

**Living With Duchenne In
Sri Lanka**



Irfan Hafiz

I Am Irfan Hafiz
Welcome To
My Life



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About Me

I could study only up to grade 5. I was confined to a wheelchair at the age of 12 and I've been confined to bed since I was 18.

Childhood and School life...



Balloon Man Sri Lanka

My name is Irfan and I was born in 1981 on 28th of August in Matara, Sri Lanka. I am the third child of eight children for my parents. I have been suffering from a rare disease called Duchenne Muscular Dystrophy (DMD) which has no cure so far.

My father is a retired principal and an administrative service officer and my mother is at home, looking after me.

Since I was born, I was a normal child like other children. I could walk, but couldn't run or jump as a normal child but I could ride a bicycle. I frequently fell down. My father had noticed that I was struggling to climb steps and he had taught me several times how to climb because I used to touch my knees and leaned on the door frame while I climbed steps. Not only was that but my gait also looked a bit strange. I got admitted to the school where my father had his education and I could get on foot to school till I came to grade 3 and later had difficulties in walking. So, I was taken to school on a bicycle by my elder brother.

I was not that bright in studies as my siblings but I managed to do well as far as I could. I had a hard time with mathematics. I did well at class work but could not do well in exams. My class teacher paid extra attention on me and she came to my desk to do the corrections. My classmates were also very helpful whenever I needed any help. I spent the whole time inside the classroom as I feared that I might fall. One day I fell down while I was attending the morning assembly and then my class teacher gave permission to stay in the class during the assembly thereafter. Since then, I never left the classroom.

One day when I was in grade one, I had to participate in a kid's race at our school and I found it very difficult to run and I came last in the race. My class teacher noticed it and informed my father about how I was struggling to run in the race. After noticing other peculiar changes in me such as my wobbling gait, difficulty in climbing steps and frequent falling, my parents decided to take me to a doctor.

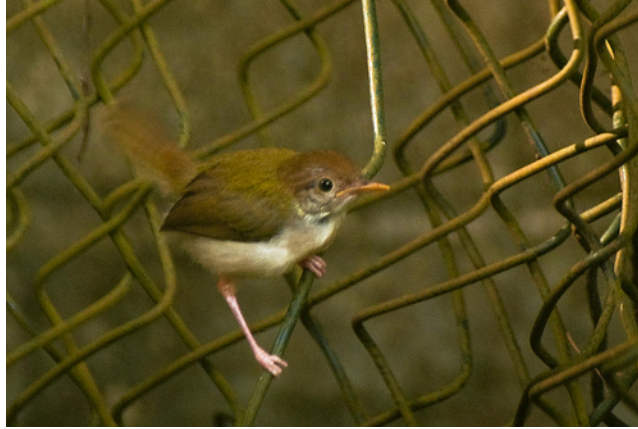
Diagnosis...

My mother was asked by father to take me to a hospital in Matara for a checkup and then for a clinical examination, a lady doctor

suspected it might be DMD and had asked my mother to go for a second opinion. Then I was taken to a hospital in Colombo for further checkups. Finally, after a needle biopsy test it was confirmed as DMD and I was seven years then. Soon after I was diagnosed with DMD, my father had been told by the doctors that there is no cure for DMD and I might live only up to about 18 years. This news had made father very depressed. My father was really heartbroken to know about his son's disease. It was only recently and through my paternal grandmother that I came to know how much he was devastated by the news. He had never showed his emotions in front of me. I think it was a great thing about him because he knew well that I should not be affected mentally.

I was at the hospital for more than a week and all I got was only some vitamin tablets. Amidst all these happenings in my life, to be frank, I was totally unaware of what was going on. I had no idea about what I have been diagnosed with and what kind of an illness it was. I really enjoyed my stay in the hospital. There was a place for kids to play and I rode a tricycle. There were a see-saw and a swing too. I watched cartoons on TV mounted on the wall in my ward. My mother stayed with me and she had a very hard time as there wasn't any proper place to sleep for those who stayed with the patients. My father came almost every day on his motorcycle all the way from home in Dharga Town which is about 50 km from Colombo. My uncle (Father's first younger brother) lives in Colombo and he too often visited me. I had to stay for many more days in Colombo for further checkups after being discharged from the hospital. So I stayed at my uncle's house. I received great hospitality from my uncle and especially my aunt who also had to care for her children as they were very small at that time. I am so grateful to my uncle and aunt for their care and love.

Parents' struggle and my life with DMD...



Common Tailorbird

Soon after it was confirmed as DMD which had no cure, my parents had been going through a very difficult period and our neighbors and relatives had started to drive them mad with their various suggestions and advice. So, I was taken to native doctors, spiritual healers and even to a sorcerer but every effort went in vain. I had to miss many months of schooling while I was getting treatment from a native doctor.

After the vacation in August when I was in grade five, I had to turn back on my way to school as I felt very uncomfortable to be seated on the bicycle bar. So, my brother took me back home and then he left for school. It was my last day to leave for school but unfortunately I could not reach the school. I spent my time at home and started to undergo a different kind of life. My elder brother did his best to teach me the subjects that were taught in my class. However I lost interest in studying all the subjects and eventually concentrated only on English and Computer. I had been playing an Electronic Organ since I was small and my father taught me Do Re Me. Now I can play many songs. I read a lot of books in Tamil as well as in English. I could improve my English knowledge by reading. Meanwhile, I spent a lot of time at my father's printing press which was adjacent to my home and I learned a lot of things about printing. I even did composing types which was very interesting. My father even appointed me as the manager of the printing press as he had to go for lectures at the Teachers' Training College where he worked as a lecturer.

Becoming chair-bound...

I became chair-bound at 12 years and since then my life became very boring and some kind of frustration crept in to my mind. My movements were restricted and the things I wanted to do became almost impossible. It made me very frustrated. However, I did not realize that I had developed an inner frustration in my mind but it came out in my behavior. I started to shout even for small matters. Even if I wanted to call my mother for any help, I would scream. Very often I got angry with my siblings even for petty reasons. I also became very stubborn. My paternal grand mother used to advise me not to be this much stubborn and angry but I was not ready to listen to any advice from anyone except my father.

My elder brother used to take me out in my wheel chair to our front yard in the evenings. He wheeled me around the yard and it made me very happy. I enjoyed those moments very much as I could see many things. I used to watch my younger brother and cousins playing cricket in our front yard. I served as the umpire for their matches and everyone respected my decisions as they knew I had a good knowledge of umpiring. I could learn a lot about the game of Cricket by watching matches on TV. I didn't miss to watch even a single match that was telecast on TV. Although I had a dream of playing cricket, even just watching and umpiring gave me a lot of pleasure and fulfilled my desire to some extent.

Happy moments...



Blue Tiger

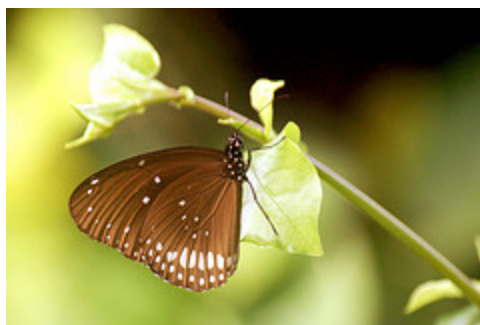
Before I was chair-bound, I had a wonderful opportunity to go on a trip to Yala National Park and there I had a very adventurous time. It was very memorable. We saw a lot of wild animals, especially elephants. There was an elephant which came very close to our vehicle! I was very excited and also a bit scared. I am very much grateful to my maternal uncle who initiated this trip. I enjoyed the trip very much and had a nice time. After I became wheelchair-bound, I got an opportunity to travel to the hill country, where I was very eager to visit. Since my childhood I had heard many people say that it's freezing cold in the hill country. So, I was so eager to pay a visit there to get that experience. This trip was also arranged by my uncle who took me to Yala National Park. I traveled being seated in a van and the wheelchair was in back of the van to be used whenever I needed to move around. I was so fortunate to visit these places when I had been able to travel.

Some years later, before I got totally bedridden, my father took me to Colombo in one of my uncles' van and this time I travelled being seated in the wheelchair. We visited our uncle's house and had dinner and then went to my maternal uncle's house. There a painful accident was waiting for me because while I was being taken out of the van with my wheelchair, I almost fell down and my left ankle got hurt. It hurt me a lot and I screamed in pain. Somehow my father got hold of me and managed to keep me back in the wheelchair. As I was very heavy, it was very difficult for others to carry me. However we could reach home safely and I had to spend many weeks in bed till I recovered.

Becoming bedridden...

Days and years passed by.....I was almost 18 and sitting in the wheelchair became very uncomfortable to me as I started to suffer from back pain after sitting for long hours. One day while I was seated on an arm chair, I started to have very strange feelings and my face turned pale. Slowly but surely I felt difficulties in breathing. When I told it to mother, she immediately laid me on the bed and phoned father as he was out. It was my first experience with difficulty in breathing. My father realized that it was because I was not getting enough oxygen as my respiratory muscles were getting weaker. The weakness of the muscles that help breathing is caused by the progressive loss of strength in all my muscles and it is one of the main affects of DMD. Since then, I started to spend most of my time in bed and didn't get on to wheelchair often. As days passed, I became totally bedridden. I couldn't even sit for a moment as I got difficulty in breathing. My life became even more boring and time started to pass very slowly for me.

Dawning of a distant light...



Common Crow

As I became a matured boy, I could slowly but clearly realize what was in store for me in my life. My father used to sit beside me and would explain what life is all about and how we should prepare ourselves to face this life. From his words, I could realize

that I shouldn't keep big hopes in my life.

During this period, when everything looked gloomy for my family, there dawned a distant light when my eldest paternal uncle while surfing the Internet, could find about the Duchenne Parent Project in USA. He got our family registered on behalf of my father. After a few weeks, my father got a pack of useful information on DMD from the president of the Parent Project. Then a letter from Dr. Elizabeth Vroom, the president of the Dutch Parent Project, followed with an invitation to a Parents' Conference in Holland. She also has a DMD son. With all these happenings, suddenly my father's life and world outlook started to change. I gained a lot of hopes and courage after my father became a member of the Parent Project. My dad says he could gain more knowledge about DMD and meet hundreds of parents like him from all over the world by attending parents' conferences in USA and Europe.

A struggle for buying a Ventilator...

My dad realized the need of a ventilator for me very soon. But buying a ventilator was beyond his reach because a new ventilator cost more than US\$ 3,000 and he was not in a position to afford that much of money. My father's income was barely sufficient to feed our family. He was desperate to get a ventilator somehow as he was well aware that I would badly need one very soon. So, he contacted many ventilator manufacturers and his friends around the world to get assistance. After a long struggle, the president of the Dutch Parent Project, Elizabeth who is a good friend of my father, came forward to help us. She gifted me a new ventilator! We were so amazed at her kindness and my father was relieved to get a ventilator at last after a long struggle. My ventilator gave me a new life! It made things very easy and the fear of breathing difficulty vanished... I was so grateful to my father and Elizabeth who gifted the ventilator.

Life becomes more difficult...



Walking Showman

In the mean time, as I was bedridden, I started to have bed-sores. It spread from mid-chest to rib areas. Bed-sores became very annoying and painful to me. My mother and elder sister applied medicine to sores after washing them. Later my first younger sister took over the job with mother. It was so painful and I tolerated all my pains as much as I could but whenever I couldn't, I wept. Although life became so frustrating with all these difficulties, I did not lose the courage and patience. My strong religious belief helped me to face all sorts of odds and defy them in my life.

With the ventilator on, I could sleep well at night and I became almost addicted to it as I couldn't sleep a single night without it. My ventilator worked for more than 8 hours a day. After so many years of continuous use, it became noisier and it started to give trouble as I had been using it for long hours. One day, it stopped working and later it was found that its motor unit had broken down. But thanks to my elder brother he got it repaired for me in two days through one of his friends who was a technician. So, I was relieved to get my ventilator back as I feared I might have to spend sleepless nights without it. Although it was repaired, the technician warned us that it could stop at any moment.

Life saved...

The progressive muscle weakness due to DMD, leads to serious medical problems, particularly issues relating to the heart and lungs. As my lungs got weaker, things became very hard for me whenever I got cold and phlegm. For me, it's very difficult to cough as my lungs are weak. Thanks to my ventilator, my life was saved. I went through a very difficult period when I suffered a lot with cold and phlegm. I couldn't stay without the ventilator even for ten minutes because the phlegm made it so hard to breath. Therefore, the ventilator worked for about two weeks, non stop. Everyone in my family stayed up beside me in turn all those nights. After many days of hard time, I got well.

Greatest shock...



Hairy Flower

I faced the greatest shock and sorrow in my life when I lost my elder brother. He was so close to me and did everything he could to make me happy. He kept company in all my difficulties and dedicated his life to my welfare as a true sibling would do. His love and care comforted my life. He taught me whatever he gained new. He sacrificed many trips and outings by staying with me at home when all others in my family went.

He was so strong and energetic until he was diagnosed with Leukemia. We were greatly shocked by the news and we all went through a period of tremendous grief. He was taken to India for

treatment and after the first two phases of chemotherapy, his condition got better and he even came home. But he had to be taken back to India for the third phase and there his condition got worsened just after the start of that phase. My brother had tolerated all his sufferings and pains and had managed to be positive amidst all those difficulties.

Father and my younger brother were there with him in India. They had gone through a mentally devastating period. My dad had to encounter many challenges and was mentally crushed by going through my elder brother's sufferings. But my father didn't lose hope till the last moment as we did. Anyway everything came to an end when my brother's heart stopped peacefully on a Friday morning on 14th of April in 2006. When we heard that our brother had left us and this world, we couldn't tolerate that pain in our hearts. We couldn't do anything but weep. I had never wept that much in my entire life. I missed his love and care. I lost a great brother. I consoled myself by praying to Almighty God to grant my beloved brother paradise.

It took us very long to overcome the sorrow of his loss. My father was so demoralized by the loss of his beloved son and used to weep whenever he remembered his son. Our strong religious belief gave us enough courage to tolerate all the sufferings and losses in our life. I miss him a lot...

An excellent solution...

As years passed by, I began to experience difficulty in breathing even during the day times, which was unusual for me. Things got worse as I started to get it even after a slight change in my posture. So, I had a very hard time when I got this respiratory problem. Father was desperate to find a solution for this and fortunately it was time to attend the Parents' conference in US. There he could meet a doctor and she had prescribed Lisinopril for me. Soon after I began to take Lisinopril, I started to feel very comfortable and the breathing difficulty slowly but surely eased. I

felt so relieved and I was amazed by Lisinopril's effectiveness! I take two tablets per day. Again my life returned to normal.

Gift of my life...



Jamaican Cherry Flower

As time passed by, the need of a new ventilator was seriously felt as my ventilator was becoming very noisy and as the technician warned us, it could stop at any moment. As my life was hanging on my ventilator, it seemed risky to rely on this ailing ventilator. So, my father started to look for a replacement. As he didn't have the financial resources to buy one, he tried to get a used one through his friends in Europe and the USA. Although my father's friends tried their best, they couldn't find a suitable ventilator for me.

In the mean time, my younger brother also was worried as what to do to get a ventilator. He was pursuing a course in Quantity Surveying at a college in Colombo and there he had access to the internet. We didn't have internet access at our home then. So, he could find the website of the manufacturer of my ventilator while he searching the internet. Then he kept on asking me to write a letter to BREAS, the manufacturers of my ventilator. I wrote a letter to them explaining my plight on a sheet of paper and then the next day my younger brother typed it and emailed it through his college computer. There was no response to my mail from

them but for a misaddressed email from a lady called Marie who was the Marketing Executive of BREAS. Soon after that, she had sent us a mail apologizing for her mistake. We replied her saying it was ok and reminded her about our email. Months went by and we could hear nothing from them. I and even my brother started to lose hope.

One day, there was a phone call and I answered it as father was out. I couldn't believe my ears to hear what the person from the other side had to tell me! The caller was from the local agency of BREAS company of Sweden and he said that I have received a brand new ventilator absolutely free from BREAS and asked to come and collect it!! Then only I remembered the email I sent to BREAS a few months ago. I was totally stunned to hear this great news and without wasting anymore seconds, I phoned to my father to tell him about the gift of my life! Father was so relieved to hear the news as he too had lost hope of getting a ventilator after all his efforts to get even a used one for me. My younger brother was in Colombo when we heard this surprise and father phoned him to tell about this. Father asked him to go and collect the gift and bring it home on his way back. He too was very excited to hear it because he played an important part in getting this. He was the one who forced me to write a mail as I had no hope of getting a ventilator in such a way.

Ms. Marie Nygren of BREAS, who was behind the scene, was very happy when I phoned her to convey my kind gratitude. I was very much stunned by all these happenings and I still couldn't believe the things that took place on that day in my life! I was overwhelmed by the generosity of those people who extended their kind help by giving the gift of my life! I began to use the new ventilator and I felt very much relieved. The new machine started to perform its duty for its master just a year ago! No trouble... no worries at all.

Another excitement...

Just after I got my new ventilator, another excitement in my life was the supply of broad band internet connection to our home! I was so eager to have access to the net for a long time and my father could fulfill my desire. I started to use the computer full time. Now I spend a lot of time in surfing the net and time just flies for me with the net. I made some nice friends through chatting. I could keep up with the latest news worldwide and so on. I could find whatever things I wanted to search. So, I became excited a lot and I felt internet could bring more happiness to my life and it made me forget my disabilities and sorrow to some extent.

What I got from Duchenne...



Common Jezebel

What I could learn in my life so far is if you can build up a strong mind with courage, you would be able to face and defy whatever the difficulties and grievances that you come across in your life. At the same time you should have a strong religious belief and you should never lose that belief even if you have to face the most difficult time in your life.

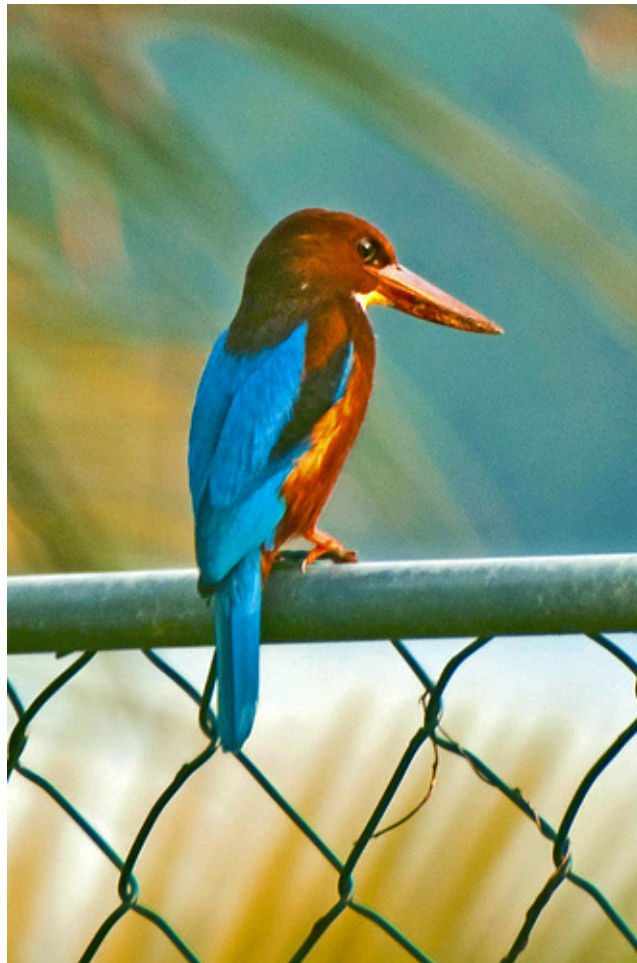
I sincerely think that Duchenne has taught me patience and tolerance in my life. Duchenne has united parents all over the world. Duchenne has helped us identify good people in this world. Duchenne made us to know that still there are a lot of amazingly

generous men and women in this world. Duchenne has specially helped me to identify true friends of mine!

by Irfan Hafiz

<http://www.irfanhfz.blogspot.com/>

What My Father Had To Say



White-throated Kingfisher

I live in Sri Lanka, a small island nation just south of India. My second son Irfan was diagnosed with DMD in 1988. For the past 20 years we have experienced all sorts of ups and downs that come with DMD. Now Irfan is 27 years old. He's been bedridden for the past 14 years and now uses a BiPap ventilator at night.

He is confined to his bed and was using a PC for his communication with the outside world. As he is unable to use a normal keyboard due to restricted movement of his fingers, he typed by clicking with a mouse on the on-screen keyboard. Now he uses a laptop and he has been able to type using his fingers as the laptop keyboard is very small and also with the help of on-screen keyboard to press keys that he can't reach with his fingers.

Luckily for us, he always maintains a very pleasant and jovial mood and never complains about his disabilities and sufferings. He says his religious belief has given him the courage and wisdom to face the reality and to defy the odds in life..

He has his own e-mail: irfanhfz@gmail.com, anyone can contact him by e-mail or through his mobile phone: +94 71 9081 478. He is fluent in English. He is one of the oldest people with DMD in this part of the world. Not single physician or clinician has seen him for the past 17 years. Would you believe?