

## Poor public infrastructure makes living with multiple sclerosis a struggle for patients

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In recent times, a wide range of innovative therapies have become available that can now target the different types of MS. Unfortunately most patients are unable to benefit from this development as they cannot afford these therapies. Also, insurance companies have been reluctant to cover this lifelong disease under medical coverage. Poor public infrastructure adds to the patients misery.

The Draft Rights of Persons with the Disabilities Bill 2012, prepared by the Ministry of Social Justice and empowerment recommends including multiple sclerosis amongst others to the standard seven disabilities recognized under the existing Persons with Disabilities (PWD) Act 1995. Once passed, the bill would enable a person living with multiple sclerosis to entitlement of the same legal rights and benefits similar to those living with blindness or loco-motor disabilities. The bill would also protect disabled persons against discrimination, provide affirmative action and penalize and punish offenses committed against them.

As per Dr B S Singhal, Director, Department of Neurology, Bombay Hospital, Mumbai, "Multiple Sclerosis is believed to be an autoimmune disorder but the precise cause of multiple sclerosis is not known. It is more common in females and the common age of onset is in the most productive age group of 25-35 years. With increase in the number of neurologists and easy availability of MRI machines we are diagnosing more cases in India.

The awareness about multiple sclerosis is gradually increasing in urban cities but multiple sclerosis remains undiagnosed in the large section of the rural population and there is yet greater need for improving awareness in both urban and rural areas. The of lack of knowledge about this condition, employers often fail to understand the plight of employees with multiple sclerosis. Shortage of rehabilitation centers and specially trained nurses clubbed with poor public infrastructure makes living with multiple sclerosis a struggle for patients."

Dr Joy Desai, Consultant Neurologist, Jaslok Hospital and Research Center, Mumbai said, "Patients sometimes face discrimination at work place and in the society as a whole, mainly due to lack of awareness about the disease. They have low self esteem as they lose their rigor of youth and subsequently the ability to function optimally at workplace. Society should be more sensitive towards these patients and recognize the fact that the human body is vulnerable to auto-immune diseases, and their occurrence is beyond human control."

The average cost of patented multiple sclerosis injection comes around Rs 40,000 per month. According to estimates, there is between 100,000 - 200,000 multiple sclerosis patients in India, however there are no exact statistics available.