



## Rare Lives: Learning the hard way

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Education is the foundation on which a person can build their lives. Going to class and learning are essential steps that everybody needs to take to be independent later on in life. So much depends on this- our first friends are from school, our jobs later on in life -- are related to our experiences as students.

But for rare individuals, being able to go to school or college is not a guarantee..For some its a distant dream.

Hi, I am Avantika Shrivastava, the host of Rare Lives. Rare Lives is the second season of the 1 in 20,000 podcast series which shines a light on the experiences of people with rare diseases, and their families.

Often, people with rare diseases have to give up on the dream of education because of challenges that able bodied people cannot even think of.

In the last episode, guest host Menaka Rao spoke to a 15-year old teenager, Ira, who has thalassemia. Thalassaemia is a rare blood disorder which causes blood to have less hemoglobin. Ira has to take time off from schooling for blood transfusion. This is something her life depends on.

In this episode, we want to understand the challenges rare individuals go through while pursuing education. I spoke to Kypa Sujatha for this episode. She offered insight as an adult woman who had to power through both discrimination and a chronic illness to realise her dreams.

Sujatha is 45 years old and is based in Chennai. She has Achondroplasia which is an extremely rare form of dwarfism and leads to a lifetime of physical pain. This is a degenerative disorder, her disability slowly increased over a period of time. This means that she was more mobile as a child than as an adult. This condition is hereditary in her case- her father suffers from the a similarly debilitating condition

When I spoke to her, she was finding it difficult to hold the phone. She explained her condition.

**Sujatha:** To my knowledge, only 124 cases have been registered and this is a case wherein the bone undergoes progressive degeneration at a very faster rate in the early stage itself and then vitamin D levels will go down very fast very soon. So because of bone degeneration I have a I'm having polyarthrititis so rather than the bone degeneration is at the finger level.

Sometimes you know I find it difficult even to hold a pen or a phone. Now I'm finding it difficult to handle the phone itself. Sometimes I find it difficult to brush my teeth because of the pain in the finger, they will be giving me strengthening exercises and I have to do it continuously throughout my life. And what even that was the weakness will be adding the other finger level also to that much it's as if it becomes that much weak I find it difficult even to take rice to have food.

*Sujatha lived in pain all her life, but the extent of pain was much lower when she was a child. She was studious, and held the ambition of doing well in her studies. But would often have to take leave on account of the rare illness.*

**Sujatha:** During my periods I will be having extreme pain. Cramps will be there, managing my periods will be much difficult during my schooling, and college days. During those times I used to take leave, that's all when I take leave. They won't say anything but if I take leave I'll be missing my classes. So during college time also the same thing, if I miss my practicals definitely I'll be missing my own thing. I have to manage things I managed without missing classes. Sometimes I'll be taking a rest. I'll be going in the morning. I need most of the time I won't take leave at all, but I'll come with pain to attend the classes.

*Sujatha loved science. As we know in India, the science stream is most competitive. Despite having done well in her board exams, she was denied a seat on account of her disability. This was in 1993.*

**Sujatha:** You know after completing schooling, I was denied a science group in college saying that I am a disabled. And they told me that they were giving me a seat, a seat in literature. So stating that I cannot do practical. But I took it as a challenge and I told them that I'm a topper in the list. Wherever I applied for a Bsc Zoology they denied me that course, they themselves decided that I cannot do practicals. But I proved, I told that I will need an assistant, that's all. An assistant will be there in the lab. So not only that, my friends will be there, friends will be there during the practical time, and I can get their help also. So I struggled a lot to get a seat to get a science school seat.

*Sujatha decided to go to the University's secretariat and complain about this denial of seat to her. Her persistence came through and she got a seat.*

**Sujatha:** Through the secretariat, they immediately gave a call to the principal of the college. And then they also rechecked once again, after joining college, whether I am really going there. They have really given me the seat or not.

*She had to constantly prove herself capable of studying science. She had a good set of friends who helped her through college, especially with travel. One of her teachers also helped her and continues to be in touch with her.*

**Sujatha:** Previously I was able to walk. Then I'm in college and college time I used to walk taking rest in between the walking few steps like 10 steps and then sit. And then take rest for

five or ten minutes then I need to walk and then sit. When I was 20, I was in college, Bsc under graduation during that time, because I'm born in a middle class family, I used to go board the bus. As my friends will be there, I have very good friends. My mother used to help me to get into the bus, my friends will be there, they used to help me to get into the bus, and they dropped me from college to the bus stand and through their vehicle, and then they used to help me to get into the bus. Reference work: they were willing to help me take me to the library. I had very good friends, my backbone, I had one of my one one good professors called Shilpa Nasheer. She supported me a lot till now she's my backbone I can say.

*She used to manage school and college, but had the hardest time writing examinations.*

**Sujatha:** In school I was having low back pain, low back pain and I won't be in a condition to write much very fast, I can write fast, but I'll have pain in my hand to say write much during school, I suffered and suffered a lot during my examinations time. I'm a science student, I'm very much interested in science. So I have to write a lot. I will be suffering from pain, I may need some break up in between, and then I won't be able to complete in time, like that, like two and a half to three hours. But that is not enough for me because the extreme pain will be there, throughout my hand, right from the upper arm to the finger finger level. I'll have that much pain after half an hour. So that that was my greatest challenge during my schooling and college days. So during school days, during my public examination, I didn't get any extra time. Even during my UG they didn't give me any extra time the University people didn't come to my aid at all.

*She topped in post graduation despite all the struggle. However, during her Mphil she missed one exam. Sujatha feels that her inability to continuously write exams cost her a gold medal in her Mphil exams.*

**Sujatha:** I felt very bad when I missed my gold medal in Mphil because, Mphil in Mphil you know usually, during examination time, there will be a gap between one exam and another exam. But in Mphil, you know, continuously I had faced two two exams the next day consecutively. So after completing one exam, I have to write nearly a hundred pages after writing that I couldn't even. My right hand was not functioning properly. And I was suffering with that much pain, neck pain, everything, I cannot bend too much. Throughout my body, I had severe back pain. I took medication and painkillers for that. And then now I couldn't appear for the next day. So I get arrears for that. So that I missed gold medal, in Mphil.

*Sujatha was expected to follow the rigours of education and prove herself constantly as a good student. As she said earlier, if she missed classes or practicals, she was going to lose out and there was nobody to help her. Reasonable accommodations should have been made for her condition so that she is treated on par with the other students. But this was not done in her case. Sujatha said that she was not exposed to disability rights activism which did not give her the language and right avenues to approach when she was having trouble writing exams or taking practicals.*

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*In early 2000, after Sujatha had finished her post graduation, she wanted to apply for a post in the college as a lecturer. But she said that she was discriminated against repeatedly.*

**Sujatha:** After completing my college I actually topped for, to become, to become a lecturer guest lecturer. There also I was discriminated against and humiliated a lot. For the lecturer post also I didn't get it there though being topper and also I did well all the interview. Everything I was denied the seat I didn't, they didn't give me the seat. So after that I didn't apply for a lecturer post.

*Why did you deny this?*

**Sujatha:** They said that you're a disabled person. Moreover, you are a woman and they say that I cannot take classes. Though I said I have transparencies I can use their projectors to take classes, I can use the board which is easily drawable so that it is accessible for me I can take classes, I can sit and take classes also, I can stand for a few minutes. Second, the classes and everything like if I have a projector definitely all the colleges are having projectors, so I can use the projector so I can use images to take classes. They didn't consider me. They just simply, they didn't hear me. They just simply say that I'm a disabled person and they humiliated me a lot. When I suffered a lot I cried a lot. So that's how I missed to teach the same way in all the government colleges, everywhere, wherever I applied I suffered a lot.

*Despite being very qualified she had to work as an LIC agent which was a far cry from what she had studied.*

**Sujatha:** Actually you know in the beginning. After, since I didn't get any income source, I just started my career as an LIC agent, then I couldn't do much because there will be targets. I did it. Somehow I was always successfully an LIC agent. I couldn't complete them but still I struggled to do it. Then after that, I came to the disability sector, I got an opportunity to serve the disability sector as a HR I worked. I worked on the unemployment of the disabled person. So I worked for that employment opportunity in the corporate world for the disabled. So this is how I've been working till 2016. After that I become completely bedridden. But still, I'm struggling to do some work. And I'm doing sometimes when I get some work as a consultant in the disability sector of the disability sector, or to some through some NGOs I'll be doing my work. So this is how I've been keeping myself completely occupied.

*Sujatha's progressive disability became harder and harder to handle as she grew older. She now finds it hard to get out of bed.*

**Sujatha:** It's very difficult day by day for me if I finish a day it's a very great thing for me. Sometimes when the pain comes when I'm in bed I need someone to pull up the bed sheet so I'm not even able to pull up that much pain I have and there is no strength in the hand. Sometimes I'll be okay but sometimes when I when the pain shoots up it will be really terrific all the joints sometimes sometimes you know one part will be affected sometimes throughout my body will have been affected now this time now I'm having throughout my body right from scapula, clavicle. biceps everything backbone, full backbone, and then and then down the pelvis also I'm having pain so that much pain I'm having right now. So I'm finding it very difficult

and then managing with others. With these medicines and sometimes you know, I have to go for crocin. And so it's nothing. No medicine solves it, only therapy therapy is the only solution for me. So at that time, we feel very bad for not being born as a regular baby so that's how I feel but still I've been doing things, managing things. But now it seems very progressive, you know, now I'm finding it more very, very difficult.

*Her father who is 81 years old is also bedridden. Her mother has depression. She had a brother who passed away, while not from a rare illness. She feels alone and worries about how she will take care of her parents. I asked her if she considered getting married at any point in her life.*

**Sujatha:** Initially, I thought I didn't want to get married. But now what I see is that I'm suffering a lot. My dad, my dad has become very old now he's 81 years old, my mother she's also very old and sick. And she's also having a psychosocial disability. I am suffering a lot without any support in my house. And my friends know now everyone has settled in their life and they are busy with their family life. So now I feel aloof. I thought I didn't want to get married in the beginning . Now I sometimes feel that I missed an opportunity like that.

*During the lockdown, she got a month's ration and medicines through the Disability commissioner's office. While some people close to them are helping them financially, its not enough for the care of the family. Sujatha said that she needs financial support for caregivers in the house and medicines for them. She also needs accessible support in the house. She wants someone to understand her condition and offer her a job.*

**Sujatha:** I'm also looking out for a good job that suits my disability even now also, I can speak or maybe I cannot sit over a computer on the type messages because of my hand and finger pain. But I can speak now, so I'm looking out for a good job that suits my disability, even now at this stage . So that I can meet my goal of making both ends meet.

*A report published by the United Nations in 2019 has made disappointing revelations. Almost 2% of India's children are living with disabilities. A quarter of these children in the age group of 5 to 19 years did not attend any educational institution.*

*This situation is in spite of numerous Indian laws and international conventions on the rights of people with disabilities allowing for reasonable accommodations, inclusive education and assistance to people with disabilities.*

*Sujatha's story is telling of how people with disabilities fail to find proper education or decent livelihoods after.*

*As it is for any able bodied adult, she contributes in taking care of her elderly parents, and her education and a proper job could have made all the difference. The stakes for children with rare illnesses and also with disabilities thus seem way higher than their able bodied peers.*

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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.*