

Case Story -1

Mother's blessing cum curse

'jug jugjiyo mere laal, tujhe meri bhi umar lag jaye' this blessing usually comes from a mother, from the core of her heart which is as pure as God but here in this case it has proved ironically. It is a case of absolute ignorance and lack of awareness over the decades that have resulted into Hepatitis B transmission from a mother to a child; the child who is now a 30 year old boy and has his own family and kid too.

This boy belonging to Delhi, a middle-income family with an old mother (recently diagnosed as Hepatitis B carrier), wife, a son and six married sisters is the only bread-earner of this family having a govt job in hand (currently working in one of the Judicial Office in Delhi). Like others, they were living a routine and healthy life till the time her mother complained for unbearable pain due to gall bladder stone. They approached the city hospital (in Feb 2018) for the gall-bladder stone removal surgery and underwent certain specific tests as required for pre-surgery protocols. The diagnosis came to them as a trembling shock and revealed that the lady is infected with Hepatitis B and made the whole story upside-down and put a pause to her main surgical intervention. Now, she is undergoing treatment (at ILBS) to control and manage the viral load of the Hep B virus so that her main surgery can be targeted.

This diagnosis has put the whole family under tremendous social and emotional pressure which made them go through Hepatitis screening because the main risk-factor of Hep B transmission is from a mother to a child; so it was mandatory for all the members to undergo the screening. Call it fortune or misfortune; out of the all (boy himself, his wife, his son (who was Hep B vaccinated at the time of birth), his six married sisters), this boy got Hepatitis B infection from his mother, probably at the time of birth while the others were diagnosed negative but they still took precautionary vaccination.

Now the boy is facing social and emotional trauma at work-place where he has not even declared it to the Office suspecting job-risk though being in a govt job but his close-friends who are acquainted with his health information has resulted into a very formal relationship by cutting corners with him and keeping distance as if this virus is communicable though it is not.

His family life is also going through the ups and downs as they were initially planning to extend their family by having a second child but this diagnosis has put all this under scan though his wife is Hep B negative but still they are re-thinking whether they should really extend their family or no. Will it pose risk to the unborn child? Will it pose infection risk to his wife? Will it pose risk of life to the boy himself? All these and many more are the questions which are going in their mind day and night, putting them at unease and depression, all the time.

It is a matter of concern to educate people and healthcare practitioners through mass awareness so that the public at large can be made acquainted with this health information to avoid the risks and understand the symptoms before it is too late to cost a life. It is empirical that there must be many other untold cases that are yet to come forth; may be because of the undue stigma or the fear they are not approaching the healthcare workers. We should be committed towards society to educate the people about the disease and its infection incidence.

Case Story -2

The story of struggle, survival and resilience.....

Mr. A (anonymous) waiting for his liver biopsy comes across as a cheerful person. When asked about his medical condition, he informed that he was a kidney patient and had undergone Kidney transplant twice (1998 and 2003) and the second one was successful. It was during the second transplant duration that he was told that he had contracted Hepatitis C. He feels during this treatment period, with several dialysis rounds in hospitals, he must have contracted Hepatitis C. At that time he was informed that he could live 10-12 years without major complications.

When the medication came in 2015 he was put on sofosbuvir. It is interesting to note that Mr. A's concern was not hepatitis C but how with a successful kidney transplant he would lead a successful life post 2003. His eyes sparkled when he shared his life situations after kidney transplant post 2003 till 2014. Kidney complications aggravated in late 90's and subsequent search for donors and medical treatment made his life miserable from 98 to 2003. When he received a willing donor and kidney transplant was a success, all he wanted was a good life. He says he had a very supporting wife and she along with his children ensured his wellbeing and happiness during this time. It was a second life for him post transplantation till 2014, he lived a fulfilling life. The Hepatitis C condition did not bother him much as the complications were not visible and after the five years ordeal all he wanted was some stability and peaceful life. In 2015 when the medication was available for hepatitis C, he got treated of hepatitis C but a follow up test after 6 months again showed the virus in his blood. The treatment was started again and he says he got cured again.

Since last year he has been suffering from fluid accumulation, he says the tests findings rule out presence of tuberculosis or malignancy. His liver condition is also manageable; he is waiting for the biopsy to be conducted to know the real cause behind frequent accumulation of fluid when all the other organ functions are fine. He says he has seen the worst situations and grateful for the fact that he lived a good life post transplant which was possible because of the support and care he received from his family especially his wife (she died in 2014 due to breast cancer). His treatment costs till now have been manageable. The family members (his two sons and a daughter) till now have not undergone Hepatitis tests. The family is educated with sound financial situation but somewhere may be because of lack of awareness the screening of family members have not taken place.

Mr. A feels in any chronic condition if the patient receives the care and support from his family then the situation becomes better. He was lucky to have a caring family. He awaits the result of further examination calmly. Perhaps the ordeal from 98 to 2003 and a satisfied post life after kidney transplant overshadowed the anxiety and fear associated with hepatitis C.

Case Story-3

“The desire to give is even stronger. I don’t feel defeated”

Ashish Kumar Chaudhary (name changed) visits ILBS every six months since the past two years for HBV Treatment. He hails from Champaran, Bihar.

Young, dynamic, emerging politician of his native area, he is a father of two children. He tells us that it was during his examination for removal of tonsils, he was diagnosed with HBV in the year 2013 at Banaras Hindu University Medical College. He didn’t notice any symptoms before the diagnosis. He does recall that at the age of 4-5 he had contracted jaundice and was completely recovered. His fitness level can be gauged from the fact that he was selected for Bihar Police constable post from 21 districts but the government never completed the recruitment process.

Today he earns his living with small fishery business and farming. He mostly spends time in politics and social work. He has got his family tested but was reluctant to divulge on the fact if his wife is tested positive for HBV or not.

He says he did have some idea about the disease as he remembers in his early 20’s actor Amitabh Bachchan did awareness campaign on the issue and it was telecasted on TV and other platforms but never tried to learn more about it. He says: “who would know that one day I would be contracted with this disease?”.

The moment he got aware of his condition, he was in disbelief. After the diagnosis he along with his wife kept travelling here and there for three days. There was acute sense of despair. But for the sake of his family and friends he picked up. It has been 5 years and he has been very regular with the medicines and checkups. What is interesting to know in Sanjay’s case is that in all these 5 years he was never given proper counselling by anybody. He was definitely told about medicine, food and general precautions but never proper counselling. He told us the initial information gathering from posters, info graphics outside hospital wards really helped him and he follows them diligently. Life after HBV has been extremely challenging but it has made him realise that he is even more accountable towards his actions now.

He aspires to be a prominent politician, social worker in his native town. He spreads awareness regarding this disease in his home town. He feels lack of proper counselling makes things worse for patients. He makes available information to that anybody who needs guidance on diagnosis and medicines, references regarding hospitals

He says that he has faith in god, he is regular with medication and his family and friends support him and these positive things will support him to sustain him further in life. He does wish to be alive to see his family do well in life. Today his desire to give to the society is even stronger and he wants to enjoy every healthy moment of his life

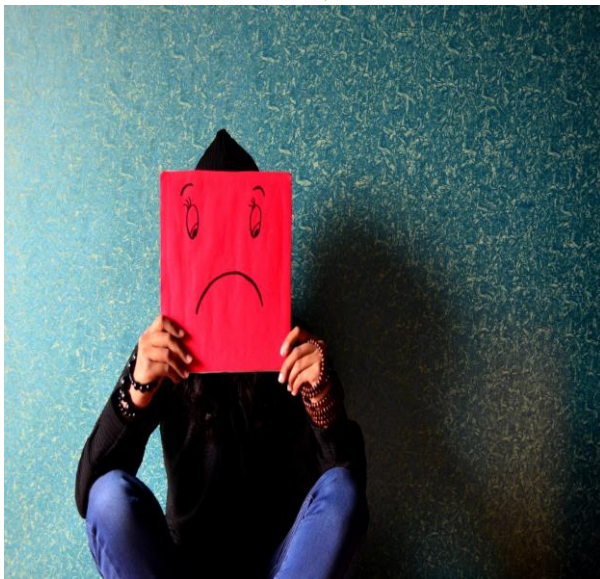
Some Stories and Experiences of Patients



Stories of disturbed relationships:

Harish (name changed) hails from Punjab and is consulting a doctor for hepatitis B infection. Unaware of the reason of contracting the infection, Harish cries in grief and mostly when he is alone. Perhaps he has no one to whom he can express his emotions to and therefore asks God “why me”? He feels that there is a certain stigma (perceived in this case) attached to the illness so he does not reveal his status to anyone. He wants to start a married life and is constantly worried.

STORY OF “FEAR, STIGMA and IDENTIFICATION”



There is fear of being identified”

A 28 year old young man, a chartered accountant (CA) by profession and a body builder by passion, found that he is Hepatitis B positive when he went to donate blood to one of his friends. He started seeking treatment but due to fear of discrimination & stigma, he did not share this at his workplace with anyone. His fear of getting isolated was increasing day by day. He kept hiding his medicines and test reports from his friends and colleagues but due to frequent

visits to hospitals and his fear of loneliness & losing the job, he left his well-paid corporate job. He feels all he is left with in his life is 'Medicines, hospital visits and Hepatitis'.

STORIES OF... "WISH WE WERE AWARE...."

Neer (name changed), a 40 years old married man, who was diagnosed with hepatitis B in the year 2010. When asked about his overall feelings and life after being diagnosed with hepatitis, he was apprehensive and had tears in his eyes and said, ".....Why me? I never did anything wrong...I only use to drink alcohol occasionally... the entire world does it but only I had to get this infection....I do not know what will happen to my life now....I now worry about my family too including my two sons whom I fear may have contracted this infection too...it's all my fault". There was a sense of guilt and regret in his speaking. He mentioned that he feels his life is 'wasted'. "It is killing me everyday"

"...I want to give this message to the world that since general public does now know about this disease and how it spreads....it is very important to be spread awareness on viral hepatitis"