

## **Usher Syndrome Coalition | Ask the Therapist with Rebecca Alexander, LCSW-R (Recorded Live Session)**

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I am Nancy Corderman, founder and president of the USH Partner Organization, the Usher Syndrome Society, and a board member of the Usher Syndrome Coalition. I have two young adult children living with Usher syndrome.

And hi everyone, I'm Krista Vasi. I am the executive director of the Usher Syndrome Coalition.

Welcome to Ask The Therapist with Rebecca Alexander. Rebecca Alexander is a psychodynamic psychotherapist specializing in the treatment of anxiety, depression, grief loss, eating disorders, addiction, and disability. She has a full time psychotherapy practice and holds two master's degrees from Columbia University in clinical social work and public health. Rebecca also has Usher syndrome type 3.

Today Rebecca will try to answer as many of your questions as possible. Krista and I will be asking the submitted questions to Rebecca live on this webinar. If you would like to ask a question, please submit your questions in the Q&A area at the bottom of the screen at the center on the right hand side. We will do our best to ask it to Rebecca. Now I'd like to introduce our main speaker, Rebecca Alexander.

Hi, everybody. Thank you for joining me today, and I tried to add as much lighting as I could in here to make me as visible as possible, so I apologize that I don't have the best lighting, but this is how we're all living these days working from home. And I just want to give you a side note that because we are operating from home these days that you may get a special visit from my mini golden doodle Olive. She has a tendency to bark at will, so that's my gift to you.

So I want to give you just a little bit of background about who I am, and my work as a therapist, and then I just want us to jump into these questions and obviously we ask people to presubmit questions so that we would be able to really try to bring the questions that were very similar together, and address all of the issues. But the difficulty with being on a webinar like this is that it doesn't feel as much like a conversation, and I wish that we could make that happen. And so maybe your live questions will be able to make this feel a bit more engaging instead of me just talking to you. Or at you.

So I'm Rebecca Alexander. I have Usher syndrome type 3A. I was diagnosed with RP, retinitis pigmentosa at the age of 12, and I had difficulty seeing the blackboard at school. I told my dad I thought I needed glasses. We went to an optometrist. The optometrist said there was something in

the back of my eye. their equipment wasn't sophisticated enough to identify what it was. So we were sent to various different medical centers.

I was born and raised in the San Francisco Bay Area, and we went to UCSF, we went to Stanford, and they told my parents that I had RP. And then when I was about 19 years old I woke up one morning with really significant ringing in my ears. Tinnitus or tinnitus, which is associated with hearing loss as many of us know.

When I was probably somewhere between 10 and 13, and I think my mom is on this call and it's too bad she can't be the one to tell you this part of the story because she probably remembers it and knows it better than I do. So this is all very general. But I had a cookie bite of hearing loss. And we suspected that maybe it was from having frequent ear infections, it wasn't entirely clear why I had that cookie bite of hearing loss. But there was not yet a connection made between the vision and the hearing loss.

So I was given hearing aids, probably at some point in middle to high school for that cookie bite of loss, but of course I rarely if ever wore the hearing aid, mostly because it actually amplified so much sound that was a bit overwhelming for me. And I ended up wearing it really just in my AP history class my senior year of high school, and not miss the gist of it. But at the age of 19, at the University of Michigan, I woke up with really loud ringing in my ears. The sensation was that I could not hear people speak to me over the ringing. And I liken it to what people often experience, musicians experience it or people who've attended a really loud concert, or veterans who come back from war and been exposed to very loud sounds oftentimes experienced tinnitus, and that was what I was experiencing.

So after a week or so of it not subsiding, I went to an otolaryngologist at the University of Michigan and they further diagnosed me with Usher syndrome. They said that they'd never seen it as it presented itself in me, so they couldn't tell me specifically what type I had. And it was a lot of research on my mom's part and researchers in Helsinki, Finland that about 10 years later or so they were able to identify that I had Usher syndrome type 3A. And I was the first one to be diagnosed with this type.

So that is just sort of the general gist of my diagnosis. And one of the things that I have really stressed the importance of with Krista, who for those of you I think now everybody is familiar with who Krista Vasi is, but she is the backbone to this organization. She works tirelessly, and we all really admire her for the dedication that she puts into everything that we bring to you guys.

But one of the things I've stressed to her over the last few years at different conferences, and I kept saying Krista, we gotta have something about the mental health piece of having Usher syndrome, because it's such a huge piece that oftentimes goes missing, and these conferences tend to be much more clinical, they tend to be much more research based, and you being able to form these connections I think with other families and other people is so crucial and important to our own process of living with, coming to terms with, and going through all of the changes that we experience in living with Usher syndrome, or loving someone with Usher syndrome.

And actually speaking about it, talking about it, knowing how to access the right resources in terms of mental health I think is so important to this process. And of course I'm a psychotherapist, so I would think this. But I can tell you that from my own personal experience, not only as a psychotherapist but as someone living with Usher syndrome, that the therapeutic process for me has been an instrumental piece of my ability to come to terms with, to live with Usher syndrome.

So I put that out there. Nancy, maybe we'll pop into the questions. Yeah.

Absolutely. So I'm sort of dividing it out into different kinds of categories. Hopefully we'll hit all of them. And of course, please enter your questions live if you are able. As someone who is diagnosed with Usher later in life, late 30s, I find that I'm still struggling with the grief of feeling like the rug has been pulled out from under me, disrupting the plans I had for my future. How do I get to the point where I start making plans again, and more importantly, how on earth do I find a therapist who understands disabilities?

So that's a really good question and it's multifaceted, obviously. We all get diagnosed at different times. And so we all experience and come to know what Usher syndrome is, and more importantly, how it affects us in different ways. And also at different times in our lives. One of the things that you mentioned was that you had these ideas for what you were planning for your future, what your life was going to look like. And making plans. And so now that your trajectory looks different, it sounds like you've stopped making those plans. And that's because it's not going exactly in sort of the direction that you had anticipated, I'm assuming. And I wish I knew more about what sort of those plans were.

But I'm trying to understand the connection between getting a diagnosis with Usher syndrome, and not making plans. Because I think what we're talking about here is being able to deal with the grief and loss. Being able to experience the emotions, the fears, the uncertainty that come with your diagnosis. And then also figuring out what it is that you want for yourself and your life.

Having a diagnosis with Usher syndrome does not mean that you will not have, or cannot have a very meaningful and fulfilling life. What it does mean is that some of the plans you have made may need to incorporate other people. You may need to use assistive technology when that time comes, or if that time has come. And so I think being able to develop the comfort with being able to use assistive technology, being able to create networks of support with friends, with family, with the Usher community. That is going to be I think a pivotal part of your ability to move forward and to continue to live your life in a fulfilling and meaningful way.

I don't think anybody moves forward living their lives without fear and uncertainty. And so in terms of finding a therapist, this is always asked of me. How do I find a therapist who really understands Usher syndrome or disability? And that is something we continue to work on in terms of developing the skills among therapists at large. But I oftentimes encourage people to find a therapist who specializes in grief and loss.

Because a lot of what we're dealing with, although we have all these other issues that make up our life, we are also dealing with grief and loss on a fairly consistent and regular basis. And I think there are very parallel and universal themes with grief and loss that people with Usher syndrome experience, that professionals who specialize in grief and loss can really be helpful.

OK, how do you deal with the waves of depression? Sometimes I'm in the mentality of I'm not going to get let-- I'm not going to let Usher's control my life, but other times I get depressed and feel trapped because of Usher's.

So here's the thing about being, first of all, human. But being human with Usher syndrome is that we experience a wave of emotions. Right? And that depression I think often comes because of fear. Because of anxiety. And so I often say, when you feel that sense of depression. What is it that you are feeling afraid of? How do you dig deeper and try to understand more about what that depression actually is?

And more importantly, I think you need to allow yourself to feel the emotions that come with it. And I wish there was sort of an easy way out or an easy answer to that. But I think that depression itself can happen for so many of us, just based on the world we live in. So to couple it with having this very uncertain future I think oftentimes makes us feel sort of paralyzed, or stuck, or incapable of moving forward. And I think you need you to take it in sort of smaller pieces.

I also think that there are a lot of really important behavioral techniques that you employ when you

get into these sort of bouts or phases of depression. And pardon the example here, but for lack of a better example, I have a lot of patients who live with ADD or ADHD. So many of them have to take medications and the medications oftentimes affect their appetite, and so they have this disconnect about being able to eat or get their hunger cues, and also take their medication and stay focused.

And so because it affects their ability to recognize their hunger, they oftentimes feel nauseous. And the nausea makes them feel like they don't want to eat. The last thing they want to do is eat, because it's going to make them feel more nauseous. And yet actually it's the not eating that makes them feel more nauseous and continues to make them feel worse. And so part of what I encourage them to do is that sort of plan for eating has to be scheduled into their day, even if they can't rely on their hunger cues. That actually when they eat they end up feeling better, they end up feeling less nauseous, and more focused.

And the reason why I use this example, and I'm sorry that I don't have a better one, is because when we deal with depression, we have to employ similar strategies. And one of those strategies, for instance, is when I feel depressed, I feel a heaviness, I feel a sense of not wanting to get out of bed, I feel a sense of not wanting to leave my environment. There's a stuckness, there's a sort of this dark cocoon that we feel like we're in. And that's actually the time where you do have to employ behavioral strategies like getting out of your house or your apartment.

Now I understand that we are different circumstances right now. But there have to be ways in which you can sort of create a break in that zone that you get into a depression. Because depression thrives on depression. So when you feel depressed and you end up isolating yourself, you are then further isolating and making yourself feel more depressed. So I encourage people to wash their face, I encourage them to change their environment, I encourage them to have three steps that they use when they get in these states of feeling down that can help them sort of break that up.

And I think that journaling. There's a lot of writing prompts that I provide for patients of mine. Because being able to answer, I think, questions that we might not ask ourselves in a journal like style can be very helpful.

So this leads to the next question actually that we're just about touching on. How do the deafblind adapt and cope with complete isolation, particularly in this time of a pandemic and social distancing, with the possibility of a permanent lifestyle changes?

Right. So listen, I don't know how much of this is a psychotherapeutic question. I think this is-- there's so many different factors into that. I don't know if this-- who this question specifically is coming from,

and so I feel like it helps when I have a better sense of what your circumstances are. But there are areas of the country that--

[RINGING]

Sorry. That are far more adaptive to the deafblind community. Obviously Seattle has a very large population, as we know. There are different parts of the country like New York City, where I live. In San Francisco Bay Area, where there is just a more sort of disability friendly, SSP ready system set up. But I think that's the position we're all in. Right? Of trying to figure out what our sort of circumstances are going to look like.

And I don't know that we can say. I don't believe that anything so much is permanent as much as we need to sort of be able and willing to adapt. I do you think that being able to have these support systems for yourself is very, very important. So I think that question, although I appreciate it, is much bigger than even this discussion.

Can you discuss how to cope with the feeling that freedom will be lost once my sight is gone?

Yes. So. The idea that our freedom will be lost once we lose our vision, or if we lose our vision, and I want to be very careful here. Because one of the things that oftentimes happens, I just want to-- I'm seeing the interpreter on and not you, Nancy, but I'm-- it's fine, I just want to make sure that everything is fine on your end. Yeah?

Yes.

OK, OK. So one of the things that I think is important is that we oftentimes focus on the negative, on the bad, on the like-- it's almost like catastrophic. We focus on all of the things that are going to go wrong and how do we prepare ourselves. It's like this, you know? Like putting your brakes on. And that, I think, is actually what contributes to these feelings of being depressed. These feelings of not knowing how we will go on.

As opposed to thinking, which I know takes a lot of self awareness and self exploration, and the ability to experience the emotions that come with having Usher syndrome, but instead of focusing on, how do I maintain my independence? What do I have that I can work with?

And I think that the vision loss piece is particularly difficult, because we have oriented ourselves with our vision. We are, for all intents and purposes, many of us have been sighted. And it's much different to be born without vision, to be born blind, than it is to have had vision and to progressively lose it.

But my question for you is, what is it about your vision that gives you freedom? And how is that freedom something you can continue to maintain with other, again, adaptive technologies, whether it's using a cane. This to me wants to know, well, what is your comfort level with using a cane?

How do you feel asking for help? Because I think that a lot of the reasons why we become isolated is because we are afraid to put ourselves out in the world and be seen by others as someone with a disability. We're afraid that other people will judge us. They will mistreat us. We have all of these preconceived ideas.

And then the more we sit at home and think about these things, the greater and more overwhelming and paralyzing these ideas become. And so when I maintain my independence, sometimes I'm using my cane, it depends on the environment. If I have someone with me I'm grabbing onto someone's arm. I know that I live right at home at an intersection.

And I remember one day, it was early in the morning, and there was an elderly woman who was crossing the street. And she was using a walker and the crosswalk is so short that even a very strongly able-bodied young person would have a difficult time making it all the way across without the light switching to the red hand. And so I offered her my help, and she said sure, that would be great. Thank you, I'm always worried that I'm never going to make it across in time and someone won't see me. And she has her hands on her walker, so it's not like she can put her hand up.

And when we got to the other end of the street, she thanked me and she said, she felt so much more relieved knowing that there was someone there with her to hold their hand up. And we laughed and I felt such a sense of purpose, such a sense of value, knowing that I had helped this woman.

And I tell you this story because I think it's important for us to know that when we ask others for help, if we're using our cane, or if somebody offers to help us, our instinct is to say, no, I've got this. No, I can do it, I'm fine. Because to us it makes us feel like we're incapable, or that we're not independent. And independence actually is being able to recognize and receive help from other people.

And not only does it help you maintain your independence, but when you ask for help, when you receive help from other people, you are also engendering something in them. What you're engendering in them is letting them know that they matter. That they're helpful. That they are sort of making your day a little better, and I think that there is nothing in this world that we want to know more than anything than that we matter.

OK. So does Usher, or more specifically hearing loss, a factor in how a deaf person handles stress or conflict? For example, when I remove my hearing aids it is a quiet, non-stressful, peaceful place. But when I have my hearing aids in, and I am part of a conversation, especially with multiple people, I miss out on a lot. It requires much effort to keep pace with the conversation. It is easy then to want to just withdraw and be by myself, but others interpret this as me being moody, or controlling by sulking, even when I assure them that it's merely easier to withdraw than to feel alienated because I can't keep pace.

So I so appreciate this question, because there is nothing that makes me happier, more relieved, than taking my ears off. And I started wearing hearing aids. I'm now cochlear implanted on both sides. So when I take my ears off, I am completely deaf, and it is phenomenal. It is probably-- I think of silence is my religion. Because I so understand what you mean about that peace and that calm and that silence and the lack of anxiety.

So I think part of it is being able, again, to speak your needs. When you're in an environment for all of us who have any type of assistive listening devices or technology, being in a loud, noisy, crowded place is always going to be a struggle. And so there are many ways of sort of handling that. One of which is, and I don't know if you have a microphone and how you feel about having people use that if that would be helpful, but when people are responding to you and think that you're being moody or that you're being rude, and I have received that type of reaction myself in my own life with my hearing aids when we would go to restaurants, and I would end up playing Tetris on my phone because I couldn't follow the conversation. And that was so much more frustrating for me than actually playing the game. That way I felt like I had control over the situation. What I could see, hear and do.

But I think that your friends, or the people around you, they want you to be a part of the conversation. But I think we likely also adapt so well to our circumstances that people don't know what we're hearing or what we're not hearing. And so I think part of it is being able to communicate your needs.

Oftentimes I remember before, when I had hearing aids, if we were going somewhere and I knew that there was someone who just talked all the time, but didn't necessarily have anything that was that useful as input into the conversation, I would put them on my worse ear. And I know that it's sort of funny and I hope that this is making some of you laugh, because this is life. Right? There are always those people who are there who just aren't necessarily the first person we want to talk to, or favorite people.



And so I say put yourself in a position where you are next to or close to the person who you feel most comfortable with. Someone who is willing to repeat things if you need to have them repeated. And I think that it's OK for you to say to them, listen guys, I really have loved spending time with you, but it's just overwhelming for me. So I'm going to step away or I'm going to say good night, or whatever it is, and that's self care. And whether people think it's rude or not, I think if you communicate yourself in an authentic and honest way, that's not your problem. That's something you have to do to take care of yourself.

OK, we're going to make a little switch to parent child questions right now. We have a lot, so we sort of put some of them together. Hopefully we're addressing as many as we can. If not please type in some questions. But big one. When is the correct time to tell your children about Usher syndrome? How do we tell them, and how and if we should prepare them from an early age?

Now I want to also add to that an additional question was, how do you recommend to talk to a young child about their diagnosis when there are changes going on with their hearing and vision that are documented at appointments? So when do you tell them, how do you tell them, but at the same time as we all know, they are going to these appointments. These lengthy appointments. And there's results right in front of you. So.

So I just want to acknowledge that our dear friend and co-board member Tori Banu who sent us a text that said to speak slower. Tori, thank you for sending that. I just saw that message, and it is a very important reminder. So thank you for that. Particularly because we have captioning, and we have interpreters. So thank you.

OK, so we're talking about essentially having a diagnosis for our children, whether they're babies, whether they're adolescents or teenagers. And people often say, well, how much do I tell them? What do I tell them? How do I explain this to them?

And I think that what's most important is that this is about meeting your child wherever they are. So if you have a 3-year-old child, if you have 4-year-old child, a 6-year-old child, what is age appropriate in terms of your explanation? It could not-- a 3, 6, 3-year-old, 6-year-old would never be able to comprehend if you said you have a condition called Usher syndrome that causes progressive deaf blindness. OK, mommy. Can you change this battery for me? I mean, it just goes totally over their heads.

So what is age appropriate? So for someone who is 6 years old, or 8 years old, who gets a diagnosis, I

think what you say is, you have difficulty seeing in the dark. So if you need to grab my arm or someone's arm, make sure that you ask. Or if they're having difficulty hearing. Being able to encourage them to take proactive steps to whether it's to wear their hearing devices, or whether it's to put the closed captioning on. Part of it is your ability to recognize that this is something that they need in order to help them stay sort of assimilated into the world, and that is with captioning, for instance.

And I think a lot of it in terms of vision is being able to tell them what is most relevant to their lives in the present time. So if it's that they need to turn on the light before they go in somewhere, if you need to teach them in a tactile way where the light is so that it's not that they're using their vision to try to find it, but that they actually know spatially where to put their hand to turn the light on. Telling them, for instance, my parents told me at 12 that my night vision was not very good, and that when we went to movie theaters. I would have to hold on to someone's arm, or that they also said to me that my vision below me was not very strong. And so I had to make sure that I was scanning.

And oftentimes we had golden retrievers when I was growing up, and I tripped over them all the time. But what my parents did instead of getting mad at the dog, or getting angry about the situation, they taught me to scan. And that I needed to remember to do that. And that was a part of using my ability as best as I could.

That's great. OK. So this is sort of about a 16-year-old. We have a 16-year-old daughter. She has USH1B, bilateral cochlear implants, fluent in three languages. Since about eight we have known her condition because of genetic testing. She knows about her sight problems, her balance difficulties, and of course of her deafness, and that it is a genetic disease. But we still haven't pronounced the word Usher to her because we are scared of what she will find on the internet about it. I know we should have told her before, but it's so hard to see her struggle. How do we tell her?

So, I appreciate that question. First of all, let's definitely applaud the fact that your daughter speaks three languages. That's pretty incredible. So I can understand this feeling of how do you finally kind of rip the Band-Aid off. Right? So to speak.

So here's my thought. I think sometimes we feel like if we say to someone that they have these vision issues, and they need to wear cochlear implants, and they have balance issues, it actually creates more confusion than having a diagnosis. Than actually having a name for it. So because-- and I suspect if this is a daughter that's 16 years old and speaks three languages, she may have done the research herself. She may suspect already that she has Usher syndrome. This is not-- this is one

smart cookie.

But more importantly, my question for you is, how do you feel about the word, the name, the syndrome. Usher syndrome. What are your feelings about it? And I think that sometimes we've waited so long that it's like, we don't even know where to sort of start that conversation. And I think that it would be important for you to bring up Usher syndrome. I think you may be surprised that she actually knows more than you know she knows.

But I also want you to think about your own feelings about what that means. Do you feel a sense of responsibility that she has this? Do you feel a sense of fear yourself? Because I think addressing your own concerns and anxieties about it will also improve your ability to approach her and be available to her when you say, this is something that-- the hearing loss and the vision loss and the balance issues are all connected. And having a name for it I think actually will be more beneficial than harmful.

You're right about the internet. The internet is an abyss. It is to me a rabbit hole that people can send themselves down. But I encourage you that maybe to provide her with resources on the internet that are not that bottomless sort of abyss of just information, misinformation, opinions, and not actual useful information. So you're welcome to send her to my website. You're welcome to send her to the Usher Syndrome Coalition where we do have all of these communities that are working towards creating, not only the community, but greater access for people with Usher syndrome.

So I think that you can sort of provide her not only with the Usher syndrome information, but also with web sites or links that you have found to be particularly helpful. Ava's Voice is another wonderful organization that does a lot of empowerment work and advocacy for students, for kids living with Usher syndrome.

My 10-year-old daughter is a fierce advocate for herself, but even then she often says it's not fair that I am deafblind. What can we say or do differently to help her with her feelings and validate her pain, yet give her direction to use her life experiences to advocate for herself and the community, and not be a victim and get lost in the pain?

So I think that's part of the experience, right? In many ways I feel very fortunate that I never really felt that sense of that it's not fair that I'm deafblind. And I mention this because I think that maybe this is my very science oriented brain, that this is just the way that genetics work. And that we all receive our genetics in different ways. But generally that feeling of, this is not fair, is something that as you mentioned should be validated. You're right. It's not fair.

But I want to hear more about that. What feels so unfair? And let her communicate that. Let her communicate what is unfair. Let her be able to get that out and off of her chest, and that will allow her to continue moving forward. I think the recognition and not the dismissing of it, which it sounds like you don't do, will really allow her to own the fact that this is not fair.

But I am still going to do what I can to improve the quality of my life, to improve the quality of others' lives, by advocating on behalf of people with vision and hearing loss. Or whatever it is it makes her feel most empowered. And I think that asking her questions about what makes her feel most empowered, most able-bodied, so to speak, and letting her sort of really thrive with those activities.

Our 18-year-old with 1b is driving, but will soon have to deal with not being able to drive at all, and is currently dealing with feeling like a freeloader because he has to rely on his friends to drive him around at night. We offer to pay gas, and suggest that he talk to his friends to let them know how he feels. It's hard for him to hear this, especially from his parents. What are some ways to help him through this?

So that the driving question is such a big question. And let's be clear, I mentioned that I grew up in the San Francisco Bay Area. I moved to New York City because at the time, this was before there was any ride sharing. There was no Uber or Lyft or anything like that. And I wanted to live in a place where I felt like I was sort of in the same boat as everybody else. That I was able to navigate using public transportation, or even having to take a cab if need be. And that driving was not the primary means of how people got around.

And I say this because before living in New York, I lived in Los Angeles, which was probably the last place a person should live who is dealing with night blindness. And so I drove in Los Angeles only during the day, but I did feel very much disempowered there. So that's part of why I moved here. So I don't know where you live and what is sort of accessible.

But I do think there's two options here. One of which is, I do think it would be helpful, even if not with everyone, if he has one or two friends that he feels most comfortable sort of communicating with. And he doesn't have to go through the whole song and dance of what his diagnosis is. That's really up to him. It's a personal decision for how much or how little he shares.

But I think that he can say, I have night blindness, and I can't drive at night. So I hate not being able to be the designated driver, not be able to pitch in in this way, but I'm always going to need a ride at night. Almost like taking it off the table.

And in terms of being a freeloader, I think he can say, like that I hate this one because it does make me feel like a freeloader, but more importantly, I think it's also allowing his friends to be there to show up for him. And also to work together. OK, who's going to have an-- I don't know what your son's name is-- but, like let's say his name's Eric. Who's got Eric? And I think that actually can bring a lot of camaraderie to the situation. And it may even encourage other people to share things that they're sort of dealing with, because of the vulnerability.

Now being 18 years old it's really hard, particularly as a guy. The other thing is is that, if it's really that difficult, I encourage him to call Lyft, call an Uber. If he's offering to pay for gas, then take a Lyft or an Uber. Have options, especially he's maybe hanging out with people that he doesn't feel that comfortable with.

Yeah. Losing or not having the ability to drive is a really tough one.

That's a whole-- I feel like that's a whole other conversation, and it is, and I'm happy to speak to anyone about that, because it's a hard one.

It is.

I am interested in knowing whether or not adolescents with USH are more susceptible to anxiety issues? And if so, how to deal with them?

So, spilling on myself. So here's the difficulty. We live in a time and place where we have so much access to information, like on social media, that kids across the board, particularly adolescents and teenagers, are far more susceptible to anxiety now than they ever have been historically. And so to ask whether someone with Usher syndrome is more prone to anxiety, it depends on how their situation, how their vision and hearing loss is addressed in their primary environment, which is usually their home.

How is this child or adolescent, teenager, encouraged, empowered, and taught to practice sort of the skills that they need in order to accommodate themselves or acclimate to whatever the environment is, or bring whatever the devices are that they need? And how much of it is sort of-- like, it's OK, you're fine, I'll do this. How much of them is enabled?

Because I think that part of the important piece of teaching advocacy to children or being able to have them challenge themselves and learn these coping strategies is also a way of-- it empowers them. It allows them to have not only resources, but solutions for when these things come up. It's-- I think that Usher syndrome alone does not just cause anxiety. I think there are a lot of extenuating

circumstances.

But I certainly think that having Usher syndrome, depending on how it is handled and discussed, or not discussed, or addressed, or not just addressed in the family, can very much impact whether a child or adolescent has anxiety. Or an increase to their anxiety.

This is a nice lead into the next question, which is our youngest, oh, let's just wait. We're going to have a change of interpreters.

OK.

Our youngest daughter, 23, has social anxiety. Having Usher just makes things worse, and she spends most of her days in the internet, the most safe place. How can we help her to cope with her condition?

So, we have construction going on the background here too, so that should be helpful for her for hearing me. So just let me know if anybody has difficulty hearing me.

So I completely understand the idea of the internet being a safe place. When in reality the internet as is probably one of the unsafest places for a lot of reasons. Because it's safe in the sense that it allows you to hide. It's safe in the sense that it allows you to distract yourself. There is a reason why we treat now so many adolescents, teenagers, and young adults with internet addiction, because it is very much used as a coping strategy.

I don't know what she's doing when she's on there, whether it's meeting friends online, and sort of protecting herself from the possibility of being rejected in real life. But I think that what's most important is that internet time in general should be finite. The amount of time that your child spends on the internet should be monitored. And I know it's difficult when you have teenagers. But having the ability to be online all day tells me that there's no structure to this person's day. And structure is crucial.

The difficulty is, we are also living in a time where we're not able to go out, to come and go as freely as we were before COVID. So being able to figure out what your structure looks like now is going to be different. It's difficult because that safe space that she's created for herself is also in some ways I think like almost like an alternate reality. And it may protect her from the ability to have to speak her needs, to be able to ask questions. If you have the resources and means to be able to encourage her to see a therapist, I think that might be helpful to be able to communicate some of these feelings that

she has.

I also think that being able to connect, if she is going to be online with other teenagers with Usher syndrome, could be helpful. But I do think that you should try to limit the amount of time that she has online. And I know that that's much easier said than done, because she is not going to like to hear that. But I do think that it's important for our kids to learn these skills, and the ability to interact with the world outside of the web, the internet.

Do you have any resources or suggestions on how to get the school to understand an adolescent USH kid's needs? I feel my son's success in school heavily relies on how invested the teacher is. I would love to provide them with some articles or videos to help them understand a little more of what school and life is like for him.

So that's an excellent question. And I absolutely agree that the more the teacher understands, the more that they'll be able to support your child. There's a few things that I'm thinking of. One of which is Ava's Voice. Carly Fredericks who had a parent potluck last night. She is incredibly resourceful. Her daughter Ava has Usher 1b. And they live in New Jersey. She is so resourceful and really provides education for the school system, and provides services for the deafblind community in New Jersey. She would be a really good resource going onto to [avasvoice.org](http://avasvoice.org) could be very helpful, or even connecting with her I think could be really useful for you.

But one of the things that I did, I remember when I was in school, was we were encouraged to do projects about something we were passionate about. And I was always passionate about animals. There's nothing I love more than dogs, as most people who know me know. But I couldn't really think of something I was really passionate about that I wanted to do a 10 page paper on.

And so I spoke to my professor. This was actually in college. And he was a cancer survivor. And so somehow I felt comfortable telling him about my diagnosis. It was really right after I'd been diagnosed with Usher syndrome. And he said to me, why don't you speak to the class about this? Because it wasn't just a passion project, a writing about it. It was presenting to the class.

And I was a bit overwhelmed and taken aback because I was thinking, well, I don't even know how I feel about this. How possibly can I talk to other people about it? But it was actually in my ability to sort of own and control the narrative to educate the other students about what my situation was, that gave me this sense of-- and being able to tell them what I needed, what I could see, and what I couldn't see.

And there are so many videos out there that any of us would be happy to provide you with. But I think that if he would be willing, or you would be willing even to educate the teacher, and to provide these videos, and that would be awesome. And connecting I think with Carly would be a really important step. But I also think that it might be good for him to be able to-- even if he's nervous about it. Even if he doesn't feel necessarily so comfortable with it. There's something incredibly sort of relieving and I think almost freeing in being able to speak your truth even at that age.

And not just having kids say, well, that's weird. He trips whenever it's dark out. Or he never sees whatever it is. Being able to control that narrative and give him the opportunity to educate others I think could be really sort of a confidence booster.

My older son is 23 and just passed into the legally blind category. He has cochlear implants. His biggest of many concerns as a young adult with USH is the physiological stress of normal life things. He feels like his fight or flight sensors are always on overload. He has learned to use a cane to more easily navigate in public, but he's always on alert to avoid tripping, hitting his head, missing someone trying to get his attention, or running into something or someone. Do you have any suggestions for dealing with this type of stress and overload?

So that's interesting. I mean, what it makes me want is more information about your son in the situation, because it's not-- so it sounds like the fight or flight mode is that when he uses his cane-- and I'm assuming has he had formal cane training? Has he had more-- sometimes I think even doing more mobility instruction could be helpful in being able to address that, because there are all-- there are many different techniques that you can use with your cane. I don't know where you live.

But to me this makes me wonder what sort of-- where the anxiety started. Was it something that predated actually these changes in his vision? I mean, let's be clear. I think the majority of people, even those of us-- and I don't drive, but those- when I did drive I was legally blind. So I mean, the reality is, anybody I think with Usher syndrome or RP who is driving is likely legally blind. Doesn't take a lot for that actually to be your diagnosis.

Yeah, so I think that the mobility instruction, the O&M. Orientation mobility. Further O&M could be really helpful for him, especially navigating stressful environments. But that might be something I think that I'd be more curious to know about where this anxiety sort of started, or if it precipitated, or if it was precipitated by other factors in addition to having the vision and hearing loss.

OK. So we're going to move on to another category, which is understanding our disability. And so we'll start off with, how do I deal with the feeling that others can't really understand my disability?



So my question is, how do you understand your disability? How do you communicate about your disability? How do you interact with others when your disability feels like it's sort of very present? That it or the concerns that you have of people seeing you with a disability? Because I think it's your own process of coming to terms with your disability, too, that is going to inform the way in which you interact with others.

Now, don't get me wrong, we are always going to interact with people or have experiences where people are insensitive, where they treat us like we're not intelligent, because for whatever reason their association is that if you have a disability, that you're not educated, or that you're unintelligent. That's about all you have to choose whether you want to fight. I personally think that's your problem and not mine. And I sort of move on.

But one of the I think important things is that the more comfortable we are, and when I say comfortable it doesn't mean that you've accepted it and you're totally fine with the fact that you're going blind and losing your hearing. If you are still losing hearing and don't use cochlear implants. But I think that what's most important is how you feel about it, and how you communicate to others about it.

And I don't see myself with this disability as lesser than, as incapable. There is nothing about my disability that means that I'm not smart enough or incapable of interacting with the world. Now, I can't control what jerks are out there, and aren't going to respond well. But I also know that there is tremendous kindness out in the world. And there are people who really want to help. And there are people who will always sort of be there to offer us-- sometimes in more ways than we even want them to. And I encourage you to focus on those people.

And I encourage you to focus on being able to develop your own comfort with it so that, for instance, right now we're at a phase where everybody's wearing masks. And again, that's a whole other conversation. But what I say to people immediately is, I'm hard of hearing. I wear cochlear implants. So I don't-- I'm not going to hear you well, because I can't read your lips. So if I say what, it means you likely need to enunciate, or I may ask you to repeat yourself.

And it's almost like giving that information ahead of time will help manage their expectations. When we're just saying, what? What? Where we seem frustrated? Then it makes them frustrated. When you come to a situation-- for instance with my friends they know about my vision and my hearing loss. I tell them how I need them to help me. Or if someone offers to help me across the street, and I feel comfortable crossing on my own with my cane, I will say, instead of saying, no, I'm good, I'll say, no

thanks, I think I'm OK. Or I try to have a positive response to let them know that I appreciate their asking to help. But that I feel comfortable doing this on my own.

So I think to answer your question, I really think it's important for you to work on your own level of comfort and ability to speak your needs, and that, I think in turn, will really cause an effect on how other people respond to you. And we can't change everyone. We can't inform everybody. There will always be people who just don't get it. And that's frustrating. But it's also the world we live in.

Yeah, the second question that I was going to ask. Which you've answered it, but it's true. It's, how can I be honest with others about having Usher syndrome when I'm scared to know what they will think of me? You've answered that. But it's a really important thing to address. So OK. How can therapy help people living with Usher syndrome? Do you recommend a specific type of therapy, therapists, for people living with Usher syndrome, are deafblind people better to have a deafblind therapist?

So there's a few things. As I mentioned early on in this discussion, I do think that when we're struggling to find a therapist who really gets it, that I would encourage you to try to find a therapist potentially who specializes in grief and loss. Because I think that there are similar patterns and experiences that we experience having both progressive vision and hearing loss, that people who specialize in grief and loss can understand. And there will always be a bit of education. Right?

The other thing I would say is that your Usher syndrome may not be your primary problem. I think that sometimes we use Usher syndrome because it's an easy crutch, right? It's easy to say, well, I don't see and hear very well, so I don't-- I have a difficult time making friends. Because nobody can understand me.

Well, certainly nobody can understand you if you're not willing to help them understand you. If you're not willing to put yourself out there and be vulnerable. And I think that when we're consumed with how other people will see us, or what they'll think of us, we end up behaving and being inauthentic. And who are you authentically? Who are you when you're not consumed with trying to fit in? And that's a hard question to ask. It's a hard question to sort of figure out.

But I think there are people out there, sometimes we're more afraid that other people won't accept us. It's because we have our own issues of accepting our circumstances, and we're also afraid of being rejected. And I think everybody has that fear of being rejected. Right?

And I have to say that, and trust me in my own history of dating-- which, again, is another conversation-- I've been rejected so many times because I disclosed my diagnosis, my Usher

syndrome. And when that happened, I felt-- I remembered there was one guy I went out with, and we had a great first date, and he-- I think he maybe he looked me up, and this was a long time ago, or I told him about my vision and hearing loss, I think.

And I noticed that he didn't reach out to me to set up another date. So I was like, OK, something's not right here. And so I just reached out and I said, hey, had so much fun. Would love to see you again. And I got this long winded email back, that was, my dad has Alzheimer's, it's going to be too much for me to deal with, I can't take this on too. And I'm thinking, whoa, dude. I just want to know if you want to go on a second date. I'm not talking about marrying you.

And by the way, that attitude sucks. Right? I mean, obviously I understand that, and we all have that fear. And there will be a lot of people who feel that way. I've gotten that type of rejection in various different forms so many different times. And initially it does feel like a rejection and I do feel hurt by it. And then I realized, oh my God. If this is somebody who is so freaked out about having this kind of conversation, about having an unpredictable future-- which by the way, all of our futures are unpredictable-- then this is not somebody that I want on my side. This is not somebody that I want to try to build a relationship with, because this shows me that this person maybe doesn't have that type of wherewithal or resilience.

And to be quite honest, I say this is their-- and I use an expletive. But this is their stuff, not mine. And that sometimes is a good mantra to use. Like this is their stuff, not mine. This is their stuff, not mine. Because having Usher syndrome does not by any means make you flawed or incapable of having a very meaningful, loving relationship.

What types of mental health services are available to the deafblind, and how can we find these services in our state? How can we advocate for those services if they don't exist? Is the source of contact for mental health services the same from state to state?

It's definitely not the same from state to state. We did-- Nance, where did we put up the?

We posted a document under Ask The Therapists. You can get it on the Whova app. There is a document posted of resources with links from state to state. So hopefully that will be a beginning place to start.

So here's the thing, and I put together a very-- I have I think all the states in there. But some of them may be dated. I worked with everything that I could find to try to put some resources together. And I can't say, unfortunately, from every state what every state has in terms of their availability.

You're right. How do we advocate for our needs when they don't exist? And trust me, that is the battle that we are all sort of living with. I mean there is so much work that I personally do on advocacy and education to be able to create greater access. We just had a really, really encouraging step made with Peloton, not that most people can afford Peloton, because it's so stupidly expensive.

Hold on, Rebecca, let's change interpreters for one minute.

OK.

There.

So but we just had a big step that we made with Peloton in working with them too, they have screens that they use. I happened to look up to see how many users on Peloton, and this was some time ago. How many of them-- and remember, I have a background in fitness and being a fitness instructor-- how many of the people on here actually have the word blind in their user name? And I found that there were over 300 people.

And so I have a screen name on there, but I'm not-- but it doesn't have blind in it. So those are the people who do have blind in it, I don't know how many of them are blind and how many aren't. But it tells me that there is a need here. And so we worked closely with them, and they now have not only the captions on their technology on their screens, but they have the screen readers for the blind.

So this is just an example of, you have to-- you do have to do the work. And I can tell you that when you do put that time and energy into this stuff, which is exhausting, and seemingly not our responsibility, but it is very empowering and rewarding to know that you're providing not only access for yourself, or creating it, but that you're doing this for other people. And if you yourself don't have the time or the energy to do it, then you want to reach out to the people in your community, in your state, to let them know what it is specifically you need.

I regularly reach out to accessibility at Apple.com, give them a list of the things that are not accessible on Apple. And they respond to me. And I think that's-- all of this smart invert and inverting, everything they've done recently has only made their accessibility features worse. And they need to hear this.

So if you have complaints or feelings about it, or suggestions, by all means, you need to reach out and provide those. Because being frustrated and complaining about it is not going to create change.

OK. What was getting your degree and license like? What have you had to do when you work to accommodate for your needs? Have you experienced any pushback from patients that may perceive a lack of ability to give them care?

That is an excellent question. So there is a few things, and I write a lot about this in my memoir, *Not Fade Away*, which if you haven't read, I highly recommend. Sorry, bad joke. But what I will say is that the University of Michigan, when I attended there for undergrad, was so helpful. That was where I really, really learned a lot of my advocacy skills.

My parents were very, very strong advocates on my behalf when I was-- before I attended college, and so I definitely learned a lot from them. My mom was very active in figuring out with the schools what I needed. But my needs in high school were not nearly as significant as when I continued on. When I went to Columbia, I basically went to the disability services office and I said, I need to have my books enlarged, or I need to-- these are the needs that I have. And they said, great, here's the copy machine. You can go and take your reader over to the copy machine and enlarge your print. And I sort of looked around like, are you kidding me? Like absolutely not.

And luckily I knew that according to the ADA, that it was not-- only was that illegal, that they had to provide me with this. So if you go up to Columbia you will hear my name being whispered through the trees, and not in a loving way. But I can tell you that I created a lot of change in terms of their accessibility.

In terms of getting my license, I applied for the extended time and large text for the licensing exam. The other thing that I did when I was doing my analytic training, I remember being at the American Institute for Psychoanalysis, and one of the analysts who was one of the directors of the program, when I was going on for further training, she said to me, how are you going to be able to provide therapy for people when you're blind? And I was so angry and so taken aback by the fact that somebody who, with that level of experience and seemingly understanding of the human condition, that she thought that being blind would be a barrier to being able to help others.

And I educated her about that. And I told her that I was really offended by that question. And more than offended, I was disappointed. So it has definitely been an upward battle. The Institute where I trained, they were not willing, at least initially, to provide me with readings. Remember for analysis, we had readings that were maybe in eight point font. I mean, there was no way that I could read it, let alone anyone who is above the age of 35.

So it was a lot of challenging the system. And fortunately or unfortunately, there's nothing I love more

than challenging the system, to think outside of sort of traditional roles and needs.

But in terms of my own practice, I have had many patients. Before I was implanted I had a microphone, and I would put it on the armrest of the chair that the people I worked with sat in, and I told them, I wear hearing aids. This is not a recording device. It's actually a microphone that streams directly to my hearing aids so that I don't have to hear all the background noise, and so that I hear your voice directly.

And when I got implanted, I always let people know. It's the first thing I tell them. That I'm cochlear implanted. Sometimes I have my hair up so you'll see my implants, and I just want you to know from me what they are, so there's no confusion. Whether I address my vision or not depends on a, the patient. I have to assume that everyone who comes into my office Google's me and likely knows, and whether they address it or not, I can't control.

But I will tell you that I've had people who didn't speak loudly, and I say to them, I told you that I have hearing loss, and you're mumbling and almost whispering. I can't imagine how difficult it is to share some of these things out loud, but I can tell you that if I can't hear you, I can't help you. And I've definitely terminated with patients who were not able to accommodate me. And I would say to them, I just don't think I'm the best person to help you because I have needs also.

I think that historically therapists have been seen as sort of this wall without problems, and all the answers. And that is by no means the case. In fact, I think it's the humanistic part of you that will allow your patients or allow patients to feel more connected to their therapists. Listen, I wish there were deafblind therapists all over the place, because I do think that when you have personally dealt with whatever the issues are that someone is dealing with, that you do have an insight that is unlike what maybe other people have. But just because you are not deafblind does not mean that you have not experienced adversity, or had resilience that you have had to create in your own life based on your own experiences.

Are you taking patients?

So I have fairly limited availability in my practice. And I will tell you that I'm a highly interactive therapist, and a highly sort of motivated therapist. So if you have any questions about your own motivation to make changes, and I will tell you that I'm not probably the right therapist for you. But I do have limited availability.

Now, on to the cane.

Uh-huh.

I use a mobility cane to travel in airports, train stations, and at night. I am legally blind but have no problem reading a book. I just can't get across a crowded train station. I am caught in the land between sight and blindness, and it sucks. I feel like I have to act more blind or like a fake blind person whenever I use my white cane. Is this normal?

Amen! I think that is just like-- I mean if that is not the meat of what it is to live with Usher syndrome, then I don't know what is. Because we are so caught in between being sighted and being blind. People don't understand that even if you say you're legally blind, that that means that you can see. To be low vision. What does even-- what does low vision even mean, right? Most people don't even-- haven't even heard the term low vision.

So I don't know who made that comment, but I wish I could give you, and I am giving you a huge virtual hug, because I feel you. Even hearing Nancy say that, sort of ask that question gave me goose bumps, because it was almost like I could have spoken the same question. And I totally, totally get it. And I think that here's the issue.

I remember a long time ago I was waiting for the bus. And I got on the bus. And when I got on the bus I wanted to take my book out to read. But I'd been using my cane. And I put my cane away, and I thought, God, I really want to get to this next chapter. This book is so engaging. But I was so concerned that if I do this, is everyone going to be like, she's a fraud? Like, what a jerk.

And so instead of-- I sat there and I said, forget it. Like I'm just going to read my book. This is my life. And whether people understand it or not, I can't control. I've definitely gotten comments from people saying that I was a fake, and it certainly doesn't feel good. But I also know that my reality in my life is sort of-- is not subject to other people's sort of share their opinions. But I didn't invite that opinion or that feedback.

And if there are times when I decide to educate people, and there are times when I decide that like, all right. You can call me whatever expletive you want, and then we move on. Because again, this is their stuff not mine. But I do.

It's interesting. Even when we board a plane. I may not actually need my cane so much when I'm boarding the plane, because it is a narrow-- what do you call that? Runway. But the walkway that you get on. But I use my cane--

Aisle?

Yeah. The aisle, but also whatever that when you get on to-- yes. Exactly. So but I use my cane in the airport. There is nothing worse than the rolling bags on the ground. Toddlers are definitely at risk if I don't have my cane. Even when I do have my cane.

So I use it first and foremost sometimes just to give people the information to get out of my way, which by the way, most people are looking at their phones, and I end up as the person using a cane having to tell them to look up. So-- and that's definitely not a proud moment for someone when a blind person or a person using a cane tells them to look up, right?

But so I'll use my cane. I use my cane to board early. Do I need to board early? I mean, I probably can make it on there just fine. But I am legally blind, and by law I'm allowed to board early, and I want to make sure that my bag gets up above my seat. So I board early. Even though there's a part of me that almost feels guilty that I have vision, some vision, and I'm boarding early.

And that is all a part of living with Usher syndrome. So what I say to you is, I totally get it. And I think we all play more blind sometimes, not because we feel like we have to for ourselves, but that we have to for other people to understand. But I've found myself more and more recently not having to act as blind, or being more-- any differently abled than I already am, and kind of allowed it to be their sort of issue of me making eye contact.

By the way, Sophia from Mexico just says, it's called a jet bridge. She texted.

Thank you, Soph. That's my dear friend Sophia, also a board member for the Usher syndrome. Thanks, Soph.

So in addition to that question, how does someone get past the anxiety, and not be concerned with what others think?

So, I think that that's an anxiety that we all have. Right? It definitely, with Usher syndrome, I think it's more pronounced, because it's interesting that people oftentimes who need to start using their cane, and you may not need to use your cane in every environment. Around my block, when I take Monkey, my dog, for a walk? I sometimes won't use my cane. And why? Because I know my block like the back of my hand. I know where there is a dip in the pavement. I know where her favorite spot to go potty. So that may be a place where I don't use it.

But so, I think that there is a universal theme about being concerned about what other people will



think. But with the cane, people tend to use or start using their cane anywhere between 5 and 15 years after they really could benefit from using their cane. That is an extraordinary amount of time of, to me, suffering. To me, being concerned with how other people will treat you.

And I have to tell you, and I often say this when I give talks, that the first five or six times I used my cane in public, I cried. And fortunately in New York City, using a cane and crying may not draw that much attention. But I do think you have to allow yourself the experience of using your cane, and the emotions that come up for you when you do that to allow yourself to get to a point where you can move on.

When I was able to get through the emotions of having to be a person with a disability in public, meaning what was diagnosed and projected for me when I was 12 was actually coming true. That it had come true. That it was being realized. That was a very emotional experience for me.

But when I was able to work through that, and really quite literally get through it, I was able to realize how much the cane helped me. And I got to tell you, there is all this assistive technology these days, but there is nothing that gives me more information when I'm using my cane than the tip of that cane. So I find it to be very useful. But I think that dealing with other people is-- and their sort of your fears about how they'll treat you-- I think the first place to start is your own level of comfort with the circumstances.

OK, we're going to move on to some interesting questions about caregivers. First is, what is your best advice for a caregiver brother living with an older 68-year-old person with Usher? It can be very challenging at times, especially during quarantine. Patience is one of my mantras. I see a therapist myself for self-care and communication hints. Asking for and accepting help seems to be one of my brother's biggest challenges.

So I just got another text from my mom telling me to talk slower. So I'm apologizing for that, and thanks mom for reminding me. That's a huge question. Being able to teach your brother how to be better about asking for help suggests to me that there may be some real co-dependence and enabling in the relationship of him being able to rely on you, and you feeling a tremendous sense of obligation of doing things for him.

So I think that, how do you teach for lack of a better way of saying it, how do you teach an old dog new tricks, right? Well, in what ways do you do things for him or help him, so to speak, where he could actually be helping himself? And are you able to teach him what he needs to know in order to do it on his own?

It may initially take more work for you to teach him, and it will be based on tactile skills. But I think that that will actually go a lot further, and save you a lot of time, if you're able to help him become more self-reliant. It will also help him develop his self-esteem and confidence, and give you a greater sense of independence as well.

OK, so this is the flip side. How do you become a caregiver for someone else when you are in an advanced stage of Usher syndrome?

So, I'm trying to understand it. So?

So this person--

Has Usher syndrome in an advanced stage, I understand exactly what the situation is.

Her mom had a stroke. And they now become the caregiver. How do you navigate through that?

So I think that is an important time and place to seek outside resources to help you support this other person with Usher syndrome. It's sort of the blind leading the blind, which many of us in this community are very familiar with. But I would look into external resources that could be helpful to you. I know that this in addition to having potentially, I think that for a lot of states they do have the ability to apply for assistance in the home.

I know that then having an SSP, someone who can help in terms of the communication is an issue. But listen, that is a difficult situation, and a difficult question. I think that part of it is seeking resources outside of the home, whether it's through the state or in the community. And also being able to use whatever abilities this person has to create assistive or adaptive ways of helping them. And we do have to be very creative, I think.

OK, I'm going to invite Krista on now, who has been going through some more questions.

You're muted.

Yes, hi. Hello. Again. So I'm going to start answering questions that have come in live. If you are diagnosed early, do you have any suggestions about how to make plans and find ways to live your life in the fullest way?

So, I don't know what early means. But your plans for your life, I think we have this idea-- part of what makes us so anxious and overwhelmed is thinking too far ahead. You need to live presently. You need

to live in the moment. And we all want to make plans for the future. But I think you have to think within reason.

There's a book that many of you may know that's called *Welcome to Holland*. And long of the short is, it's about a family having a child. And essentially the idea is, they thought that they were going to Spain. And they were so excited about all the sights they were going to see. They were getting on this flight, and this is sort of-- this is figurative, it's not literal. But they were getting on this flight to go to Spain, and they were anticipating all the sights that they would see.

And when the plane landed, that is when the mom gave birth, the plane landed and they said *Welcome to Holland*. When the mom gave birth, she had a child with Down syndrome. And all of the sudden everything was disrupted. All of the plans they had for this sort of figurative way of thinking of it, was going to be in Spain, and all of the sights they were going to see and the experiences they were going to have. But instead they ended up in Holland. That had much different experiences, that had a much different way of doing things, a different language.

And I use this example, because having Usher syndrome is not by any means mean that you are not going to have a fulfilling, meaningful life. That you shouldn't have goals and things that you look forward to and plan for. But it does mean that your trajectory may not be traditional or follow the path of someone who is fully sighted and fully hearing. So you will have to access the resources to be able to create the possibilities and the opportunities for you to navigate whatever those goals or those plans are based on what your needs are. So to me, where there's a will, there's a way.

Great. Because of the COVID-19 pandemic, my organization had to shut down indefinitely and I lost my dream job. Searching for a new opportunity during a pandemic is already hard on my mental health, but I had-- but I find the Usher is limiting my already small pool of potential opportunities. What is your advice on staying mentally strong and being an advocate for yourself during a job search?

And listen, I give you so much credit, because this is-- what part of what's difficult about this situation right now is that so many people are going through this, that it almost feels like it takes away from our experience. Because how can we be concerned or complain about this when so many people are also going through it? So this is just a way of acknowledging what you're dealing with, because it is really, really difficult.

So my best suggestion is, I definitely suggest that you create structure, if you haven't already. You must maintain structure in your days. At least during that Monday through Friday, five days a week,

workweek. Create that structure and also make sure that you're doing things that are proactive. So for instance, every morning I wake up. Which believe me, it took me a long time to get to this place. But I meditate.

And I'm not saying I meditate for 30 minutes and I align all my chakras and all of that. This morning I meditated for five minutes. That was all I had. But the reason why I do that is because I have found that it has been tremendously grounding, particularly because it allows us and forces us to focus on our breathing.

And I think that our anxiety and fear and mental health is very much connected to this disconnect between our mind and our body. So when we're able to really allow ourselves to be connected to our breathing, I think that we can feel more grounded, and we can start the day on our terms.

So applying for jobs, absolutely. That's a part of your structure. I think physical activity is very important. I know then people say, well, how am I going to do physical activity? I can't see or hear well. I do my workout in my living room, with no equipment, and no ears on. And I'm able to create a workout for myself to get my heart rate up.

I don't do this because I'm so consumed with being in shape. I do this for my mental health. Physical activity can be done in so many different ways, and it is essential for our mental health. Getting our endorphins going is so important. So I encourage you to do that as well.

And I also want you to think, during this time. What are the things that you have been putting off? What are things that you have been sort of afraid to address? This might be a good time to focus on some of those things, to help open you up to more possibility and opportunity for yourself in terms of job opportunities. And self-acceptance and confidence.

But listen, I give you so much credit. This is a very, very difficult time.

So, Rebecca, I was just going to say, with four minutes remaining I know we're closing up. But there might be an opportunity to end with one final question on a high note for you, Rebecca. What has been one positive side to having Usher syndrome in your life? If so how has it impacted your life for the good? So I'll let you close up with that.

So I love this question. I so appreciate it, because it sort of goes back again to what I was saying about, we are inclined and taught and learned to think about life in terms-- and Usher syndrome-- in terms of losing, in terms of being robbed of, in all of these very negative ways that make us feel

afraid. Because these are words that elicit fear. Right?

So I think part of it is, that's a part of having Usher syndrome. That's a part of actually being alive. Right? Of experiencing the range of emotions that come with fear, anxiety, loss. But what I can also tell you is that, having Usher syndrome has created the greatest sense of purpose and meaning in my life. We all often think, what would my life be like if I didn't have Usher syndrome? If I wasn't losing my vision and hearing? I think there's not a person with Usher syndrome who hasn't thought about that, right?

And I can't possibly know what my life would have been like. I don't know if I would have taken on a different profession. I did go into this profession because I knew there was longevity for me, given my hearing and vision loss. So here are the things that have been positive.

As difficult as it is to deal with assistive technology, and when things fail and break and having to get them exchanged, and dealing with insurance not covering it, that's a nightmare, right? But there's nothing greater for me than taking my ears off and being deaf. I learned sign language when I was in college because I thought I knew, at the time, that maybe it would help in the future. And so I was able to develop these relationships with the deaf community, and later the deaf/blind community, and that has been so meaningful for me. It's so meaningful.

My relationships with people are far more meaningful. It's really cut out a lot of the, for lack of a better way of saying it, and I won't say the word, but BS. It's cut out so much of the BS. And you know why? Because I don't have the time and I don't have the energy for the BS, for the superficial sort of things that happen in life.

And I appreciate having Usher syndrome to help me sort of streamline to what's most important. And so, there's so many different ways it's encouraged me to ask other people for help. It's encouraged me to be able to develop relationships with people, so that I can not only be a good friend to them, but they can be a good friend to me.

I know that we need to end. But I do think that there is this misconception that being someone with Usher syndrome means that you are always on the receiving end of a friendship. And that's a terrible sort of way of thinking. It's certainly a terrible way of feeling. I think that my friends rely on me in many ways as much as I rely on them. And being able to see that value and work you have in your friendships, even though you can't help them with anything sight or hearing related, you can help them as being-- in many other ways. And that for me has been so meaningful.

In terms of my career, in terms of what I spend myself my time doing, I really don't waste time. And I think that good or bad, it's because I'm keenly aware of how precious time is. So yeah.

And I can also tell you lastly that yesterday I was going to be on the potluck, parent potluck live call, and I was stuck at Columbia's ophthalmology department with my eyes dilated having my cataracts checked. So I think I talk about all of this stuff, and also please know that I am just as much in the thick of all of this as everyone living with Usher syndrome is. And I don't take that for granted, and I really appreciate everyone showing up today, and for your vulnerable questions. Yeah. And thanks to mom and Tori for reminding me to slow down.

Thank you so much, Rebecca.

Thank you everyone for joining us. We'll see you through the rest of the week. Take care.

Thank you, Dena. Thank you Melissa.

Thank you.

Thank you.