a little guy. I had begun the book prior to his diagnosis and then I actually noticed the symptoms in which he was thirsty and having to go to the bathroom. Then one night at midnight I tested his blood sugar in our bedroom and it came back high and at that moment we knew he had diabetes and it was certainly the most heartbreaking event because it's a chronic disease, there's no cure and his entire life had just changed at a moment's notice. Now he was going to have to face all of these challenges for the rest of his life. Just the fact that he was so young. At age 3, he was old enough to fight back because he didn't like the shots but too young to really understand what was going on and what was happening. I think my reaction was pretty typical for any parent in that circumstance.

JEANNE BLAKE: Of course.

JAMES HIRSCH: I said in the book, at that point for most parents in that situation they feared the unknown and in my case I knew too much. The good news is that he's 6 years old now. He's in first grade and he's doing great. He's adjusted as well as we could have hoped for. He's on an insulin pump now. He's a terrific athlete so he's growing up and he's strong and healthy and well adjusted. It's definitely still a daily challenge but the important thing if you have diabetes at any age is that you identify the problem and then try to get access to the best healthcare possible and the best healthcare providers. The larger public healthcare problem in America is that so many people with diabetes Type I and Type II do not have access to that type of care.

JEANNE BLAKE: That's a constant. There's a constant undertone of you addressing that throughout the book and I detected an anger about it that seems so justified. There are a lot of different elements. One, I wrote down the comment that one doctor, she wasn't your physician was saying that optimal management is the best that we can hope for and when you pushed back, I think it might have been at a conference, she said, you're talking like a diabetic. I was like, wow, ouch!

JAMES HIRSCH: That conversation occurred with a diabetes researcher who had spent like 40 years investigating the disease and the question had to do with will there ever be a cure? She said to me, “No there will not be a cure.” There are other scientists who think we can cure but she said the best you can hope for is optimum care and I said to her that response will not be accepted by many families with diabetes and then she said, you’re talking like a diabetic, which I could only plead guilty to.

JEANNE BLAKE: Yes! Sorry.

JAMES HIRSCH: That kind of is a separate issue but the whole kind of sobering search for the cure which we have been looking for for so many years, driven largely by the parents of diabetic children who are the ones who are the most passionate about finding the cure. They’re the ones out there raising the money and going to the fundraisers and doing all the marches and trying to finance the scientists to try to find the cure.

JEANNE BLAKE: Before we go, I do want to talk with you about research but before we get off the point of healthcare and the search for good healthcare we should visit that for a few minutes or at least 8 to 12 minutes as you say in your book patients get per visit typically with a doctor and that’s just simply not enough to go over all of the information. There is a real catch 22 there.

JAMES HIRSCH: Right. The basic problem with our healthcare system is that for various historic reasons, we reimburse very generously for procedures, for emergency room visits, for operations, where we recognize the importance of providing that type of care. What we don’t reimburse for are things like education, preventative care and disease management. That’s what diabetes is all about. It’s not about curing, it’s about learning to live with it and that takes time because you have to manage all these different variables. The medications, the lifestyle issues, the emotional issues and it takes time and we just don’t pay whether it’s doctors, nurses, nutritionists, the kind of money that they

need to sit down with patients for not ten to twelve minutes which is what most patients get for a hospital visit but you need sixty minutes with a doctor. That is really the huge problem in our healthcare system.

JEANNE BLAKE: It's been that way forever and I think, actually not forever, it's gotten worse, but I think it's a major frustration for many physicians and other healthcare providers too because they will see a patient not get the care that they need and come back with problems with their eyes, problems with their kidneys which are then going to cost exponentially more.

JAMES HIRSCH: Exactly.

JEANNE BLAKE: So what do you think the solution is?

JAMES HIRSCH: What we need in this country because the scope of the problem is so significant is national leadership that recognizes that diabetes is the number one health priority in this country. Jeanne right now more than 4,000 Americans are diagnosed each day with diabetes.

JEANNE BLAKE: 4,000 a day.

JAMES HIRSCH: 4,000 a day. If your child is born in the year 2000 or beyond he or she has a one in three likelihood of developing diabetes in the course of his or her lifetime. We don't have enough leadership at the top of the country who are drawing attention to this problem. The fact that our healthcare system is not designed to treat a chronic disease like diabetes it's designed to treat acute illness. What we need today is what we got in the 1930's with FDR when he declared Polio as a national priority and he personalized it because he had Polio. He said that we are going to find a cure for this as we marshaled the resources and we drew attention to it and we did find a vaccine. That's

what we need today. It's a much more complicated problem than Polio because it's so intertwined with lifestyles and so much of the solution as you ask is going to ultimately come not just on the research front, not just on the medical and healthcare front, but also on the lifestyle front. Trying to create healthier communities that promote better eating and promote exercise, that allow schools to have after school sports programs and better nutrition in the schools. It's a huge, massive undertaking and it could only be done if you have someone like the President of the United States or someone like a Colin Powell who is widely respected to actually get on the stop and say we have to draw our attention to this crisis.

JAMES HIRSCH: Speaking to the lack of leadership, it's right there in the NIH budget and it says expenditures have grown by 261% but the dollars for diabetes have declined slightly as the number of diabetics has doubled. NIH spent in 2004 \$68 per person with diabetes compared to \$16,000 per person with West Nile Virus. We've not done, we meaning with diabetes, have not always done the best job in advocating for ourselves. In part this is due to the fact that many people with diabetes are reluctant to come out and talk about it. They don't want to acknowledge that they have the disease and so they are not out in the streets protesting. There is also a historical reason, when insulin was discovered in 1922, that was hailed as the miracle cure and there's always been this perception that diabetes is kind of cured because of insulin or it's really not that serious of disease and so there hasn't been that crisis mentality that we associate with other types of illnesses. I don't like to compare diabetes with other diseases in terms of which is better or which is worse but I do like to point out what the numbers are and just to kind of convey what the scope of the problem is and as you just pointed out. The cost of neglect is overwhelming because what happens with uncontrolled diabetes is that patients do develop these complications where they need heart surgery because they have heart attacks.

JEANNE BLAKE: Sure.

JAMES HIRSCH: They have amputations. They need kidney dialysis because their kidneys fail. They have nerve problems. These are extremely costly to the healthcare system and this is what's draining billions of dollars each year. What we try to argue is that if we put money up front and we explain things like nutrition and exercise which are relatively inexpensive expenditures to promote better care that will reduce the need to those more expensive treatments down the line.

JEANNE BLAKE: Pay now, say it later. We only have two minutes left but I don't want to leave this program without talking about Dr. Diane Faustman who you write about in her research. Some people think she's a freak, some people think she's a genius and I have an imaginary list of people that I want to have for dinner and I'd like her to come and sit at the table. I think that she sounds really interesting. In our minute and a half left, tell us about the research that she's doing, that you're doing, that she's doing on diabetes and where you think the greatest hope for a cure rests if indeed you do believe that it's possible?

JAMES HIRSCH: Very briefly. Faustman is, she was able to cure diabetic mice and she believes that it's possible, for Type I diabetes. She believes it's possible to reverse the immune system's attack on the beta cells with this concoction of drugs that she has arrayed and then believes it's possible for the pancreas to regenerate its own beta cells which when she first posited this theory some years ago was completely non-conventional and people thought she was crazy. She's had a lot of good results in diabetic mice and so she's pursuing this now with human beings, she has FDA approval to do a clinical trial with humans. So that's one hope. People should go on line – Diane Faustman – to read more about it. Is she going to cure diabetes? It's a long shot. I think a cure under any circumstance for Type I diabetes is a long shot because the immune system is an incredibly, intricate, powerful system in your body and trying to figure out how to reverse what it does in destroying the beta cells, we just may not ever be smart enough. I believe the more exciting landscape lies in

the improvements in technology that will allow us to care for diabetes on a day-to-day basis, maintain more normal blood sugars and make complications a thing of the past. I think that's where the real hope lies.

JEANNE BLAKE: For you and for Garrett and the many millions of others who are living with diabetes we hope so too.

JAMES HIRSCH: Thank you.

JEANNE BLAKE: Jim Hirsch, you've made a great contribution. Your mother can be very proud of you. Thank you so much for joining us on About Health.

JAMES HIRSCH: Thanks Jeanne.

JEANNE BLAKE: Thank you for joining us on this edition of *About Health TV*. I'm Jeanne Blake. I'll see you next time.