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[Podcast Ziek, episode 8](#)

Beforehand

Tamar: Welcome to Sick. The podcast. I am Tamar Doorduyn and in this podcast I report from the rag basket. Because since I fell ill more than two years ago, I still don't get the world. Doctors who get angry when you look up things on the internet, have to wait for your wheelchair for a year and a half, sick women and people of color who are taken less seriously ... In this podcast I talk to other sick and disabled people and try chocolate again of the world.

This is the last episode of Sick. The old style podcast. Like I said last time, Sick is going to change a lot. Eline and I will tell you all about it in the next episode. The next episode is expected to be online at the end of August, so keep an eye on us!

Introduction

Tamar: In this last old-style episode, I spoke to Darice de Cuba. Darice is a very cool young queer woman from Aruba with a great haircut. Really, you have to go to her social media for a moment to view her photo. Darice looks like a kind of Elvis queer - better than Elvis actually!

T: Anyway, Darice has a rare genetic disorder: Fechtner syndrome. This syndrome affects the blood platelets, kidneys and hearing. When Darice was young, the Genetics specialization was not yet well developed and all this was not yet known. It was quite a shock to her when her kidneys gave way around the age of twenty and she appeared to need a donor kidney.

T: Darice is also late deaf. This means that she was born with good hearing which slowly declined until one day she could no longer hear anything. Darice says that this puts her in a kind of no-man's land between the hearing and the deaf world. I found it very special to discover that I could just interview a deaf person for an audio medium such as this podcast. It worked like this: Darice had brought a writing interpreter who typed everything I said on a special ergonomic keyboard. In the meantime, Darice had a screen on which the typed text appeared. It worked great, but it was a bit different than a conversation between two hearing people. Darice herself tells in the interview that people often have to get used to a different way of communicating and I noticed that myself. It made me a little giggly and a little embarrassing, I noticed when I listened back to the recording. At the same time, it also got used quickly and

you will notice that as listeners. I have largely silenced the silences in which the interpreter typed out my questions and I had to wait a little while for an answer. Occasionally, however, I have left them in it, so that you still get a bit of an idea of how that went. In our [Instagram Highlights there](#) is a video about the assembly process.

T: Besides having learned a lot about being deaf, this conversation with Darice also gave me a lot of insights into how different the experiences of chronically ill people can be. For example, Darice has had to deal with #DokterDrama, but not really with the kind of #DokterDrama that I am used to. She especially noticed that doctors have little patience with her deafness, but they take her condition very seriously - that's how it should be. Darice has the type of chronic illness that is associated with a lot of anxiety and scary medical procedures. She has learned to cope with this by keeping herself strong, but she eventually noticed that it is also important to face her own vulnerability and fears to cope with all the difficult moments she has experienced.

T: Darice and I talked for about two hours and there was actually too much interesting material in the interview to limit it to one episode. That is why I made another bonus episode this time, which is already in your podcast feed. Do you want more? Then, after this episode, continue with the bonus episode!

T: Furthermore, it is good to know that this episode was already recorded a year ago, so now and then it is a bit dated. If you want to know how Darice is doing now, check her blog at www.darice.org.

Fixed heading: #DokterDrama

T: Before we start, it's time for the permanent section #DokterDrama. We remain in the theme, because this time it's also about being deaf. One of our listeners, Eva, wrote me an email in which she told me how it was for her to wake up deaf one day:

"It was the end of September. Together with Peter, my husband, I slept a few nights in a hotel in Apeldoorn. We do that often. Because of his muscular disease we are a bit limited in our vacation options, but a few nights in an accessible hotel is going well. Having a nice breakfast, drinking coffee somewhere and visiting a museum or place of interest - we enjoy it to the full. Until that one night. "Something is not going well with my ears," I told Peter, "I have become deaf." I had been wearing hearing aids for several years, and with that I could hear well. There was actually little that escaped my attention, but this was different. Completely different. I knew that the hearing loss of that night could not be compensated with hearing aids, this was too much, too

bad. A few days later I came to the ENT doctor (throat-nose-ear-doctor). He noticed a severe hearing loss in both ears, but he was laconic. "Yes, unfortunately, you sometimes have that. Nothing to do about it." So: that was that? Almost deaf, no longer good to compensate with hearing aids and find out yourself? I came back to him a few times, completely in a panic I was sitting in the waiting room among the children who got tubes in their ears or whose tonsils had to be removed. The ENT doctor responded with irritation, he could do nothing and literally sent me away. It was as if my life fell apart completely. I saw myself as childless and ultimately without a partner, mother alone sitting in a house, with no-one contact, just some Facebook and Twitter contacts. My brothers indicated that they were busy with their wife and children, they didn't think about how things should go. I also had to stop volunteering. I always had dreams, could become anything and achieve anything, even if my partner died unexpectedly. And now: nothing more. An ink-black future. Eventually I ended up at the GGMD, a social work for deaf and hard of hearing people. With a social worker, who is also hard of hearing, I now try to see what is still possible. I am still terribly angry with the ENT doctor who offered me nothing. No psychological help, no investigations, no empathy, nothing. That's not how it should be. Help people who get a bad diagnosis, doctors, please! "

T: So this is really an incredible bad story, which I think speaks for itself. Darice will also discuss the loneliness that deafness can bring with it at a later age, so *without further ado* we will now continue with Darice.

Interview with Darice: Introduction

Darice: My name is Darice de Cuba, I am 36 years old. I live in The Hague and I work in Rotterdam as a part-time web developer. I was born and raised in Aruba, my 19^e I came to the Netherlands to study and I stayed here. Just before I graduated, I fell ill and my plans changed, so I have been living in the Netherlands for 18 years.

Tamar: You have Fechtner syndrome, how long have you known that? How did you find out?

D: When I was two my mother noticed that I started to get blue spots. Then the medical merry-go-round kind of started. I went to America for research. If a child gets bruises, they often say it has leukemia, but research has shown that in my case, only my platelets were very low in number and larger than normal. That was all they knew. The suspicion was that I would not live long, but that

was in 1983 and so much was unknown at the time. So I just had to live and watch out for bruises and bleeding.

T: Because those platelets are so large, what do you notice? Does that only manifest itself in those bruises or does that also have an effect on other things?

D: I don't notice it myself, the only thing is that I get a bruise with every shot. Someone who has good platelets only gets a bruise, I just have to push myself softly.

T: Do you also get a bruise from the way you sit in that chair?

D: No, luckily it's not going so fast. But for example if someone bumps my shoulder playfully. So my case is very rare, they don't know any other patients who have it. To my 25^{email} the only problem seemed to be my platelets, but when my kidneys did suddenly you on. In the meantime, I had become very hard of hearing too slowly. When my illness became very bad around 2004, with bad kidneys and almost deaf, some genetic tests had become available. I was tested and only then did it emerge that I had Fechtner syndrome. Beware my 25^{email} I got a name for what I have and I could understand my illness. The low platelet count was associated with my kidneys and I was then told that I would be completely deaf.

T: So you didn't know beforehand that you would be deaf?

D: As a child I noticed that my hearing was deteriorating, so I had always assumed that I would be deaf. I could put that aside. Only that my kidneys would stop working, I didn't know that. That was a total surprise, I had a severe stomach flu and went to the First Aid for that. As always, your blood is first checked there and then they saw that it was completely wrong. I was immediately admitted. A month later I heard that I needed a kidney transplant. The period between the moment I heard that my kidneys were no longer working and the moment I heard that I needed a kidney transplant was very short.

T: What did that do to you? Did you live in the Netherlands on your own, were your parents still on Aruba?

D: I was studying and living at that time with my sister, who was also studying. My mother lived on Aruba, so he had to fly over urgently when I was admitted. At that moment you are in the middle of it and everything goes so fast, I try not to worry too much about it. It happened, you can't do much about it.

T: You also tell it all smiling.

D: I have always said that all those experiences have shaped me into the person I am today. Look, if I had had a choice, I would naturally have wanted a carefree life. On the other hand, I would not be myself without that experience.

Interview with Darice: Communication with writing interpreter and lip reading

Tamar: What is it like for you to always have to communicate with people with the help of a writing interpreter or lip reading?

Darice: In the beginning it took a lot of getting used to. I also don't really use a writing interpreter in private situations, during a party or something. In such situations I use lip-reading or I ask people to write it down on a phone. Lip reading is difficult and many people talk under the mouth, which makes it extra difficult. In Papiamentu I can read lip very well, on the one hand because it is my native language and on the other hand because you articulate much more in that language (clear mouth image). If I am one on one with people who speak Papiamentu, that's no problem. If people have a very clear mouth picture, that is not such a problem, but I often ask people to type it.

T: How's my mouth image?

D: Yours is inside, no clear articulation

T: I thought so [laughs]! Then I will try to learn something more ar-ti-cu.

Interview with Darice: Daily life and E.R.

Tamar: What does your daily regime look like? What should you do because of the illness you have?

Darice: I'd say I have a tight routine. Fortunately I received a kidney transplant in 2009, after almost 3 years of dialysis. Since then I take a lot of medication against rejection of the donor kidney. I have to take it exactly at 8:30 in the morning with some other medicines, including Prednisone [\[1\]](#) . I have to take those medicines for the rest of my life . In the evening at 8:30 punctually I have to take the same medication. That taking time is very strict, so even though the weekend or I am in another time zone abroad, I have to take the medication with exactly 12 hours in between. For example, if I go to Aruba I have to start a week in advance with that shift in time. That sometimes means that I have to wake up in the middle of the night to take my medication.

T: Can you tell something more about your work in combination with your illness?

D: I work 5 hours a day, a total of 20 hours a week. I do that to manage my energy. For most people who have had a kidney transplant, their energy level goes up again, but because of my rare illness and deafness, daily life costs me extra energy. I am completely deaf and live in the middle of the city. Imagine this: you are walking on the street and you do not hear any bicycle bells ringing, scooters coming from behind or trams coming up. So you have to be constantly 100% alert to what is happening around you. So I have to concentrate very well outside, it takes a lot of energy. It can therefore be dangerous, especially if people decide not to obey the rules. The same applies when I communicate with people. On the way here, for example, I got lost and met someone, so when I asked that person for the way, I had to pay extra attention and concentrate. Fortunately, that went well, but people do not know what I have at first sight.

T: You wrote that it is very difficult when you go to the First Aid.

D: That is very difficult indeed. Many chronic patients know their body better than the doctors. When you get to the First Aid the first thing that is done is taking blood. With me you immediately see the low number of blood platelets. That is not the problem for me, but often people want to give a platelet transfusion. In my case you have to be very careful because of antibodies. If my current donor kidney should ever stop, I would like to be eligible for another. If you get transfusions, your body builds up more antibodies and the chance that a second transplant starts is getting smaller.

Interview with Darice: Fear of dying and enjoying little things

Tamar: At which moment do you notice most that you are chronically ill? And vice versa: at which moments do you almost forget it?

Darice: I have to go to the nephrologist (kidney specialist) and the hematologist (blood specialist) every 3 months. Every 6 months I have to go to a nephrologist in the medical center in Leiden, where they check the donor kidney very well. They always take blood at those moments and that is very stressful for me. My way of life has taken over that rhythm of 3 months each time, because I never know what the result is. It has happened that my kidney function was very bad when I tried out a new type of medication. I also had an internal bleeding last year and I had to get a CT scan. Then the doctors discovered all sorts of proliferation around my kidneys, it came very hard. The drugs that I take against shedding can cause cancer, so when they saw that tissue on the scan, I thought

stress at work, stress, those things are nothing compared to moments like this. They press very hard on reality. Moments when I almost forget my chronic illness are nice moments, for example when I'm with family. Last week there was a party with many people from Aruba and that was a very nice day. At moments like that I forget it for a moment. But in fact it is always present, for example because of the medication. I like to go out for dinner, you can see that on my Instagram account, but I don't just do that. If I want to do that, I have to plan in advance, I have to take into account how much salt and protein I eat in order not to burden my kidneys too much. I measure my blood pressure every day and also try not to overload my kidneys, for example by alternately eating meat and vegetarian. Many people do not see that, but I am always very aware of what I eat. I do not mean that I only eat a leaf of lettuce, but I mean that I take into account how much salt and protein is in my food and whether I should balance the next day.

T: You just said that you actually live from one three months to the next three months. That naturally causes a lot of stress. For example, are you also busy with death?

D: No, I'm not so concerned with death. Every patient who has had a kidney transplant knows that it will not last for the rest of your life, especially when you are young. Realistically, there will come a time when I have to go back. It is difficult for me to know what my life will look like in 1, 2 or 5 years. That of course applies to everyone, but I hate the question: "Where will you see yourself in 5 years?" Of course nobody knows that, I experienced that for myself. Before I fell ill, I was graduating and thinking about my master's. When I got sick my life changed and everyone can do that. I didn't think I was going to get sick, I didn't think I'd be deaf - you know it can happen, but everyone who walks healthy now doesn't know where they will be in 5 years.

T: If you are chronically ill, you realize that very well indeed. I also have the idea that that is more real life and that healthy people believe in social engineering too much.

D: I am indeed more aware of it. Not that I am such a patient who fully embraces life because they know that life is short, but I appreciate it, for example, if the weather is nice just like today, or is drinking a cup of coffee or tea somewhere. Those little things that become much more important.

Interview with Darice: Accessibility

Tamar: What does accessibility look like to you?

Darice: I am concerned with accessibility a lot and I want it to get better. I am pleased that the [UN Convention was](#) ratified last year and that we now have equal rights, but that must of course be implemented. The government and commercial authorities must make money available for this. Of course I am deaf: there are nice screens at train stations, but if the trains are no longer running, it does not say that you have to get off. Those kind of little things. I am independent and live alone, my sister is my contact if something happens. If the hospital wants to pass on something small, they call me, but of course it doesn't help me. I have sometimes asked if they can put in the system that I am deaf, but that was not possible. Those things annoy me and I know it can be better. I want to help make that better, it's not that hard to make it possible to enter into that system whether a patient is deaf or blind or uses a wheelchair. Certainly at a hospital! I even wrote an (English) [blog](#) about how difficult hospitals find taking things into account. We laugh about it now, but at moments like that it is very frustrating. I am very aware of it every day. Another example is Dutch cinemas, for example Dutch films have no subtitles so I can never go there. I canceled my own cable television subscription because I was so tired of the poor quality of the subtitles, if there was one. The subtitles are behind or fall away completely, so if you see that every night, that will frustrate you. Luckily there is also a lot available online, so I don't have to miss anything. Then I'll watch Netflix, done. Accessibility is very important and I know from experience that not only deaf and hard of hearing people use subtitles. Hearing people sometimes just want to add subtitles, for example if someone speaks with an accent or is learning the language. I always say that accessibility is a win-win situation for everyone.

T: What systems exist or could be invented so that, for example, a hospital can reach you easily? Maybe send an app?

D: WhatsApp or e-mail is suitable for me. For example, you can contact ABN Amro (bank) via WhatsApp, although you must search the website carefully before you can find that option. They do not respond immediately, but there is a possibility. E-mailing has become more difficult since the entry into force of the new General Data Protection Regulation (AVG). For example, I was in the hospital last week and had to get MRI results, but it is very difficult to get an appointment because they only do outpatient surgery on Monday morning and I cannot. So I asked the surgeon if he could e-mail it. She said that that was not possible due to privacy, unless I gave explicit permission. I know that privacy laws are not there for nothing, but emails are simply the most convenient for me. In principle, everything that goes through text works best for me. I ensure that I always have my phone with me and have an internet connection, because I cannot receive calls.

Interview with Darice: Impatient doctors

Tamar: How do people around you deal with being chronically ill and deaf?

Darice: My close family and friends are used to it, who know that I have to pay attention with energy and food. They take that into account, so I never really had a problem with that. When you meet new people it is a different story per person. For example, they do not understand the difference between sick and chronically ill. I think being chronically ill and deaf is a good pillar of human knowledge. It is understandable that when someone is confronted with it for the first time, it is just as awkward. Some people cannot or will not deal with it, that is complicated. I think that not so much my chronic illness is a problem, but especially the deafness. Some people feel uncomfortable or have difficulty adjusting their communication. I always clearly state that I am deaf and ask if they want to write it down. Some people find that uncomfortable, but others have no problems with it at all. Sometimes they write it down before I have to ask, that's great. It differs per person, it is a human thing.

T: What is the best way for people to deal with it?

D: If they don't find it a problem, it's best for me to type things on the app or on the phone. I think that's great, especially since everyone has been busy with their phone all day anyway. I can read body language well, so sometimes I see a twitch when I ask someone to type something in and they have difficulty with it. Why would it be difficult to type something for a deaf person if you have been on your phone all day? The only difference is that I am right in front of you. Fortunately, other people have no trouble with it at all and I like that very much. It is of course also a matter of getting used to, the longer I know someone, the better the communication often goes. When I meet new people, it is always a question of whether that person is open to suitable communication and wants to invest in it. If we have a shared interest, for example at conferences or meet-ups, then it often goes better. Certainly, if we have a shared interest in accessibility, I will meet the best people there. Such environments are very nice. When it comes to 'just' making a social contact it is very difficult. We live in a time where everything goes fast, people don't have time, everything has to go on and people without limitations do not even give each other a real chance.

When I arrive with my deafness and ask for something extra, many people don't feel like it. Unfortunately, that is my experience.

T: What is the most annoying reaction you have had so far?

D: I was lucky, I can't remember very annoying reactions. Ironically, my most unpleasant experiences with doctors are. Fortunately, not my own regular doctors, but sometimes I have to go to a specialist that I see once a year. When I did not understand what he was saying and asked him to write it down I noticed that he was losing his temper. I understand that it is stressful work and that doctors are busy, but those moments are really bad. It is of course not meant to be personal, but they should know better.

T: It is bizarre, in fact, that you encounter the most inaccessibility and misunderstanding in healthcare.

D: They are only people, but it is striking. There is a high workload and I can well imagine that, but on the other hand you are there as a patient and you may be a bit nervous. If the doctor then tells you what he or she has seen and you do not understand it is not nice if they then become impatient when you ask if they want to write it down. I tried to change doctors in that specific situation, but it didn't work. So I still have that same doctor, but luckily I only see him every so many years. The last time happened to go very well, so I think they did explain why I wanted someone else.

T: Do you remember what the doctor said? Oh, of course not, because you didn't understand him at all [laughs].

D: He didn't say anything specific. But just his whole body position was from "Oh, again .."

T: Again?

D: Not again, just that impatient. I do not have time right now. A kind of attitude. Look, and they see so many patients, so I always pretend to see me for the first time. So from "I'm deaf, and I'm coming because of ??? [both members of the typing team could not understand, sorry!]. Look, they see you so little and so many patients. I am also realistic. Other people don't remember you when they see you so little.

Interview with Darice: Chronically ill, deaf and dating

Tamar: You like women too, just like me. And you're not the only guest in this podcast, so I think it's going to be a whole gay podcast. But tell me, you wrote something about it, that it is sometimes quite difficult.

Darice: Specially for pride month.

T: Oh yes, indeed! It will take a while before it comes online. Okay, I don't think she kept it up, so the question is, "What do you run into dating?" Are you bothered with dating? "

D: I think the same as everyone else. Thanks to the online world, you know that you are always on social media, so people have unrealistic demands. It is mainly to swap photos, even in real life. I think: "then you will be deaf and have a chronic illness, that's hard." I think. The dating world I find so superficial, and I am not like that. Some people say: "yes, but why do you tell them that you are chronically ill? Wait until they know you well!" But I'm not like that. I am a very honest person. I don't like those games, so like: "I'm going to present myself very well and then if they know me long enough then I'll show my real me." I'm not like that. You know, if you get to know me, and of course you don't see everything, I am only human. We all behave in an exemplary way. But I'm not going to hide that I'm chronically ill, no. I am not going to hide my motto of 'living by the day' to impress. And I also once read a very good story about someone on a blog that is date and chronically ill. I also said that **T:** the first thing I say is 'I am chronically ill' and if that person cannot deal with it then I know immediately, next! And actually it is. People often ask me: do you exercise? And I say no. But I am an athlete. The worst thing that happened to me because of my illness is that I am not allowed to exercise anymore. In high school, for those platelets, that was the first time I had a spontaneous bleeding. I was really an athlete, tennis was my sport, exercising three times a week. At school too, gym. I was so sporty that I was allowed to complete the boys' team during football and basketball. But the doctor told me to stop. In addition to being deaf, I think that was the worst blow of being sick. And then I start dating now, and then people ask: "are you exercising?" I always like types that are sporty. So then I say "No." I like sports, but I am not allowed to exercise. I can enjoy playing tennis or something. But do you want to crossfit, climb a wall and then run a lap? No, that is not possible. So yes, the things that are popular, that people would like to know, so do you sport, or do you like to travel ... But I think that many people without diseases will also encounter that. You know, it has become so superficial now and people no longer take the time to really get to know someone, I think.

T: Yes, while on the internet you can rely more on the content than if you meet in the pub for example.

D: That's right. But in my experience I have learned that people want to get to know you in real life as quickly as possible, because it is still something like 'is that click there?' You can chat with someone very well online, but maybe in real life you don't have a click.

T: Yes, that's right, I recognize that yes.

D: And sometimes I just don't feel like it. You just get so tired of it, you know. Now I just have an attitude of: if I meet someone, fine, then I am open to it. But I'm not going to worry or find someone anymore. Because I have too many things in life. And of course it's nice to meet someone, but a healthy life even more so.

T: Yes, because you have the feeling that it really is, how do you say that you have to choose between dating and just be able to follow your own rhythm of life?

D: Not really a choice, but, yes. I don't feel like meeting people who say, "Yes, no, thank you." Who have trouble being deaf. I do not need that.

T: Yes, sin.

D: Yes, unfortunately. And I'm deaf, you know. So it's not that I can just go to a gay party and meet someone because you're deaf. And anyway, I'm not really a party person either. I have nothing to look for there. So I just think: it is just very difficult for everyone in their thirties to date. I'm not alone in that. I read experiences and I hear from other people: if you are over 35, making friends is difficult, especially if you are not married and have children. Many of my friends who are getting married and who have children, their experience changes completely. And I'm still detached. I am not a party animal, but I do have a free life, I can do whatever I want. And then you have to meet people who can do that too, it is very difficult for everyone. And then you are also chronically ill and deaf. That also makes it difficult.

T: Yes, the more you have already built up your life the way you want it, the more difficult I think it will be to find someone with whom that *matches*. Because then you know what it's like to be able to determine everything yourself.

D: Right, because you know yourself better. I also have requirements to whom I want and I don't *settle down* just because someone likes me and I can't find anyone. Oh no? I am chronically ill, I am deaf, but I am very independent. I do everything myself, I only go to the doctor, I manage fine myself. And if it has to happen very occasionally that calls have to be made, I will arrange that myself. So I am independent. And I think, I hope, that I radiate that. I think people might think, "Yes, but then I have to do everything for you." No, I don't like it when people do things for me, so I have demands. I am also someone with a lot of general knowledge. I love reading and deep things, and I just don't often meet people who are like that. I also met very nice people, where you also think: "Oh, here it will work out!" And then it went well, but then you get to know each

other better and then you don't have the same wishes. Then you separate. That also happens. It's just hard. But with me, and everyone else with a disability, an extra layer is difficult.

T: Do you think it's a misunderstanding about being chronically ill? That you are not independent?

D: I think if people don't come into contact with people who are chronically ill, then they might be able to think, "Yes, someone with a chronic illness, maybe they need me," and I don't need that. I already do everything alone and actually I have a satisfied life. I don't need someone to do that for me. But I can imagine that if someone has never been in contact with someone with a chronic illness ... On the other hand, I can of course go from chronically ill to ill, right? But a healthy person can also wake up sick tomorrow, and you won't run away from that, right? And I don't think people realize that illness can happen to anyone.

Interview with Darice: Don't belong anywhere

Tamar: You also wrote something about being in isolation for a while.

Darice: No, not being in isolation for a while, more so when you are deaf you are a bit in isolation. For example, you are at an event where there are a lot of people, and then a lot of things happen around you, but you don't get them all anymore. Except when someone is nice enough to say "that happens, and that happens." In my case I am late-deaf, so I was hearing first and now I am deaf. So I'm not in the deaf culture either, I'm really in the middle. I do not belong to the deaf culture. I am not hearing impaired, I am completely deaf. I don't wear an implant, a kind of bionic hearing aid. I don't wear that either. If you wear that, you can call yourself a little deaf and hard of hearing, because you will hear something. But no, I am really deaf. Look, how often do people have funny stories in which they are on the train and then people next to them hear what they are all talking. Those things. That will all pass you by. And that is what I mean by that isolation.

T: But you don't belong to the deaf culture, can you explain that?

D: That culture consists of people who were born deaf. Their native language is actually sign language and not Dutch. They really have their own world. I was not born deaf, I grew up hearing. I was hard of hearing, but for my experience I grew up hearing. I just enjoyed music. I normally went to school. It is only when I became very ill that the deafness was added.

T: Can we go back to that period and can you tell in detail how it went deaf for you?

D: Well, I was around 25 and I wore hearing aids. And with hearing aids I managed fine. The following year my kidneys stopped and I had to undergo dialysis. But due to a complication I got a peritoneal infection. Before that I got very strong antibiotics. And antibiotics and some other medication are known to cause hearing damage. Even someone who has no hearing problems can become deaf. This is incidentally a suspicion, because I am not 100% sure, but when I recovered after the brain haemorrhage I noticed that I was deaf on the right. The ENT doctor suspects it came from medication. That left right earlier. So then I only had my left hearing with hearing aid. A year later that also stopped.

T: Sudden?

D: Yes, I think it is gradually coming. You don't notice that so quickly. It goes gradually. One morning it was just completely gone. So I was not suddenly deaf, no, it was just slowly that I became deaf.

T: Tell me about that morning.

D: It's very funny. It seemed like a radio that suddenly started to work badly. It just cracked, my hearing. I thought maybe it is the phone that is not working properly. Or maybe my headphones didn't work properly. But then it suddenly stopped. So I went urgently to the ENT doctor who went to see, and he said: Yes, you are deaf. He did another hearing test, just to be sure, but I was deaf. And at that time it didn't really come as a blow, it was just a very unrealistic experience. Then I also noticed that I was able to lip-read myself. My sister speaks Papiamentu so I just followed her. At the ENT there, the man was very clear, so that went well. Only much later did the realization come. For me it was a very late response. Years later the realization came and that I really had to deal with it, being deaf.

T: How did that go?

D: Not nice, no. I had to work on it for months.

T: How did that express itself? Were you gloomy?

D: Panic attacks. I have had severe panic attacks for a long time. Very heavy. I had to seek help with that. I don't want to take medication, I can't take medication because of my illness, so I completely solved it with talk therapy. So that was hard work. It wasn't swallowing pills, I had to work very hard on it.

T: And what did you discover then? In that therapy?

D: It's just a kind of processing. You can say a kind of mourning period, and then you process things like "Oja, I have become deaf" and "I had almost died during brain haemorrhage" and "Oja, I was very lucky to have a kidney after three

years . " You only process that later. I am also someone who knows that I can die young. I am not afraid of death itself, but rather that I do not want to be sick and suffer. If I have to die, let it happen immediately, I have no problem with that. But being sick and staying sick, that's a problem for me. I think everyone has trouble with that.

T: And is it really suffering, or, for example, being dependent, or certain things can no longer be done?

D: Yes, I mean, lie in the hospital and know it will never be okay. That seems terrible. If I know people who can go through it, then I feel like that. That is terrible, because you can really imagine it. Because I was in a hospital bed. And luckily I knew it would be okay, but to know that it would not be okay ... that seems really bad.

T: Yes, because have you often been in the hospital, have you actually admitted?

D: Yes, what is often?

T: I spoke to someone yesterday and he had been admitted forty times.

D: Okay, no, I don't mind 40 times. I didn't count them, I don't keep up. I can tell you how often I was admitted last year. I was admitted three times last year. Twice for an investigation for which I had to receive a transfusion and then they will take you in for certainty.

T: And how do you like being in the hospital?

D: I always make the best of it. Look, if I am a room for myself then it is fine there. It is now better than before when I dialyzed. I was in the hospital quite often then. In the past there was only television. Smartphones were not really like they are now. So that was really a bit annoying. But now I bring my laptop and I can enjoy Netflix and if I have a room for myself with a clean toilet, I don't have a problem with that. The worst thing is the doctor's round in the morning where they come and tell you how bad or bad your health is. That's the worst thing about being in the hospital.

T: What's so bad about that?

D: Don't you mind? Every morning, when they do a round?

T: Well, I've never been recorded. It may be crazy, but I don't have that experience at all.

D: Well, trust me, hey take blood every day to look at my kidney function and then they come to you in the morning how good or not good it is. I find it terrible, then you are always waiting in the morning for all the white coats to come in. That is not nice. And the food is not really 'wow!' of course. So I always

ask when people come to visit if they want to take something with them. But I do feel safe when I am in the hospital, because I know that I am being looked after. But if I can go home I am also very happy.

T: And you get used to it?

D: The hospitalization? On its own. You have no choice, so you get used to it. You can struggle against it, but that only makes it difficult for yourself. Only during the period of the brain hemorrhage have I been in the hospital for a long time, two months in total. But then I needed so much help, then you won't say "I want to go home." I had to learn to use my left leg again, and then you really go home. In addition, you are of course afraid that you will get a brain haemorrhage again, then you would rather be in the hospital than at home. But since then I have been very lucky and the recordings were all little ones. So then I'm happy. I don't mind small things. You get used to it. It is part of my life. It is not fun and there is a voltage level below, but I know nothing else. I know what it is.

T: Because you are naturally chronically ill since your second.

D: Only in the past did I not have hospitalization. It was very stable. It was just blood sampling to look at those platelets, and that was mainly my life. Taking blood samples and looking at platelets. It is only after the kidney that recording starts.

T: Ah, so you don't really think you had a chronically ill life as a child.

D: No, as a child I was very innocent. It was mainly the bloody noses that did not want to stop. That was really my first medical intervention. Then the ENT doctor went completely with such a long small tube in your nose. Yes, I just had to sit very still, then he went in with a long rod with a camera and light. I experienced that when I was 14 years old. And the first epidural, that wasn't fine either, the bone marrow puncture.

T: What did you do that for?

D: They take some marrow to look at the platelets. When they investigated the platelets, they did a bone marrow puncture with me as a child. Then I was maybe under 4-5 years old. And on my 11th they did it again. Those were the worst things I experienced as a child.

Interview with Darice: About being strong and vulnerable

Tamar: How do you deal with being sick? What kind of person are you in that? Are you someone who finds it important to be strong, or do you think it is important to be vulnerable?

Darice: To be strong, I used to be very strong. I have cried two or three times during the entire period of my brain hemorrhage? And now it's vulnerable again. That is psychologically better. So I have a mix of strong and vulnerability, but mostly strong. But I also make sure that I remain vulnerable. But I remain strong.

T: How did that change?

D: That is really an analytical question from myself. How can I explain words, you know? To undergo examinations, you must be strong. An MRI scan is not nothing. If you have a scan made because you have torn a muscle, for example, that is nothing, but if you are going to make a scan to look because they do not know what is going on, that is very exciting. You have to be strong then. By being strong I mean a little ... Put it aside. So that you can continue with your daily life. With the vulnerability, then the moment you know what's going on, after the first results, you really let that affect you. Instead of thinking "oh well, keep going."

T: And it has really been a process for you, so in which you also went to a psychologist, was that also when you learned that you have to let it affect you?

D: No, I am not saying that the psychologist did not help, you learn a lot to analyze yourself and recognize what triggers are panic attacks. But, and it may be very cliché to say, what really helped me with my vulnerability is Brene Brown 's book and [TED talk](#) about *vulnerability* . That was life-changing for me. Not that it worked out right away, no, but I read that book and I saw the TED talks several times. I've always written, but more than two years ago I really started again. When my kidneys stopped, I really started writing again what I was experiencing, and not in a depressive way, but just. And then I also started to talk more about it, that's why I'm here too. I think if you had asked me that a year ago, I wouldn't have done it. But what we are doing now is actually that vulnerability. And you learn to do that better and better.

T: I can imagine it so well. I don't know, I think I'm on the other side of that spectrum a lot. I used to find blood samples scary, and meanwhile I have less. I don't know if I had told something about my own situation?

D: So your vulnerability was that you found blood samples scary?

T: No, no, anyway, I'm not such a tough type at all. I'm pretty frightened.

D: I know that too, I have been having blood test since I can remember, I cannot remember a period when I did not have blood test, that was already the case in Aruba. So I went for a blood test with my grandmother and grandfather, and it always made me very nervous. I got a stomachache. And the hospital in the 1980s was really an old kind of hospital. With the ammonia scent, and then you had to wait for them to poke you with a needle. I was very nervous. But now those are fine memories for me. My grandfather and grandmother were like parents to me. So then I remember from the past. But blood tests, that abdominal pain, that went away when I had experienced worse things. Then suddenly it was 'Blood sampling? Yes, okay.' Now I have something like 'You have to puncture here and use that needle'. I now know better how to do that and I also want them to do well.

T: But I can also imagine that the more often you experience something like that, and also when you experience painful and difficult things, you also have to harden in order to get through it.

D: Yes, I do not know how high my pain threshold is, but I have had very painful examinations and interventions. Then blood sampling is suddenly the least bad thing that happened to me in the hospital, really.

T: Tell something about something very painful that you have experienced?

Darice: Something that really makes me shiver is: when you get a kidney transplant, a catheter is placed. If your kidneys stop, then you no longer have urine production. If you get new kidneys, that will get going again, but your kidneys will also have to get used to it. So there will be a kind of catheter. They put them on during the operation, but then they simply take them out again. Without anesthesia, without nothing. I really thought I'd faint. Another painful reminder is that I had to wear braces. My jaws were just not right and that hurt. That was four years ago. But for my braces, all my molars had to be removed, and they were very stuck in my jaw. I did get an anesthetic, but that dentist — it was a woman, not much taller than me — was sitting with her full upper body trying to get that tooth out of my mouth. That was real, you don't feel it, but you are just scared and you can feel the cracking. Yes, those are things for me. Blood sampling is nothing in comparison.

T: No, it is actually not too bad. I often have to think about my questions for a moment [laughs], then your interpreter will be looking at me questioningly and then I will be completely nervous. Where was I ... How do you weather such a thing? Do you have tips for that? If you need something very painful?

D: For example, last week I had to make an MRI for my lower abdomen, because the previous MRI had gone wrong. So I was told 'we have no result, the

MRI needs to be repeated'. So of course I am nervous and frustrated. Making an MRI is not fun. I don't know if you know that? It is a magnetic scan and then you have to go through such a tube. You have to lie in it for at least half an hour, very quiet. You are actually locked in the device. So if you are claustrophobic ... I am not that myself, but it is so small that it even makes me nervous. So luckily I took a calming pill. I always have that with me. I don't take them as standard, but at times when we unexpectedly make an MRI. What I do then is think to myself: "Okay, when I'm done with this, I'll go eat something delicious and then I'll go home." Sometimes I take that food with me, because I don't feel like sitting among people when I'm so stressed. I treat myself. It can also be something else, I can also buy a book for myself. But it's just being nice to yourself. Because of that pill I had to go home to sleep afterwards, because it has to work out. So I can't really go anywhere because of that pill, but before that pill had completely took effect, I could still treat myself. Even if I have had a good doctor's visit. Hey, it was good, I'm just going to celebrate that by doing something fun. That's it, treat yourself. Life is too short! If possible and allowed, go eat that hamburger.

T: Haha, your motto for life. If possible, go eat a hamburger.

D: Look, I take care of myself, but life is short. You must enjoy it too.

T: I often do that too, so I can have an ice cream. Yes, I can't handle sugar that well.

D: Yes, just grab something that you like and just do it!

T: Yes, that's a good tip. And what I often do is keep talking to myself. That, when I notice that I just get a little scared, I'm just going to say things to myself. "This is just as annoying now, but it will be fine again. Soon, it will be over in ten minutes "

D: I do that too! I do that too! And you know, even if it's not good, you'll be fine. If it is bad then you will also get through it. Often healthy people say 'I don't know what I would do if I were', but yes, you do it, because there is no other option. You will get through it, because it cannot be otherwise. It must be. It'll be fine. You cannot imagine what you will do when you fall ill. But people are built to live. It'll be fine.

T: And you also find that power at the moment itself, or something.

D: I just encourage myself. Look, I used to play tennis, that's a very mental sport. You are really alone on that job. You are really alone. And I also have such an attitude now, when I am sitting in a waiting room, I am courageous. And if it is bad news then it is: "Okay, then you are going to do that and that, and then you are going to do it that way." can grab.

T: You're just really still an athlete.

D: Yes.

T: You just stay that way!

Outro

Tamar: Thank you for listening to this podcast. Would you like to continue listening to the rest of the interview? Then check the bonus delivery. In the bonus episode, Darice and I also talk about self-confidence, the policy on donor organs (in which I ask a lot of stupid questions that she really answers very well) and about a brilliant idea that Darice has to make the world more accessible to deaf and hard of hearing people.