

## Rare Lives: Climbing the job ladder with a chronic rare illness

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In the last episode, I spoke with Sujatha who has a rare disease and has gone through her schooling and college life with little support. This feeling that the body is a liability becomes stronger as a rare individual goes through numerous experiences of discrimination, inadequate support systems to help them thrive or plainly - the lack of empathy from people they encounter at each stage in life.

The despair over an acutely malfunctioning body, that only gets weaker with age, is part and parcel of a rare individual. But the other side of the coin is emotional resilience or being able to withstand life's challenges. Emotional resilience is the pillar on which all rare individuals, including myself, have built their lives.

Adulthood is a stage where one should be able to live independently. When one can earn a living. Able bodied peers don't have to think twice about these facets of life. But, should a rare individual have a disability, the severity of the disability can determine whether they can get and hold a job or become self-employed.

For this episode, I spoke with two people about the challenges of working in spite of a rare ailment. The first of them is Kedar Indurkar, a 43-year old -who has cerebral palsy since birth. Cerebral palsy affects the brain and muscles of a child leading to developmental delays. He speaks haltingly, because of his condition.

**Kedar:** Mai janam se chal nahi sakta. I have, mere ko cerebral palsy hai cerebral palsy cerebral palsy so from a, I have struggled a lot in life but I am trying to fight it out, as much as I can.

**Translation:** I cannot walk since birth, I have cerebral palsy. I have struggled a lot in life but I am trying to fight it out as much as I can.

**In 2010, the President of India awarded Kedar with the National Award for the Empowerment of Persons with Disabilities for translating books to Braille.**

**Kedar:** Maine 30- mai andhe logo ke liye kaam krta hu. I have done 30 books in Braille, 30 books in Braille, I can type in Hindi, English and Marathi in three languages and I can sit on computer hours together till work finishes, so I love working.

**Translation:** I work for the blind, I have translated 30 books into Braille, I can type in Hindi, English and Marathi, in three languages and I can sit on computer hours together till work finishes, so I love working.

While he is a wheelchair user, he is qualified at using the computer, and can type in Hindi, English and Marathi. As he says he can sit for hours together and work on the computer.

Kedar is currently at an old age home in Nagpur and is working on writing stories and dramas for children these days. His elderly mother and younger sister stay in touch with him and encourage him to work. His mother's perspective will feature in an upcoming episode.

While it's hard for him to make longer conversations, he uses his words carefully and is pointed and deliberate. I asked him what he wanted to do with his life.

**Kedar:** I want that people should not ignore me. They should listen to me What I'm saying and doing, matlab dhyan nahi dete, kuch kaam nahi dete. kuch kaam krna hota hai toh kehte hai denge denge pr nahi dete basically what happens is people don't know what I can do what disabled people can do they are slightly afraid you can understand what I'm saying? Because of that people don't want to encourage ..they think that yeh kar sake..disabled people can do things or not..i don't know why it is so. Maine ab tak -- maine president award liya hai for my braille translation in 2010. 2010 ko mereko president award mila hai for braille translation.

**Translation:** I want people to not ignore me, they should listen to me and give me work, they say that they will give me work but never do. Basically what happens is people don't know what I can do, what disabled people can do they are slightly afraid you can understand what I'm saying? Because of that people don't want to encourage, they think that because he is disabled he won't be able to do anything. I don't know why it is so, I have even received the President's award for my braille translations in 2010.

**Kedar stresses that people with disabilities need opportunities to work. As per Census 2011 there are 2.68 crore people with disabilities in India. This means over 2 percent of the Indian population lives with some or the other kind of disability. But results of a Survey of Persons with Disabilities published by the National Statistical Office in 2019 reveals that where persons with disabilities were earning livelihoods, regular salaried workers constituted only 15%, and, close to 60% were self-employed.**

**Manav Goyal echoes Kedar's sentiment. He is 40 years old and was diagnosed with facioscapulohumeral muscular dystrophy or FSHD. The disorder impacts the muscles, affecting a person's ability to walk and do routine tasks. Manav too is a wheelchair user now. He is ambitious. As a young boy, when was diagnosed with this condition, it took him a long while to accept it.**

**Manav:** I think I would like 13 or 14 years of age when I started seeing the symptoms. And it's been quite a long journey since then. Yeah. So initially, it was very difficult for me to understand and accept it. Because I was very strong at that point in time. Very strong and full of confidence. But eventually, when things started, you know, going down one thing at a time, you know, it's a very slow progression. So when it started going down, you know, day by day, then it was difficult for me to accept that it was initially like, you know, the world has gone down. So, I mean, life in itself, you know, it's a total gamut of a lot of activities, you have to do anything and everything which any other person on the planet has to do. So that you do not

get a discount on those terms. Right. So people have to earn a living, they have to prepare their own food, they have to do clothing, washing, cleaning, okay, and maintain a social circle. So everything has to go hand in hand. It's just that when you are not too mobile, it's a challenge to compete. If you don't have that much energy, you get tired, or worn out so easily. So that's a challenge. But then yes, people attempt to understand. So that it is what it is, life doesn't stop.

**Manav completed his MBA in international business and joined the cut-throat world of business. While his health was on the downslide, Manav was also working full time in a demanding job even shifting out to Africa. He was qualified and bright. He says he was racing against time, and wanted to build his financial strength. But he burned out soon.**

**Manav:** Well, I am a commerce graduate. And then after that, I did my MBA in international business. Okay, started working early on to 23 years of age with an export house. After that I shifted a couple of companies to work with American, British and African clients. So my interest is into FMCG and project management. So the major challenge I tell you Avantika is because I knew that I will not be mobile in my entire life. So I could see that I have to do a lot of things in order to, you know, sustain myself. So the problem is I was working double or you know three times than what was required. If I say that a normal person or anybody in the market has a Challenge Level 100, then a person with Muscular Dystrophy or any rare condition would have a certain level of say 180-190, or maybe more. Yeah. So it's already there. which impacts normal business operations. I remember that in the initial days when I started working, so there was a struggle for most one, one and a half years. And after that I have been the top performer all throughout my career in on top performance, that's kind of an addictive thing. So I said, okay, yes, this is something, some recognition that I received, and I've achieved. So that actually motivated me to go on. I said, I can do it. Yes, I have done this, I can do it. So there have been times like in the office when nobody else could do something, they used to come to me and I used to fix it. Okay. I mean, some accounts were not like that, they were very difficult and nobody else in the client location or our location was able to fix them, I could fix them. Of course, it took me some time to do a lot of rapport building and things like that to make the trust happen. So yes, over time, it just has shown me a lot of good results. It has shown me a lot of good opportunities. Yeah. So but yes, it has its own set of setbacks. And what I wanted to do, I wanted to fly, but I just could not, you know, catapult from the strong base that I had. And eventually, with time, I'm just like, seeing a slower degradation in my capacity. Since then, I've started you know, taking less initiatives, because I know I wouldn't be able to do them. So that's what has happened. Eventually, I mean with time, my body worn out, and I could not handle that much pressure. So I have to, you know, like, move on to different avenues than my regular ones.

**He is now working as a freelancer, helping businesses improve their efficiency levels.**

**Manav:** I have been helping businesses with their processes and improvement in their efficiency levels. So that's what I have been doing. So this skill, these skills, all these skills are gathered with, you know, my work that I've done with my last companies. And currently, right now, what I'm doing is I'm doing a service audits for different companies, I go there, evaluate them according to their parameters, and do market research in terms of what is the impact

what is the value they bring to the customers, okay, and I give them reports, misses that they do a lot of corrective action. So I do a lot of service audits. There is a kind of freelance assignment that I'm doing right now.

**Manav wants to establish his own business venture sometime in the future. But there are several considerations that are stopping him from taking the step.**

**Manav:** What I look forward to in the future as maybe a business, like a full time business, but for that, I would need more strength. So that I can, you know, spend more time regularly. And I would also need a good helper who can be with me, like for a very long time, like a good commitment. Yeah. So yeah, caregiver, see, because now I'm not that strong, I need support to get up, you know, and do the basic daily tasks. And, you know, I can walk a little with support. But then that said, I cannot do long distances anymore. I have a wheelchair that I used to go to small places, like small distances.

**His condition sometimes makes it hard for him to focus on work. He said that because the muscles break in his body, it releases a lot of sugar which impact his concentration and gives him nausea.**

**Manav:** So that you cannot put your head straight in business, you have to be very active 24/7, to make sure like, your capital is safe, your property, customers are safe. And they are, you know, like you are dealing with them day in day out, you're managing everything. So yes, we can hire people, but you have to manage people as well. Okay. And at the end of the day, it's, it's your money, it's your, you know, property and everything is at stake.

**He has had a tough time getting family support too.**

**Manav:** I had to struggle with my family too in order to make my own mark. So yes, my relatives were not very supportive. And let alone relatives my dad even was not that supportive. So that's kind of what makes things hard for me. Like very hard. But I had to struggle in my office, I had to struggle in my personal relations, I had to struggle in my own life. And plus I struggle in my family. So that actually, you know, was something which actually frustrated me a lot, you know, you tried to get some sort of support and help from something, but then there was one point in time, I could not see anything I would like so lost and alone. And being alone, believe me is not a good thing. It really, you know, teaches confidence and your thoughts and your emotions and power for a toss, that breaks you big time. So that is see being alone is a byproduct of FSHD. And that has broken me more than FSHD itself.

**All in all, he feels lonely and believes that he is alone because of his ailment**

**Manav:** I believe, if I had like, a lot of good friends, I would have sailed through if I had like, a lot of good family members who have supported me, I would have sailed through, if I would have had a supportive partner, I would have sailed through, if I would have understand understanding a company or a boss or something or a team, I would have sailed through through.

**Keda too had a similar message.**

**Kedar:** Aur kuch matlab as a disabled people, life is tough for disabled people. They should fight, they should not lose heart. Itna hi kehna chahta hu bas.

**Translation:** Life is tough for disabled people, I encourage them to keep on fighting and not lose heart, that's all I want to say.

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