

I am number 17
Prabhjot's experience

I live with an invisible rare disease called polymyositis; it is an autoimmune disease which effects the muscles. It inflames your muscles and their related tissues, like the blood vessels that supply them. It can cause muscle weakness and pain, often on both sides of your body particularly in the belly (abdomen), shoulders, upper arms. Most people who have polymyositis get diagnosed between the ages of 30 and 60. It's very rare in children, and it affects women more often than men. No one knows the exact cause of polymyositis. Rare diseases can take average of three to four years to be diagnosed, however in my case it took almost eight years.

It all began in 2007 in India, I was riding a motorbike and my mum was sitting behind me. We were travelling at normal speed. Suddenly I felt like I lost strength in my hands, and I lost control of steering. We fell off the motorbike. I stood up and rode my motorbike back home as if nothing happened. It was a complete empty road and luckily, we didn't get hit by anything. Gradually, in few months' time my arms, neck and shoulder muscles weakened, and I wasn't able to lift my own neck or even raise my arms to hold a cup of tea.

We then sought medical help. Doctors carried out biopsies and various tests. They then confirmed that I have a disease called polymyositis. The doctor said there is no cause for this disease and there is currently no cure, but we didn't give up. We went to almost all the major private hospitals in India to find out a solution but heard from every single Doctor that there's no cure for this condition, but there are treatments that can help with symptoms and can improve your muscle strength and function.

I was told by doctors in Fortis hospital, India in 2007 that you become highly prone to cancer in the very first year of polymyositis. As they didn't know about the prognosis of this disease, I was told that I had six months to live. Being diagnosed at 23, I had my whole life in front of me. I was a very studious child and all I did was study in my life. My perspective towards life changed that day. The first thing that struck me was how I should use most of my six months living happily and not crying or mourning about it.

At that time, I was doing my master's in engineering in GNDU University in India. I, somehow, managed to finish my masters with the loving support of angels like my classmates, hostel friends, professors. I survived that year because of their support. I was immediately put on a very high dose of steroids and my body ballooned. Right after I finished my masters, I had an on-campus placement in an IT company in India but I couldn't join because of my health and they were placing me in a province far away from my home town.

As I was sick, I came back home during my master's dissertation. The atmosphere in my home started getting bit depressed as I could see my parents and my brother crying almost every day because they could see me going through so much pain. The house that was once filled with laughter, dance & pranks was changed to a quiet house. Friends and family used to visit and sympathise with me. Suddenly, everybody around me started feeling sorry for me. I decided not to live at home anymore. I started applying for jobs and I got selected as a lecturer in a university in India. My dad never wanted me to work because of my health. He wanted me to come back to our hometown and stay with them, but I took my bags and left. That was my very first brave decision if I may say so, considering the fact that I was very sick at that time. I love teaching, therefore when I came to UK, I pursued my career in teaching too here. As teaching is highly physical job, therefore, I am considering changing my career to IT.

Having flare ups is part and parcel of living with an auto-immune disease. It varies from person to person how much the disease affects them. I had my fair share of 2-3 severe flareups in the last 12 years of living with this rare disease. During flare ups, I struggle with things like getting dressed, opening jars, bathing, climbing staircase, combing my hair, walking and my last flare up required me to use a wheelchair. I was given medication and blood plasma transfusions to keep the disease in control, which eventually failed. I am now on Chemotherapy. I have lived past 12 years refuelling, rejuvenating and working alongside happily.

When I first started using a wheelchair, I struggled to adapt. Your mind doesn't reconcile with the fact that you're not able to do things that once you could do. Being resilient, I tried to stand tons of times and had bad falls. Fortunately, I didn't harm myself. I didn't want to use a wheelchair 24/7 but eventually

I had to come to terms with it and I am still in the process of rehabilitation. I am doing physiotherapy and my GP has enrolled me in the active living plan to build the strength back in my muscles.

I started writing blogs to raise awareness of this rare disease as when I got to know about “polymyositis”, none of my family and friends had ever heard about it. I googled it. Raising awareness means more research into it, and hopefully a cure. Also, I am curious to find about the cause of this disease as this is not genetic - no one in my family has it. I've been struggling for twelve years and I really don't want any kid in the world to go through what I have been. For most of us the day-to-day challenges of managing their condition are made worse by the absence of an effective treatment. All we want is cure.

I was diagnosed at the age of 23 but I guess I was undiagnosed for 8 years before that. I was very flexible and supple as a child, I was capable of doing splits, bending my body parts very easily and could do highly difficult yoga poses. I loved sports and I am passionate about dancing.

Once you tell people that you have a rare disease, they start treating you differently. They start to sympathise with your condition. They start feeling sorry or pitying you. Although, we truly appreciate their support and concern, believe me, that's the last thing we (living with invisible diseases) want. That was the main reason that I packed my bags and moved to another city from my hometown; to stay away from pity. I Never told anyone in the new city about polymyositis and everyone treated me as an equal.

Living alone in London with this rare disease can be quite challenging sometimes. I met a few angels like my neighbours (auntie, uncle), carers, colleagues, friends, doctors, nurses who provided a burst of strength and support to get through one of the worst phases of my life. I can't even imagine my life without them. I really don't know how I would have survived without them alone in London, as all my family is back in India.

One thing that I have learned while living with a rare disease is to “NEVER give up”. We all (who are living with invisible diseases) are still struggling each and every day with the “will to survive”, “the will to fight” and the “will to live”. I really want people to understand that people who are living with a rare disease may look normal to you, but they can be struggling. I used to travel on London underground daily for work and change on 2 tubes. Sometimes, I used to get seat, sometimes not. I struggled every day with the fatigue and pain. Most night I slept with hot water bags under my swollen feet or an ice pack under my neck. I guess, it raises your threshold to survive pain, smile & move on with the life that you are given.

I get inspired by fellow patients who are trying to live their best life with so much courage and positivity. We need to fully embrace our vulnerability and make the best possible version of our life. The willingness to not give up - even after doctors gave up, the thrive, the uncertainty of life makes you actually live and enjoy life. Life is too short to be wasted on silly things. Spread love. I feel gratitude for each and every blessing that God has showered upon me.

In my recent times, if there's one thing I do know is that I have followed my bliss. Like Joseph Campbell famously said-“If you do follow your bliss you put yourself on a kind of track that has been there all the while, waiting for you and the life you ought to be living is the life you are living. So follow your bliss and don't be afraid and doors will open where you never knew they would.”

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