

### Transcript Details

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### Not Fade Away: A Memoir of Senses Lost and Found

Dr. Pickard:

Between the ages of 13 and 19, you find out that you have a genetic disease called Usher III that will leave you deaf and blind by the time you're an adult. As silence and darkness progresses, how do you deal with your fears, future plans, and desires? You're listening to ReachMD, the channel for medical professionals, and I'm your host, Dr. Maurice Pickard. And our guest today is Rebecca Alexander, a psychotherapist and recent recipient of the American Foundation for the Blind's Helen Keller Achievement Award, and she is also the author with Sascha Alper of a memoir, *Not Fade Away: A Memoir of Senses Lost and Found*. Thank you very much for joining us.

Ms. Alexander:

Thanks for having me.

Dr. Pickard:

What prompted you to write this memoir?

Ms. Alexander:

It's interesting because I was actually approached to write the book about 5 years before I actually sat down and did it, and I had some writings that were actual journal entries and finally, when I was re-approached by the literary agent who approached me 5 years prior to my original decision to write the book, I thought, "Well, I don't really have much to say that anybody would necessarily want to hear, or what makes me any different than anyone else?" And I realized that in my own process of coming to terms with my diagnosis, that reading other people's memoirs, their experiences, was very helpful to me, and it really allowed me to feel less alone. And I didn't know anyone besides Helen Keller, for instance, who had a story or a book about what it was like to lose your vision and hearing. So, I really wanted to write this book so that people would know, most importantly, that they're not alone in what they experience. Whatever your loss or your circumstances are, that we all struggle with something. And so, it was really in hopes of just being able to reach an audience of people who were struggling with any form of loss, to know that they're not alone.

Dr. Pickard:

Our audience is primarily medical professionals. And who did you want to reach with this particular book at this time?

Ms. Alexander:

You know, I think that I wanted to reach sort of a broad audience, but mostly people who either were first going through whatever their diagnosis may have been, whether it was Usher's syndrome, which is what I have, whether it was retinitis pigmentosa, or macular degeneration, or hearing loss, or even if it was any form of terminal or debilitating condition that was causing them to lose some parts of their ability to function in daily life. But, as a psychotherapist, I often find that recommending books to my patients who are

experiencing, whether it's addictions or anxiety or an eating disorder or depression, that having a wealth of knowledge of what books are out there that people may be able to read and find something that resonates with them would be important. And so, I think it's important for healthcare professionals to be aware, not just of the science and the medicine, but also to know what other resources are out there so that they can have a more holistic approach to dealing with their patients.

Dr. Pickard:

We, doctors in particular, deal with loss, personal sometimes, but also in their practice, and all losses have something in common. You know, you mentioned Helen Keller, and when I was reading your book, you did have hearing and you did have sight which gave you a sense of self and memory before losing them. How did this affect you in a negative way and a positive way as you navigated your disability so different than Anne and Helen, who went into a world that she never even knew existed?

Ms. Alexander:

I think that in some ways many people who lose their vision or lose their hearing have a much harder time adjusting to the world, because these are senses that they've had, that they've known, that they've used, to be able to explore their environment, to be able to know what their surroundings are, and to use them, really, in a way that helps them acclimate to the world. And so, when you lose those senses, it means that you have to develop your other senses. Whether knowingly or unknowingly, sometimes we do this on an unconscious level, simply because our body has a very unique way of making up for loss by strengthening its other abilities or senses. And so, sometimes I think that people who were born sighted and hearing, who are losing their senses, have a much harder time than people who were born completely deaf and blind. Because if you've never had sight or hearing you don't necessarily know what you're missing, and so there is a real experience of loss when you have had those senses. So for me, having vision and hearing and then losing it, at times, has been very sad. It's the same experience of any type of loss. There's a real grieving process. There's the sort of denial, there's the bargaining, there's sadness, the depression, the anger. There are a lot of emotions that you experience. But I think that because, you know I'm very fortunate to be in the field of psychotherapy that I've done so much work, not only in my educational and clinical training, but in my own personal experience, that I've realized that having these memories are so fond to me, and I really treasure them. I really remember what it sounds like to hear birds chirping without the assistance of hearing aids or a cochlear implant, and I know what so many sights that people take for granted look like, and I can really appreciate them for their richness and the fullness that they are, even if I can't see them the way that I used to be able to, simply because I know how special and unique it was for me to be able to have that opportunity at all; to be able at one point to see things in all their fullness and color.

Dr. Pickard:

Is that where the title comes from, especially *A Sense of Loss and Found*? You talk about taste and smell and your tactile sensations being so acute. Is that where the title comes from?

Ms. Alexander:

Yes, you know, it's funny. Originally the title that we thought of was *Dancing in the Dark* and we wanted something that maybe was a little more poignant so we came up with *Not Fade Away*, because really, that is sort of the message. That despite the losses I've experienced these memories and the experiences with my vision and my hearing that I've had, that I may no longer have and may continue to lose, will never fade. I mean they are, oftentimes, they feel just as rich and close to me. Things that happened, you know, 10, 15, 20 years ago, it feels as though I experienced them yesterday because they are such full, wonderful memories.

Dr. Pickard:

If you're just joining us, you're listening to ReachMD and I'm your host, Dr. Maurice Pickard, and our guest today is Rebecca Alexander, and we're discussing her memoir, *Not Fade Away: A Memoir of Senses Loss and Found*. You talked about dancing in your book and you've mentioned it again, and one of the things that really struck home to me was, in this era of us becoming so separated from everybody and walking into a restaurant and everybody's on their phone and no one's talking to anybody, and no one, you can't get your children's attention, no one writes letters any more, no one calls anymore. I don't want to sound like an unhappy father or grandfather.

I'm not. I'm lucky. But, you talked about tactile signing, this dance of hands and fingers in darkness. I wonder if you would talk about this because it sounds like what a gift.

Ms. Alexander:

Yes. Well, it's interesting because oftentimes when I tell people that I have a condition that's causing me to go deaf and blind, and to be clear, you know, a normally sighted person has 180 degrees of vision, and I have just 10 degrees of my central-most vision, and without the use of my cochlear implant in my right ear and my hearing aid in my left ear, I'm completely deaf. And so, people say, "Oh, I'm so sorry." I'm 37 years old. I was told that by the time I was 30 I would be completely blind and deaf. And so, when people say, "I'm so sorry," I feel like, "I'm so lucky." You know, to be able to have even 10 degrees of vision at 37 years old, when I was told that 7 years ago I would be completely blind, is really a gift. I'm very, very fortunate and hopeful in terms of research and what may be available ahead. But, having said that, it is difficult to navigate particular environments, dark environments or noisy environments, and so having the hearing loss really, in some ways, has been a gift because it caused me, or I guess precipitated me, to learn sign language and sign language is the language of the deaf, and then to further learn tactile sign language which is the language of the deaf/blind. In order to use sign language, and even more so tactile sign language, you must be fully present. You can't use your phone. You can't be multi-tasking. You need your hands and you need your attention to be directly on the person in front of you. And not only that, you are embracing the person in front of you. Essentially you are holding hands as you sign, and so it's a very intimate form of communication that really requires presence. And in this era where everyone is sort of encouraging you to meditate and practice yoga, it's really all in an effort of helping people stay present; not get too far ahead of themselves or overwhelmed. And so, when you tactile sign, in many ways it is like practicing meditation. It is very much like living so presently in the now that it's remarkable, and I'm so grateful to have this skill, to have learned this, because it's amazing how much we have grown further and further apart with technology. As you said, even as we sit next to each other, we're still on our phones, messaging other people.

Dr. Pickard:

Part of what this skill causes me to look at research of physicians, like myself, and often when surveys are done of who is a good listener and who isn't, the difference is often only 45 seconds of what patients will consider a good listener. As I read your book, you have to be one of the really good or best listeners I've ever experienced by reading your book. You must be so intense and be able to be, like you say, in the moment. This is why you must have gone into psychotherapy, because this is so key.

Ms. Alexander:

It is. You know, when, for me to listen, I actually really do have to be present. Oftentimes I have to read someone's lips. Listening is not just an auditory skill. We pick up so much communication and language and information from a person we're communicating with, simply in their body language and in their facial expression. And so, it's so important when you communicate with someone and you listen, to really gather all of the information that they're giving you, not just in what they're saying, but also in what they're communicating with their body and with their expressions.

Dr. Pickard:

Part of your book deals with a terrible fall at age 17 which leads to multiple fractures of all of your extremities except, I think, your right leg, and your recovery from it, and what most of the audience is aware of is what you called the little ball that you were blowing, and what we call incentive spirometry. We're all familiar with it, especially postoperatively. How did this turn into this mantra that you talk about: breathe in peace, breathe out fear?

Ms. Alexander:

When I had this terrible fall, and really, just about everything in my body was broken, my back, my left hand was shattered, my right hand was broken, my left foot was completely shattered, my left foot was reconstructed with hip bone, so I was really incapacitated and I was on a tremendous amount of morphine, as you can imagine for the pain, and so everything felt sort of suppressed and out of my control. And so, when I was told that I needed to work on being able to blow into the little device so that I could get the ball above the

line, it was the first time that I felt like, here is a challenge, here is something that I can do to try to produce some form of strength, to try to gain some control over my body when it felt like everything was totally out of my control. And it felt very empowering, just that very small example of being able to muster some strength. And the breathe in peace, breathe out fear, it is my mantra and it's something that came to me as I was doing the 8<sup>th</sup> Life Cycle Ride from San Francisco to LA, and I won't go into the story, because it'll encourage people to read my book so that you can really have the whole story of how I came up with this mantra, but it's one that I live by, even today. And it's something I came up with at about the age of 22 or 23, and essentially, what I found, was that I was so afraid of, I was on a bike and I was on the PCH, Pacific Coast Highway, between traffic going 80-90 miles an hour, and on the other side of me was just a rail and a cliff that went right down to the ocean. I was so afraid that I might veer into traffic, or that I might veer over the side of the guardrail, and the only way that I could keep my mind from going where it didn't need to go, the only way I could keep myself present, was by coming up with a mantra in that moment. And so, the mantra was breathe in peace, and I would breathe in through my nose (sniff), breathe out fear (whoosh) and I would say that over and over again and it got me through the next 35-40 miles and it obviously worked, because I'm still here today. But I do encourage my patients oftentimes to come up with their own mantra and the breathe in peace is that we often are so guided by our fear, that it clouds us from being able to accomplish our goals, or know what it is that we're really hoping to accomplish.

Dr. Pickard:

I was an internist, and one of the problems that I found ill-equipped to deal with was eating disorders. And in your book, you talk about how you develop an eating disorder, hardly something that we would see coming down the path, having heard how you dealt with other challenges. But of course, eating disorders give you a form of control. It does sound somewhat paradoxical though, that you become this great athlete, highly conditioned, and then had to deal with an eating disorder. Could you put that in context for us?

Ms. Alexander:

Sure. You know, I think the eating disorder actually came a bit before I really got into being an athlete. And I am an extreme athlete now and very fortunate to have gone through a lot of my own therapy and my own process of recovering from an eating disorder. But it was really around the time I was fully diagnosed with Usher's syndrome type III, and at that time I wanted to do everything I could to appear as though there was nothing "wrong with me." And I thought that if I was able to look physically as perfect as possible, and if I was able to academically study as hard as I could, and have the best grades possible, that nobody would know that there was something wrong with me, or that I was damaged goods in some way. And, in addition to that, it was the only way I could exhibit some form of control over my life when I was told that I was going deaf and blind and there was no treatment and there was no cure. There was nothing I could do about it. And so, in that time, it was a very, sort of superficial, way of trying to develop some sense of control over a diagnosis and my life that felt like it was completely out of my control. And so, at that time, I wouldn't say that it worked, but it distracted me from my diagnosis and from what I was told would be my life. And so, again, I was fortunate to recover from the eating disorder and be able to strengthen my body and understand how important it is to nourish my body, to nurture my body, and to take care of it to the best of my ability. And particularly now, given that there is no treatment for my condition, I know that the foods that I eat very much are a part of my ability to maintain and take care of the vision that I still have, and that is eating omega-3 fatty fish, and leafy greens, and nuts, and you name it.

Dr. Pickard:

Before we leave, I'd just like to touch on how you went to a major university and were shocked, actually, by the lack of attention for people with disabilities, despite the 1973 Rehabilitation Act in Section 504. You've now become an advocate. And what do you bring to this advocacy for people who are deaf and blind?

Ms. Alexander:

So, one thing is clear. At the University of Michigan, where I attended for undergrad, was actually wonderful in their services, and to this day I recommend the University of Michigan to people with disabilities because they have a wonderful Disabilities Services Program. The school that I attended for graduate school was not that way. But anyway, I think what's important is that we have to be the voice for ourselves. Nobody else is going to do this for us and I think oftentimes we are hopeful that somebody will come up with a cure, or somebody will raise the money to fund the research to find it, or that somebody will stand up for us, or that people will just know the right

thing to do when it comes to dealing with disabilities, that they'll have all the information about what our legal rights are, as people with disabilities, or Americans in general, and unfortunately, that's not the case. And I think that there's something that is so empowering about advocating for yourself and advocating for others. And to be able to live your truth. To be able to be who you are and not have to hide behind anything or anyone, really has given me such a greater sense of independence and freedom. And most importantly, I don't want to argue with people or tell them what they're doing is wrong. I simply want to educate them about what they don't know about what it means to live with a disability, or what it means to be someone who has different abilities than other people. So, advocacy work has been a huge part of how I have been able to maintain my morale and my ability to believe in change, and everyone to be able to become more accepting and understanding of people with disabilities.

Dr. Pickard:

When I closed the last page, I was struck, or at least the message that I had, is when we are working towards a goal, we must learn to especially live in the moment. This is something that you emphasize over and over and despite adversities and the associated sadness that came with it, to not let it take over your life, and to appreciate the ebb and flow of this dynamic changing cycle that is such a gift. Thank you, Rebecca, for joining us. I found your book marvelous. I encourage our audience to read it and to use it in their practices.

Ms. Alexander:

Thank you so much. I loved speaking with you today.

Dr. Pickard:

Yes, thank you. I did too. And for those of you who may not have heard all of our podcast, certainly you can go to ReachMD at your convenience, and find this podcast as well as many others in this series. Thank you for joining us.