

## **Episode 4: An equal partner (1 in 20000)**

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Welcome to the episode of **1 in 20000**. Today, I am thrilled to be talking to a very special guest. Every month I seek to bring a fresh perspective on rare medical conditions to you. she plays a very important part in a previous guest's life. In the last episode, we spoke with Mr. Vipul Goyal, a person with muscular dystrophy, Sangeeta Goyal has been his partner for 17 years. She has been with him through thick and thin and she will be sharing her perspective of what it has meant to be a couple. This episode is in Hindi. You can find the English translation on this podcast page.

**Avantika** - Welcome to our show Mrs. Goyal. According to me these questions are very simple but really means a lot and when I met you I felt that you have made an unconventional choice for a partner in life which inspired me that the way you have been thinking about your life, if other people also start thinking that way, then the condition of our country would be in a better place because when we think about people with rare conditions as it is a part of their identity and their day to day life is almost similar to other people so I have some questions for you related to all these things like what was going on in your mind when you decided to get married to Mr. Goyal ?

Sangeeta - At that time I felt Vipul had all the qualities that a life partner should have. I never thought about the physical appearance of my life partner, i just wanted somebody who understands me well and somebody whom i will understand. The qualities that Vipul possess and his way of thinking and understanding things helped me to take this decision and our relationship is based on that.

**Avantika** - People feel that if somebody is physically different and if you move forward and meet other people with rare conditions who are called inter-abled couples wherein one of them is so-called normal and the other person might have a rare condition so the mindset of the people in the society is such that if there is something different, it is not right. i want to know the opinion of your family and Vipul's family about your relationship? What was the reaction of the families when you both decided to get married?

Sangeeta - When our relationship started, we got more positive reactions and less negative reactions because there is a little age gap between me and Vipul but the reaction of my family was if you are happy, we are more than happy. Also, Vipul's family accepted me very happily and gave me the position of "badi bahu" of the family. And as far as the opinion of the society is concerned, it is also changing with time. The difference between abled and disabled is not looked at the same way now like it was before. so i just believe that the balance is the key to success and we all should move together in life. Also i feel i fit in the family very well and i am very happy.

**Avantika** - According to me, Mr. Goyal has this one positive factor that he has moved forward in life with acceptance and he has also said this in our previous episode that he gave some time to this relationship and you to think as it is a relationship for a lifetime. And in India we

have this perspective that the weddings are for a lifetime. my next question is linked to the same. If you can share some instances where you have faced some challenges in your life?

Sangeeta - The 17 years that i have spent with Vipul and now we are about to complete 18 years together next month. In these 17 years, i have never experienced any challenges where i feel i have married a person with physical disability. So there are no challenges a such, we go to public places together, we do everything very easily. And i have never felt any hardships or challenges yet and i pray to God that it remains the same in the future.

**Avantika** - I feel what you both have is very complementary. So my next question is, now that Mr. Vipul uses a wheelchair mostly, he always needs a caretaker or a third person with him. Like you have said you never face any challenge in anything but have you ever felt that this could be easier as a couple?

Sangeeta - Yes! I do feel so because whenever we go out, people feel sympathetic and we do need a car and a helper but we are always ready for that challenge and i never take it as a challenge. I always feel proud that i am somebody's wife who has given me all the freedom and right to live and do whatever i want to do.

**Avantika** - The relation that you both have has a synergy and that synergy transcends beyond the ability disability barrier. And somewhere i feel people can see the synergy beyond the differences that you both have.

Sangeeta - we have to take care of people in our family. We should take care of anyone who needs care in the family. I feel if take care of Vipul as a caretaker then yes i am his caretaker because i care for him and our lives are linked with each other. We have a son, family and i want to care double for him. I want to tell everyone that it is not important to take care of only those people who are fine, love only those people who are abled, or marry those people who are abled, do something different. And, if i tell you the truth, till the time i was unmarried i always felt this is the life, but i actually learned the meaning of life in Vipul's house and how we always try to keep each other happy.

**Avantika** - I known you guys for 3 years now and i feel what you people are doing as a family. The Hospital in Solan for people with muscular dystrophy for the society at large would not have been possible without the bonding that you have. And, Mr. Goyal also would not have been able contribute if you were not there. So it is from both the sides where you both are contributing in each others lives so you have that confidence in him that he will take care of everything and as a couple you are doing it. I also have this thought that you have a teenager son and at times teenagers are very moody and it is very difficult to be a parent of a teenager. So at present, how is your bond with your son?

Sangeeta - You said it right, it is a bit difficult to handle a teenager. The bond that we share with him is like friends. The teachings and the rituals of our family we share with him on a daily basis. He knows that his father is on wheelchair and his mother is a housewife and she looks after him and the business. And, yes we support each other in each and every thing and i have learnt this from Vipul Ji that you should always be there for others when your dreams

are fulfilled. So i try to move forward with him and support him. And Abhishek is a very understanding, naughty and a lovely child.

**Avantika** - He has developed the understanding that his father and his parents as a couple are different but the difference is not negative, it is not undesirable and that is a big thing. And he will do whatever he wants to do in his life and he would have this knowledge, empathy and understanding that yes people are different but that does not mean they are wrong or right, desirable or undesirable and he can take decisions on the basis of that so the credit goes to you that you have developed this thinking in him.

Sangeeta - Since his birth, Abhishek has seen all these things in the family, Sana didi, Atul Bhaiya and Vipul Ji, he has seen all of them since his childhood so he has understood everything. I am very glad that he understands everything and takes all the responsibilities and we we just want him to study well and be a good person. And, when his time will come he should also take out time for social work like we all are doing. And our life's rule is that we will always move forward together.

**Avantika** - You have said a very big thing that he is not tied to anything, there are no expectations but an environment is created in such a way where has the opportunity to think about all these things and he has a direction where with him he has to think about others as well. My last question is linked to this, if you have to give any message to other inter-abled couples so what what would you say?

Sangeeta - i would like to say that do not ever feel that you are less than the other person even is he/she is abled or disabled. And if he/she is disabled, do not think that you are less. I never feel that we are less than others. I don't ever think that. Lot of people have been inspired by our marriage and I would like to tell you having seen our marriage, even those who didn't want to get married or thought could get married have gotten together and are now living happily. Keep one another happy as you would keep yourself. And it is not necessary that you may not all get everything in your life and you may never know when problems arise. Be happy and content with what you have and always be thankful to God. Remember the biggest thing is that you have been given a life and we have to live it happily with all its ups and downs.

**Avantika** - I am sure when people will listen to this they will learn something new and a way of living life. We have to live happily and beautifully. Thank you so much for sharing with us and to telling us that difficulties may be many but so is the courage.

Thank you India for listening to the 4th episode of 1 in 20000 series. In this episode we got to know a seldom heard perspective on rare medical conditions and disability. Doesn't this perspective question what we already know about people with disabilities and instil a sense of hope. In the 5th episode, i will be speaking with a parent. Families play an important role in how people with disabilities and people with rare conditions lead their lives. What do parents look at when they get to know that their children have a specific medical condition?

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