

Living with thalassaemia

By Nitya Gupta

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It all started in 1991, when I was diagnosed with thalassemia major. Being a single mother, it changed my maa's whole life. Yes it is hard today too, but it was really very difficult at that time and being in India made it even harder.

Why is it so hard here in India, you ask? It was not only lack of research and development BUT awareness. Most of the time, One had to explain what thalassemia is/was to your physician before moving forward with tests. Yes! shocking but it's all true.

I still remember how I had my initial blood transfusion by spreading sheet on the floor in hospital balcony as hospital beds were occupied making the hospitals go over capacity. These conditions were more frequent than a patient's patience could tolerate it to be.

Then, there was yet another challenge in the mix, availability of blood. India being the most populated and mostly educated class (yes, I believe that we are), we are still the society full of people who do not believe in donation such as blood donation or organ donation. There have been weeks where I did not get a transfusion only because of the shortage of blood. "Blood isn't available," is probably the most fearful phrase for a thalassemia patient, but YES it happened. Yet, somehow we managed and thalassemia became a usual part of our lives.

As I grew up, there came psychological challenges that I had to face. In early childhood specially when I started school, the question that bothered me was whether to share my thalassemia status with anybody or not, including my teachers, my classmates etc. I was very comfortable with it personally as far as I remember but the thing that used to confuse me or made me double think was that how my senior thalassemia patients n fellow thalasseemics presented most of them. It made me feel like: "No, no I don't want to share it. What would people think?" Though I was never one of those kids who gets into peer influence but still sometimes you start believing the person who's sailing in same boat as you do, and I did believe them too but when I entered in my teens I started realising that I have to accept myself. I can't keep brushing this fact under the carpet forever because when you are conscious about something, you yourself start avoiding it and there comes the problem of avoiding chelation etc., but I realised I was perfectly comfortable in my own skin. That moment I realised that thalassemia is just like my other characters. I neither need to flaunt them (okay I do some of them *winks*) nor to hide and seriously nobody gave a damn, neither until then nor after that. Luckily, I never got bullied ever though I had a short height and an unbelievable attendance (sometimes it used to reach as low as 40%). I did my engineering and nobody asked or bothered. I did my masters in designing from a national institute of footwear designing and got placed in renowned footwear brand and I don't even know who knows about my thalassemia status and who not. I personally revealed my thalassemia status only to the closest and most important person in my life whom I had met in college. Other than that I think it's only handful of people who knows about it.

I am now 26, and one thing I have learnt all through my journey is Yes, people have opinions, so many opinions and I know that's daunting, but we should realise that it's ok to be imperfect, nobody is perfect. One perfect thing we can do is that we should channelise our flaws in a positive way. There is perceived notion of being normal in our society. As a part of this notion, I too was expected to be as "Normal" as the other guy and So I did. Maybe some day someone will have to make me

sit down and explain what "Normal" is and who's got the measure stick for Normal. I believe it's the this kind of thinking and views that scares us. We are not scared of our status, we are afraid of people being judgmental, no matter it's us or a fat or a short or a dark girl/guy. Why do we make a mind about normality. Our body is one of those things we don't choose. We never get a chance to choose it. So, never underestimate yourself nor do overestimate because sometimes, to prove oneself as normal, we do things which are exhausting and and that too at the stake of compromising with our blood transfusion, chelating routine etc.

Besides society the other thing which holds us from growing or managing us very well is 'self-pity'. Self-pity is the most wonderful/calming thing to be in, but one should get out of it as soon as possible and channelise towards accepting that yes, we have a condition that demands to be managed and only we can manage it by chelating, taking proper diet, having proper transfusions, and taking care of ourselves. We don't need to avoid it or to pussy footing around it. It's important to know the difference between self-pity and self-love. Pity makes you weak, while self-love, it makes you the strongest. Today, affirm that, "yes, we have a condition and all we need to do is good management."

If we are comfortable, if we are healthy, every other thing will take its damn place. So do take good care of yourself. Keep chelating. Keep loving yourself.