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[Podcast Ziek, episode 8](#)

Introduction

Welcome to this bonus episode from Ziek. The podcast. In this bonus episode you can listen to the interview with Darice. Darice had so many interesting things to say that it didn't fit in one regular episode, so I made this extra episode with some bonus material. If you have not yet been able to listen to the regular episode with Darice, do so first! If all goes well, it will be in your podcast feed below this episode.

Topics that are discussed in this last half-hour interview include self-confidence, donor organs policy and what misconceptions many people have about it, and a brilliant idea from Darice to make it easier for deaf and hard of hearing people to take the train to travel.

Enjoy listening!

Interview with Darice: Self-confidence

Tamar: I think another difficult question. I don't know if you know the concept of self stigma?

Darice: Can you explain that?

Tamar: Yes, stigma is ... Do you know the concept of stigma?

Darice: I know about, but what do you mean self-stigma?

Tamar: Because there are just certain ideas that you are inferior, or perhaps more difficult. Self-stigma means that you start to relate that to yourself. That you sometimes find yourself inferior.

Darice: I think I experienced it, but not bad. No more than someone who has no disability. I think I'm just having it at times when things aren't going so well. But I find myself worth it. I think I'm worth as much and have opportunities as others. I think I am just as entitled to it as everyone else. And yes, I have luggage because of being deaf and sick, but who has no luggage? It is of course not easy for me. I have to work on my own self-confidence. Therapy also helped with that. Because if your body doesn't cooperate for a long time, that's very difficult. Because mentally you are completely worthy and then your body does not want to go along, but I am who I am.

Tamar: Can you tell more about that, what that does to you, mentally, if your body doesn't want to come along? Is it the unpredictability?

Darice: It's an impatience. It's just impatience. I enjoy being able to walk. I never forgeT: After I had been transplanted, I went to Amsterdam to my cousin a few months later. We went into the city, it was summer, and then my sister told me, she was there too: "we went through the whole city." And then I thought oh yes, yes! We have walked through the entire city of Amsterdam. So now when the weather is nice, because I do not like that cold, when it rains or when it is winter, I immediately take the tram home. But often when I am back from work in The Hague, I do not take the tram but I walk. So even when it's hot. I enjoy being able to walk longer without getting tired. And then I just skip the tram or bus and then I walk. And just enjoying it that I can do it.

Tamar: Oh, I can really imagine that.

Interview with Darice: Donor organs

Tamar: If you like, I also wanted to talk to you about having a donor kidney, because there is so much social debate about it. And I am so curious how that is for you, that there is so much about the new law ... how does that come to you?

Darice: Yes, that subject. I can sometimes be blunt about it, but for me it's very simple. I never thought I would need a kidney transplant until one day I was told that I needed a kidney transplant. And I didn't say no, I said yes. So with the same thing it seems that when people ask you, "do you want to be a donor?" 'Yes.' And the new law is only good. If you are really against becoming a donor, then you just go online, then log in with DigiD, click no, and then it's done. It's that easy. And a doctor has written an opinion in De Volkskrant that as a doctor he never told a patient that he or she needed a transplant organ and that the patient said to him, "no, thank you." And I think people should be aware and you should be happy that you are healthy, but it can happen to all of us, that one day you wake up and a doctor says to you, "You need a transplant organ." And then you will be grateful that there is a system where your life can be saved. Because too many people die waiting for an organ. Too much. And it is something that there is a solution for. And that's just my opinion, yes.

Tamar: And what does it do to you emotionally? That there are also people who think differently about it? Because of course it affects you personally.

Darice: I personally don't know anyone who feels that way about it and I can't imagine I'm friends with someone like that. Because I was in the hospital and I

was very lucky to have a kidney within three years. I know that in the meantime the waiting list is much longer. And I've seen people suffer. And you have to imagine that sometimes there are mothers with children, with young children, and fathers with young children, I know of children who needed organs. And then you want to say, "The government wants my body, the government wants my organs." No, no, that's not an argument. They have no real argument. And like I said, you are not required. You go online and you click no. And if you do not want to go online, you go to your town hall and I think you can also indicate that you do not want to be a donor. Nobody takes your organs away from you. But there are so many people who don't bother, who really don't care and it's much easier for that. And the system works, look in Belgium. The system works and you save lives with it. And you want to say that you are saving lives? Doing it at random against saving lives, that's how I see it. It is inhuman. Instead of at random, make people aware that they can simply click no. I think that is much better than disrupting a law that saves lives.

Tamar: What I still find a good argument, but I think that it is reasonably covered, is people with intellectual disabilities. But I believe that something was conceived for that.

Darice: I don't know exactly what that is, but I think those people have a sort of, how do you say, someone who is responsible for them and decides for them. But I do not know. But there are things. I once heard an argument from someone with a university education, which shows you that it's just about misinformation. That person said to me, "I am not a donor, because I have heard that they take your organs away from you while you are still alive." And someone with a university education said that to me. I had just been transplanted myself, and I was of 'what? No no no.' They only remove an organ when you are brain dead. Totally brain-dead, if there is no chance of returning. They do tests. They do different tests. Before they even suggest taking someone's organs. It is not true, doctors are really not happy when someone is in intensive care, who will become an organ donor, no.

Tamar: I think it's also other doctors who make that decision.

Darice: Yes, it's not a doctor who decides that. It is a team of doctors who decide that. There are a whole protocol and procedures for doing those things. There really isn't that just like that, no.

Tamar: No, in that sense, it would just have to be much more knowledge. How it works exactly. I've experienced it. Not from very close by, but from the girlfriend, so the partner of a friend of mine. And the nasty thing was that it couldn't go on for a very dull reason. I mean, I experienced that she died and

she wanted to donate her organs, but that was canceled because there was no room for operating theater. And I really think that is such a dull thing.

Darice: Yes, I am always a bit skeptical about things like that, because you don't know the story first-hand. That's one. I can imagine that if they need OK room for living patients who need surgery, I can imagine that. See, when I was called up for a transplant it was on a Monday and I was not transplanted until Tuesday morning due to operating theater. So yes my doctor really didn't make any decisions just like that. I mean that I was called on Monday and only transplanted on Tuesday morning, it is not a decision they have taken lightly. It is a kind of triage process, what can wait and what can't wait. This is how an OR room is determined. But yes that shows again, I am myself when I was transplanted and my body recovered from all substances and so, I am also a donor. They allow me to use everything. I hope my organs are good for longer than my life, and my heart. I would be very happy if I could save someone's life if I died. It would be an honour.

Tamar: Yes, that's how I feel now too.

Darice: Yes, I am very happy too. I don't know anything about the kidney I have now. That is all arranged. That is all very anonymous. But every day I am grateful that that one person made that decision to become a donor.

Tamar: Yes, because is it possible to contact the family anonymously through those organizations?

Darice: It's possible. I chose not to do it. I am grateful. But if someone finds it necessary, then that person can write a letter and then the authorities that arrange it all make sure that it arrives anonymously at the family of that donor. But I was so busy with my own surgery and then you don't know what that family is like.

Tamar: No, you don't know who they are. You don't know how they feel about it.

Darice: Are they really waiting for it? I can imagine that if my organs are used as a donation, my family won't need a letter a year later.

Tamar: Yes you just don't know. It is very personal.

Darice: But if someone wants to do that. I think it's possible.

Tamar: What do you actually think of those films? I no longer know what its name is, but there is such a film about a heart transplant and, oh what was that, that someone then falls in love with the person who then has that new heart.

Darice: Oh I know that movie, that's an old movie, right? I think it was with Minnie Driver?

Tamar: Yes, she's so pretty!

Darice: I saw him on a plane. I know him. I don't know what to think about it. Nice film, but that real concept of that heart, no.

Tamar: It's very romanticized. Hahaha.

Darice: I can't imagine being honest. I just think it is unrealistic. Let's say real Hollywood. Hollywood real.

Tamar: Yes, but is that good as people .. do you see that as something positive? Or do you think it would be better for people to have a somewhat more realistic picture?

Darice: I think the best way for people to get a realistic picture is that people talk about their experience of a transplant. There is so much around it. You are not healed if you get a transplant organ. You are going to take so many medicines against rejection and so on and those medicines have side effects. And when I received information about the transplant, they hammered it on a lot. It is not a cure, it is a quality of life improvement. That is it. And some people who recover a lot from an organ and others less. For some people it completely fails, because rejection can always happen. So it's a very complicated thing. But it cannot be disputed that it saves lives.

Tamar: Yes, and that you can have a decent life again at all, without having to have dialysis every time.

Darice: Yes, I mean, if I had never had that transplant then I probably would never have been here again and thanks to that kidney I can just contribute to society. I can work, I can just enjoy, you are there for your family. And you still have a few, many years, so yes. And without dialysis of course yes.

Interview with Darice: Fellow contact

Tamar: Ok one last, lighter question. Do you find it important to be in contact with other people with your illnesses? And, I almost assume that it is over the internet, so my next question is: How important is the internet to you?

Darice: I think you mean contacting fellow sufferers? No, that is not important to me at all. I've never had anything with that. I remember when I became a kidney patient as a 25-year-old and you are often in the kidney ward, there were all older people there. I was really the youngest there. I was really the baby in the department or something. No, I have nothing to do with fellow sufferers

Tamar: And what if there were younger fellow sufferers?

Darice: I never really had that need. You know, my case is so complicated. And I am someone who feels very individual. Really feels individual. Also in terms of being deaf, I never had the need for contact with fellow sufferers, no. Internet is important, because I am deaf, because I can easily communicate with people via the internet. And you know, we also met online on Twitter. So I am someone who is always on Twitter and my Instagram account and my own website where I also blog and in that sense the internet is very important to me. It is important to me, it is also my job. I am a web developer. So internet is a big part of my life yes.

Interview with Darice: Accessibility

Tamar: Can you tell something about your job? I think that's nice too.

Darice: Well I rolled in that direction thanks to my study Communication Systems at the HBO. And I chose Web development. And it's fun. It has become much more intensive, because today's websites are much more complicated than before. I still have to keep track of everything, learn a lot, but my interest is now more in accessibility.

Tamar: Oh how cool. Do you do things with it for work?

Darice: For my work too. Yes, of course, we must ensure that a website is accessible. So I often go to workshops to learn everything. What the demands are, what the law says. But as I just said, general accessibility is becoming more important to me. And I'm working on that now. More orientation and talking with people. How can I contribute to and help make hospitals more accessible? Helping with what can be done for the train. And I know that the Dutch Railways and Prorail are working very hard on it, but you do need some experiential expertise.

Tamar: So maybe you are going to develop something that if you and other people who are deaf are on a train and something is being announced, that you can just do it too ..

Darice: Developing anyway, I already have ideas how it can be improved, though. And I often say, if they did that, if they do that, then it can be better. In my experience, so much has already been done for blind people. And that is very good, that restriction is very visible, because they often have a dog or a stick with them. But if someone is deaf, you don't know that. It is really a very invisible restriction. And I wonder how many people talk to me when I walk by

and I don't hear them, but I'm deaf. And I want more things more consciously ... the train can do better ... how the hospital can do better ... and that they don't call you. Because sometimes you know it's the hospital, but who's gonna call you? And then you become super nervous. So yes I really see points for improvement.

Tamar: Do you have a nice concrete idea that you would still like to share?

Darice: I have a great idea. Since this will be released later, it will be on my blog by that time. Well it was an experience that I had with the train. When I go home from work I get off the metro at Central Station in Rotterdam and that is downstairs. And then sometimes I have 4 minutes to catch my train, or yes the train that goes directly and I can read it in peace. That is my desired train. And then I have 4 minutes to run up a few stairs, and all those people loop around during the crowds. And then run onto the track and then you really don't have time to use the app, no, I'll go. Then I see that the door of the train is open and I don't hear it whistling, but I do see that the door is open. So I get in. And now it happened once that I stepped in and the doors closed, and it almost caught my backpack. But I did not hear a whistle, because if I knew that the doors would close, I would not have entered. And then I thought, oh dear, that was almost dangerous. Secondly, oh no, I'm going to get a fine of 300 euros because I got in that way. You get a hefty fine if you do that and the conductor sees you. And I think he saw me. He was at the very end. He doesn't know I'm deaf. So I thought I hope he doesn't go through the whole train looking for me to pay a fine. And then I thought, but why don't the doors have lights? A kind of red light that will flash on all doors and then you know it will close. And then you know: don't get in. And that seems super handy. And when I run, I sometimes think. A person who is for us who runs faster than me. So that conductor whistle and the one comes up and he probably didn't hear that whistle. And he sees that the door is open, such a person will also just board.

Tamar: Yes, because sometimes you do not hear well which train is the whistle.

Darice: Exact. Yes if more trains whistle at the same time or something, I can imagine as hearing someone that you don't know which one. And so I thought if all doors had a red light flashing when the doors closed. Then everyone knows, whistle or no whistle, deaf or not deaf, so whistle, slightly at the door. So it seems slightly super useful to me. I would be very happy if there were lights at the doors.

Tamar: Yes, nice idea. Well then we can immediately send that into the world with this podcast. Who knows where this will be picked up? Or have you already shared this with the Dutch Railways?

Darice: Well I'm going to write about it. There is already a blog on my website, so there. And as far as train life is concerned, I have really had a train life since I lived here. First for my studies and now for my work. We now have that app, but once we were stuck somewhere on the track, but I don't know where. And I had no idea what was going on. I was stuck on the train for an hour. They call it out. But look I am independent and I am also deaf. But that is really that independence and just wanting to be independent. And then it would just be super handy if the app said: we are on the train, and that is fixed, and it will take so and so and so .. I don't know how to figure out what happens. And then I have to go on twitter for the people who complain, and through them I can find out. oh yes ok, that's the matter.

Tamar: Yes, that is a smart strategy.

Darice: So twitter helps me with that. But it should just be that app. Simply life, up-to-date. That would be very handy.

Tamar: Yes, ok. Well I think we have a lot for my podcast. Is there anything else you would like to express yourself?

Darice: I think we have discussed everything.

Tamar: Okay. It was very nice to hear this story like this. Thank you very much for your participation.

Closing

Tamar: Thank you for listening to this bonus episode. Thanks to Darice, thanks to Apple Shampoo Art for the logo and thanks for the loyal typing team - in this case Margot Gerritse - who typed out this bonus episode. See you next time!