

Case Study- Manjeet

Birth Defect: Lumbosacral Spina Bifida

Dharamveer and Anita live in a joint family at Kathgarh village in Bilaspur. Dharamveer's mother and his two brothers also stay with them. One of his brothers is married and lives with his wife and two children. Dharamveer's younger brother is unmarried. Dharamveer and Anita have a daughter who is 8 years old. Manjeet is their second child. So, their family comprises 10 members. Dharamveer is a Government employee and works at Mantra Devi Mandir Shrine Board, Bilaspur. The family is economically sound and holds white ration card.

Anita's second pregnancy brought a lot of happiness to the family. Dharamveer and Anita's joy knew no bounds. Her pregnancy was altogether uneventful and without any complications. She also underwent 6 ultrasounds during her pregnancy. Everything seemed normal and no problem of any sort was detected in the baby. Anita had a gestation period of 39 weeks. Upon completion of her gestation period, Dharamveer took Anita to Civil Hospital, Jagadhari. On January 3rd, 2020 at 4:00 pm, she gave birth to her baby boy (later named as Manjeet) via C-section delivery. His birth weight was 2500 g. The couple was very happy. But destiny had some

other plans for them! Their son was born with a birth defect! He was born with Lumbosacral Spina Bifida!! Externally, it looked like a small abscess (foda) on the baby's lower back. The abscess was small in size and could even be held in hand. Both Dharamveer and Anita were agitated and distressed. They felt miserable and paralyzed seeing their little bundle of joy in such a vulnerable state.

On day three after Anita's delivery, the doctor referred their son (Manjeet) to PGI Chandigarh. Dharamveer and Anita reached PGI with their three days old baby. The doctor at PGI examined the baby and told them that the abscess will heal on its own in a period of about 6 months. Dharamveer and Anita returned home with a ray of hope that their baby will soon be healed.

Their hope was soon shattered when within 1.5 months, the size of the abscess on Manjeet's back started increasing. The scared parents again went to PGI with their child. The doctors asked Dharamveer to get Manjeet's MRI done. For MRI, Dharamveer and Anita went to the Regional Diagnostic Centre, Civil Hospital, Panchkula. Getting Manjeet's MRI done turned out to be the most difficult task for Dharamveer and Anita. MRI required the child to be calm and still, but Manjeet did not remain still. He kept moving and hence, his MRI could not be done that day. Dharamveer and Anita had to visit Panchkula again and again so that their son's MRI could be done. On

March 13 2020, after about a month of hard work and multiple visits to the MRI centre, they were finally successful in getting Manjeet's MRI done.

They reached PGI with their son's MRI report. After checking the report, the doctors at PGI asked Dharmveer and Anita to admit Manjeet in the hospital on April 20, 2020. Manjeet's operation was scheduled for April 22, 2020.

Unfortunately, another hardship awaited them! The whole world faced the threat of a global pandemic (COVID-19) and a nationwide lockdown was imposed in India for 21 days, starting from March 25, 2020 onwards. This lockdown was further extended up to May 31, 2020.

On April 20, 2020, Dharamveer and Anita reached PGI to get their son admitted. They were not allowed in by the security guard. The guard asked them to meet the same doctor who had given them the appointment for the surgery and that only after the doctor's approval, their son would be admitted. The helpless parents did not know the name of that doctor and were not able to find him. They had to go back.

Dharamveer and Anita took Manjeet to the emergency room and told the doctor about the appointment given to them for their son's surgery. After examining Manjeet, the doctor told them that their son was fine and due to the lockdown, surgeries

are performed only for life-threatening conditions. So they will not be able to perform his surgery.

The poor parents were in a state of agony. One of the attendants of PGI gave them a doctor's phone number and told them to talk on that number between 7 to 9 o'clock about their son's situation. Dharamveer tried calling on that number many times, but in vain. Nobody used to pick up his call. He also tried to book an online appointment many times, but did not succeed.

Hope was the only thing they had and they were not willing to lose it! They kept visiting PGI repeatedly with a small baby in their arms. But nothing happened. Nobody helped them. They could not afford to travel by a cab, so they used to carry their little child from their village (Kathgarh) to PGI on a bike. Nothing could stop them, neither the expenses they had to incur, nor the harsh weather. They had to spend Rs. 400 per visit in travelling on their bike. They never worried about the money. They didn't even bother about the weather. They were willing to spend all they had. They used to leave their home at 5 o'clock in the morning so that they could reach PGI by 8 o'clock and complete all the formalities like getting the entry done on the card, submitting the card, etc in time with the only wish that their son could be examined.

Dharamveer and Anita visited PGI many times during lockdown. In addition to the hurdles faced by them in the hospital, they faced a lot of troubles on the way as well. The police used to stop them on their way to PGI and used to ask them the reason for being out of homes even in the lockdown. They had to tell their story to each and every person who stopped them. They had to show their child's birth defect to each and every person who questioned them. They had to relive their pain every now and then.

Nothing was working for Dharamveer and Anita, neither their hard work nor their fate! No one listened to them in the hospital. They got no advice about the treatment of their child. They were harassed several times by the attendants in the hospital. There had been times when they were not even allowed to meet the doctor.

Dharamveer also thought of filing a complaint, but later dropped the idea. He was fed up with his repeated visits to PGI. So, he decided to visit some other hospital. Dharamveer and Anita took their son to Balaji Hospital in Karnal for consultation. They were told by the doctor at Balaji Hospital that their baby's surgery will cost them around 4 lakh rupees. They also added that Manjeet could even die during surgery. Parents thought that even after spending so much money, if their child would not survive, then what is the purpose of spending money? They

decided that it would be better that the child remains like this only.

Dharamveer also consulted Jindal Hospital. The doctor said that they could perform Manjeet's surgery. A spinal tube would be inserted during his surgery and it would cost around 3.25 lakhs. Their son would be fine after the surgery. But the parents got scared and were worried about what would happen to the child if his artificial spinal tube got infected. So, they changed their mind.

They then consulted ESIC Hospital (Karnal). After examining the baby, the doctor said that they could treat the defect of the baby but he would be operated only when he turns 3 years old. Manjeet was less than three at that time, so they came back.

They also took Manjeet to Budhiya hospital in Bilaspur. The doctor in Budhiya told them that their son would have to undergo two surgeries - One for his back and the other for his head because the defect is connected to both these parts of his body. The doctor also advised them that it would be better to get the baby treated from PGI as only PGI could perform a successful surgery for this type of birth defect. Only PGI could save the life of their son!!

So, they have now decided that they would go to PGI for Manjeet's surgery. Dharmveer is planning to visit PGI after February 2023. He is also looking for someone's reference or approach because during his multiple visits to PGI in the past, no one entertained him ever.

During these three years, the size of Manjeet's birth defect (Lumbosacral Spina Bifida) kept on increasing. Presently, its size is as big as a football. Just imagine how difficult it is for a small child to live with such a big abscess always on his back. And how miserable it would have been for his parents to see it grow that large!

Anita has tried her best to give the best of care to her son. Manjeet was exclusively breast fed by Anita for 6 months and after that she started giving complementary food to him which included *Dal, Daliya, Khichdi*, etc. At present, Manjeet likes to eat everything cooked by his mother like *Dal, Chawal, Sabji, Roti, Parantha* etc. *Khichdi* is Manjeet's favourite food. Manjeet can eat food on his own. He also likes to eat seasonal fruits. Pomegranate and mosambi juice are his favourite. Manjeet also likes to drink tea. Manjeet likes to eat soaked almonds. He eats simple food without spices added to it as eating spicy food causes blisters in his mouth. He also likes to eat '*makhan with chapati*'. He eats a pomegranate daily every morning and evening. Dharamveer does not allow him to eat chips,

chocolates or candies. Manjeet's current weight is 10 Kg. Manjeet is underweight and has wasted and stunted growth as per WHO growth standards.

Initially, it was easy for the parents to carry him or lift him up. But after a few months it was very difficult to carry him because of the increased size of Lumbosacral Spina Bifida. Although Manjeet lives in a joint family, no one allows him to sit in their lap. His family members are scared of his condition and feel that they cannot handle him with his tumour (birth defect). Manjeet also does not like to go to anyone's lap other than his parents. Now the parents also face difficulty in carrying Manjeet and get tired in about half an hour. Manjeet was also refused to be vaccinated (including Vitamin D3 drops, iron syrup and medicine for deworming) by the health workers because of his condition.

Dharamveer and Anita are scared to send their son to the Anganwadi. They fear that someone might put a foot on the child's tumour (birth defect). Anita teaches him at home. He can count up to 10. He can hold the pencil himself but is able to write only with the help of his mother. His elder sister also teaches him at home.

Manjeet takes a bath daily. He can bathe by himself. But he cannot wear clothes on his own. Parents also face difficulty in dressing the child. Manjeet's back always remains open

because his tumour (birth defect) does not fit in his clothes. His parents cover it with either a towel or a blanket. Because of this, the child feels very hot, so they always keep the fan on even in winters.

He is not able to control his urine. He is also suffering from constipation. He needs his parents' help to pass stool and in cleaning him after he passes stool. During winters and while going out, the parents use a diaper for him.

Manjeet's legs are also very weak. He can neither stand nor walk. He can only crawl/ move in a sitting position. After he gets successfully operated for Lumbosacral spina bifida, another surgery on his legs will be performed. Dharamveer and Anita never leave him alone. They generally put him on 'Manja' otherwise he will crawl/ move away to play with other children.

Manjeet likes to play with his sister, cousins and other kids from their neighbourhood. All of them take good care of him. Parents don't let him walk too much as they think due to movement his tumour (birth defect) might burst.

Initially, when the size of his birth defect was less, Dharamveer and Anita used to make him lie down straight on the bed by placing a rolled cloth or towel below his back. But now, Manjeet cannot lie straight as the size of the birth defect is huge. He has to lie on either his left or the right side. It is very difficult for him

to be in this position for long and suffers from aches in his body. The tumour is otherwise painless. It however hurts in case of a jerk to his body as during a bike ride. His hands also start paining and hurting after sometime as he crawls/ moves using his hands.

Manjeet understands everything his parents or other family members say. He is a very active and talkative child.

His family have never made him feel discriminated against because of his birth defect. They have loved him unconditionally since the day he was born. But the society and his relatives have been different and inconsiderate to him. The people look at him with pity. They also taunt Dharamveer and Anita for not being able to get their child treated. The indifferent attitude of the society has made them avoid all functions and social gatherings.

Despite all adversities, Dharmveer still believes, “PGI wale mere bachche ko bacha denge”

24 hours recall: Last morning he ate Mooli ka parantha with a cup of tea for breakfast. For lunch he ate Dal chawal and for dinner he ate ‘roti with makhan’. Next morning he again ate mooli ka parantha with a cup of tea.

Thank You!!