

## **Rare Lives: Breaking Free from the emotional costs of a rare disease**

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The COVID-19 pandemic has disrupted billions of lives. Among the ways in which this has happened is social isolation. With families and people being forced to practice quarantine and physical distancing, the space for reaching out to other people who acted as support systems has shrunk. Among the pandemic's most striking lessons then has been the immense value of mental health and emotional well-being.

People with rare diseases simultaneously live two lives. Their first life is what you will see if you come across a rare individual, manifested in little things like constantly re-adjusting to a deteriorating body because of a chronic illness, meanwhile trying to make a livelihood also continues, and so does their education or search for the best possible treatment. We've covered aspects related to medical diagnosis, treatment and disability in the previous four episodes.

But it is a second life which is often overlooked. While trying to find their place in the world, rare individuals are faced with what seem like great odds. Negative emotions such as grief over health loss, frustration with the situation, are commonly experienced. These are human emotions which are complicated but at the same time being felt by each and every human being. But why is it that the emotional well-being of patients is rarely discussed?

Hi I am Avantika Shrivastav and I spoke with Arouba Kabir, a counsellor at Enso Wellness, and a rare individual herself on how, for rare individuals, medical treatment often helps them survive, but it is emotional support that makes them thrive. Arouba has cystic fibrosis, a hereditary disease that severely affects the lungs and digestive system. Cystic fibrosis can be life-threatening.

**Arouba:** Since COVID-19, people have been talking about mental health awareness quite openly, like, I have been working as a therapist for seven years. And in the beginning, you know, I use this thing for myself, mental health therapist, whereas people are like no counselor would be more suitable that people will take you seriously. But when it started out and telling someone that I go to a therapist, you should seek therapy, if there are issues in your life, it was like a stigma. It was a taboo, oh, my God, see a therapist, am I mad am I not able to make my own decisions is there something wrong? Then the lockdown started, lots of calls started coming in about loneliness, about uncertainty, anxiety, a lot of anxiety. Whereas before lockdown, we used to see a lot of cases of depression, social anxiety or other things but lockdown all of a sudden gave that anxiety to everyone, anxiety about relationships jobs financial insecurity, body issues everything because if a person mostly if we see what our culture has done to us nowadays we wear good clothes we go outside we get a compliment

our self esteem goes up but that was not happening during the lockdown that is not happening during the COVID-19 so those compliments which people were getting that external validation which people were getting that were not there if those are not there, so you are feeling oh my God, I'm not good enough. I'm not worthy enough. But this lockdown Just opened the windows that people were ready to work on. There has been an increase of 20 to 25% in clients, calls 70% you know people would call people to inquire Okay, what do you do, People are like, Okay, let me go to a therapist and seek help and it is getting normalized. And more and more people are talking about it, be it rare or not rare. But I love working with rare people more because it's very close to my heart.

Since rare illnesses are uncommon, finding appropriate counselling or mental therapy for individuals can hardly be easy. Arouba seems to have an edge over other counsellors simply because she herself has gone through the 5 stages of grief that patients usually encounter—these are denial, anger, bargaining, depression and acceptance. This is something that is fundamental to human existence, but rare individuals often go through the stages and revert back to any one stage at any point in their life. It is a constant negotiation between the mind and body. Arouba speaks about her experiences with rare individuals.

**Arouba:** I find it easier to work with rare people. They have a medical condition, some of them know it from their childhood, some of them get diagnosed later. And some of them either know that maybe, that it runs in the family, they might get it someday. In that case there is an acceptance that my mental health might be compromised. I need to seek out help. Maybe they don't have resources, but they are still willing. I see that in rare individuals. Whereas when a person who is able bodied and, you know, normalized as a healthy person, they're like, no, I can take care of it. And it gets very late. It gets too late. When they come to a therapist when they come to a counselor, it becomes a challenge for us. At least the rare individual, they give themselves to you. They are like okay, these are my emotions, you'd help me understand. You help me cope, you tell me what to do. I will do that because I want to get better. But is it easy? No, it is not easy. Is it easy for a normal person, it is not easy for a normal person either.

The Indian government brought in a national mental health policy in 2014. This policy recognises the connection among the mind, body and soul. Its thrust is on mental illnesses, disability brought on by severe mental illness, and psychosocial distress or factors in a person's surroundings that impact their mental well-being. It seeks to serve people who are more vulnerable given their circumstances, including persons with disabilities. But a comprehensive government scheme for rare individuals, seems lacking. Arouba's own experience as a rare individual shows exactly why this is problematic.

**Arouba:** So I was a sick child like I was always unwell, while growing up, my doctors could not figure out what it was. They kept putting me on different different medications and saying its asthma, bronchiectasis, pneumonia every now and then they will come up with something. They put me on anti-tuberculosis medicine a couple of times. And it was only at the 21 when I was really unwell that all I would do is cough blood. It was all over the place. And they couldn't figure it out. And there was this wonderful doctor, just come back from the UK and he looked at me and he said, okay, let us do these tests and find out what it is. And being

in the hospital for a couple of months, being on oxygen, not being able to walk and knowing that I have a medical condition which is called cystic fibrosis which is very rare in India, I could not find a single adult case back then with whom I could talk and ask, okay, are you alive? How are you living? How are you managing? How am I going to do it? all I could see was children around me and back to back passing away. So it was quite frightening. It was like, you know, when you know that at the age of 21, you are diagnosed with a progressive or terminal disease. And you have only a few years to live when the life expectancy back then was 27 and I was 21. So I guess one is expected to go through an emotional turmoil, and I did go, I was in depression. All I would do is cry and withdraw socially, disconnected with people. There was no acceptance of the condition. I was asked to take psychiatric medicines, and there was no proper counselling who could understand what a person is going through? It wasn't like cancer. You know, I wouldn't say that cancer is a small disease and mine is a big disease. But still, you have cancer. Either you have a cure or you don't have a cure. You die or you don't die. You become a survivor. That's okay. But it was something you have to live with. There was no cure. There were no people to talk to. Your counselor is not understanding all she would tell me. It's okay. But she wasn't able to tell me soon I'll be okay. You are going to be living a normal life. It was very frustrating. But yeah, so I have always been this person who looks for the silver lining. But I guess you know, with all the support and people around me being positive, I'm blessed with good friends and family. So they were like one step at a time. Just see what you want to do? And I was like one day okay, even if I want to die, if and if I have to die not want to die if I have to die, I would not want to die in this bed. I want to travel and see the world. But to travel and see the world, I had to be able to get up on my own feet and I was in a wheelchair. I was breathless. I was overweight. I had like started, my self-esteem had gone. I had started comparing myself with each and every individual outside there.

**Arouba:** And then I knew that I have to live with this condition. If I don't take care of it. It is going to eat me. It is going to consume me and that is what is either your physical or your mental health condition that tries to monopolize you. And then you somehow tell yourself, okay, if I'm not financially dependent, maybe I can buy all that care I would need in my life. For that you need to be financially independent, you need to have that thing. So I was like, what career can I choose?

Being rare does not mean a person's family situation or life conditions become easier because they have an illness. Many times, rare children are rejected by their parents or relatives and even adults by their partners. They can be discriminated against in their local community because of lack of awareness of their needs. Instances of bullying for their appearances, needs and experiences is not unheard of. All of these can have serious consequences on a person's personality development and long-term health.

**Arouba:** So with rare disease or any kind of chronic illnesses, mostly, there are things like body image issues, self worth issues. Most of the people who are going through rare disease if they are living with their family, their family tries to provide their financial back support. There they are sorted to an extent maybe not completely, but to an extent they are sorted. But there are loads of other things like self acceptance, know that thing that why me that self blame and it can go to the family also it is because of you I got this, that self acceptance is not there. And so, as a therapist, what we do is that we first identify the issue and what can be the issue that

we need to work on. There could be a number of things we need to find out first, that can be self worth, self esteem, not accepting them themselves. Having financial insecurity is having that uncertainty about fear people, having the fear of being physically dependent. Okay, mentally I'm dependent emotionally I'm dependent financially, but I don't want to be physically dependent. And a lot of these diseases give you either your body posture changes or you have problem in your joints, you lose your hair, a lot of body, physical body changes you can see.

**Arouba:** I tell people that I will not be disabled or handicap if I'm in a wheelchair, but I will feel disabled or handicapped if I'm not able to think clearly. If my mental state is not well, that is what goes with people just because they have able bodies. And if they are being judgmental and if they are being disrespectful, they're trying to get into your space does not make them healthy people. They already have issues in their own life. And most of the time people who are curious, negatively curious and they want to know about your diagnosis about the things or you know, ask you questions about it. They have lots and lots of insecurities in their own life. They have so many unresolved issues in their own life that it is always about another person. Now, why do I feel judged? Why do I feel unaccepted when they ask me that, that issue is with me. I need to ask myself, have I accepted myself? Have accepted my medical condition and do I love myself the way I am. With one hand or with a disabled body or with you know, I cough all the time. Now, nowadays, that is a medical condition, we cough a lot. And before it was like a lot of people have been told to have you got your tuberculosis checked. Now if I give them I forget if I get offended, that is going to take a lot of energy from my end, you know that is going to take a toll on me. I tell them no, it is not about tuberculosis but yeah I got it checked thank you so much and then I cut off the topic there.

In Season 1 of this podcast series, that is, 1 in 20000, I spoke with a father of a rare individual who has gone on to build a career for himself. Ifithikar Zia described how difficult it was for his son Zoyeb, to accept the diversity of his body. Zoyeb has Ataxia which is a symptom of atrophy or improper formation of a part of the brain. Ataxia leads to problems in coordination, slurred speech, and to an observer not familiar with the illness, it may seem like a person is under the influence of alcohol. In a blog available on the episode page, Zoyeb describes how painful the truth has been and which caused him to, in his own words, "recede into a shell" .

For many rare individuals this is a common experience. As Ifithikar Zia notes of his son's experience:

What happened was it was a life turning thing for Zoyeb as well as for me because I had to make a choice with either going ahead with supporting him or going ahead by taking care of my own livelihood. So it was a very tough call which I had to take when I had to give up my job. A year I continued trying to juggle the job as well as taking care of his education and taking care of his medical needs but then I had to take a call at one point. It was either me or him so I opted to step out of my career and devote more time to his education and his career growth and I guess it was a good decision I took because he performed after that and I also had a feeling that I did the right move at that moment because if I had taken a call on, progressed on my career then I might have had to let him down. See actually what happened was, my son was at that particular moment trying to back out or rather shut himself off from everything, it

was a difficult stage for him also. Basically it is a teenage period when you would realise that things are not going the way they are supposed to be going and then he moved away from all his friends and he kind of backed out from the family also. In the sense there was a little bit of gap which came in between him and his mom and his sister also. So it was a short period I would say because that was the time when he was not coming to terms with the situation what has cropped up for him. Luckily I would say that Zoyeb was a very fun loving kind of a fellow, humorous and funny kind of a guy who is always happy and jovial and making fun and all that kind of stuff. So suddenly you see a guy who is playful like this, he was quite an active guy, he was a swimmer, he used to play football and he used to do gymnastics and apart from all this other tricks and all that. He was a very active guy and very jovial kind of a fellow. When you see a guy like this suddenly going into a shell it is difficult for others to understand what is wrong. So that kind of thing we had within the family but luckily everything worked out well.

Arouba shares how this adversity too can be overcome if only people are more understanding.

**Arouba:** A person who is dealing with an illness, they are already dealing with a lot of emotions, they have ups and downs on an everyday basis. So don't put that frustration if you have frustration in your life, if you have you know you are not satisfied with the kind of life you have with you are going to put that on the person who is going through a lot. So first work on yourself, work on your emotions, know why you are being that and how can you help yourself take breaks, know the condition.

Arouba too takes counselling sessions from a certified therapist to emotionally heal from the rigours of her illness as well as her work. This is standard practice in the counselling profession since counsellors talk to people when the clients are their most vulnerable and insecure.

**Arouba:** I still give up some days. I still have those phases where I'm like, what is this? but through this profession, I have been able to connect with people I have been able to look at the sides of people which were never visible to me before. And when I knew I feel much, much better than others there are people out there who are doing better than me. I can be one among them. So that silver lining came and I guess that gave me that thing that started traveling also, I am a solo traveller, I participate in rallies, I work with, I volunteer in organizations. I have two dogs I play with, I drive, I do everything, but with my own pace. So that is a journey of being a counselor and being a rare disease patient

If you speak with a rare individual, you will invariably find them to be mentally resilient and motivated. This comes from years of experience in dealing with their acutely malfunctioning body. However, when one scratches the surface, much like I have done in this episode, the learning becomes clearer. Each moment in their lives is precious. And even as living a life of gratitude is an often overlooked human emotion in each of our daily lives, it seems like rare individuals have that plenty!

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Rare Lives

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*Thank you for listening to this episode of Rare Lives, you can listen to 1 in 20,000 which is the first season and covers many more interesting stories and discussions into the lives of rare disease patients.*