

Experts urge for understanding of Multiple Sclerosis, call it crucial

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Degree of disability should not be the only measure for consideration as MS patients face unpredictable symptoms, say experts



Every year the last 30th of May is commemorated as the World Multiple Sclerosis day. This year Multiple Sclerosis Society of India (MSSI) organized an event in Mumbai to spread awareness about the gravity of the condition to encourage support for people suffering from Multiple Sclerosis (MS). Eminent stakeholders including Dr. S M Katrak, Dr. Satish Khadilkar, Ms. Renuka Malakar, National Secretary, MSSI and Co-founder of MSSI, Mrs. Sheela Chitnis spoke about the various aspects of MS, challenges in its long-term management and importance of awareness about the condition in India. Patients suffering from MS were also present at the event.

MS is a condition affecting the central nervous system (mainly brain and spinal cord) resulting in nerve damage. This disrupts communication between the brain and the body. It's a lifelong condition that has the potential to cause serious disability. This year, the theme for MS Day is 'Invisible MS' which addresses the invisible symptoms of MS. These could be blurry vision, urinary incontinence, fatigue, dizziness, difficulty in speech, difficulty in walking, inability to process information, etc.

Addressing the symptoms and treatment options Dr. Satish Khadilkar, Dean, Professor and Head, Department of Neurology, Bombay Hospital & Medical Research Centre said; "Early Diagnosis and availability of new drugs and treatment options can help improve the quality of a MS patients' life. MS is a condition which affects the central nervous system (mainly brain and spinal cord) resulting in nerve damage. MS is more prevalent among the youngsters; therefore, the impact is more as they age. But the fact is still that girls are more affected than boys. It affects the functioning of important parts of their body. The symptoms include blurry vision, difficulty in urination & difficulty in balancing. The need of awareness of availability of treatment options and early diagnosis is very important in this modern world."

Commenting on the condition, Dr. S.M Katrak, Neurologist, Jaslok Hospital, Mumbai said, "The current prevalence of MS in India can be estimated to be 7-10 per 100,000 people. This data is also incomplete as there are very few studies & there isn't any information available on the rural population. Increased awareness about the condition amongst neurologists and availability of MRI's have resulted in more patients being reported over the last few years. The cause of MS can be attributed to 2 factors - namely genetic and environmental. The onset of MS has been observed amongst the age group of 25-35 years with male:female ratio of 1:2. The rising incidence is an eye opener for India to be more inclusive of the condition and its disabilities."

In 2016, MS got added under the Disability Act of India. However, many don't know about it. Also, as MS shows invisible symptoms, patients have to undergo a lot of hardships to get a disability certificate. Thus, it is imperative for the disability officers to understand the nuances of the condition and help these patients get their disability certificate without a hassle of presenting visible symptoms.

The 40% criteria for benchmark disability should not be applied for MS patients. Owing to the unpredictable symptoms, the degree of disability can get worse for a patient within days. We have started speaking to multiple stakeholders to advocate rights of people with MS" said Renuka Malakar, National Secretary, MSSSI.

Commenting on the same, Mrs. Sheela Chitnis, Co-Founder of MSSSI said, "The life of an MS patient is full of obstacles not knowing what the next episode has in store. They face discrimination at work, family and social level due to their invisible symptoms. We provide counseling to these patients to tackle this social stigma. Despite the recognition in the Disability Act, patients face difficulty in getting their condition considered correctly due to the invisible symptoms. In MS, the degree of disability isn't the only measure for consideration as the patients face unpredictable symptoms. We would like to urge the disability commission to understand the ordeal of these patients and provide them with a disability parameter of over 60%. We are also working towards raising awareness to make every vicinity more disable friendly."

The event was also a platform for the patients to discuss their individual challenges and journey. With the advent of technology, MS patients have a support group online as well, 'World v/s MS' where they can draw inspiration from each other's struggles and positive stories.