

THE JOY OF QUADRIPLEGIA

Rajinder Johar

Rajinder Johar (53) the recipient of NATIONAL AWARD for Best Self Employed Disabled Person in 96 is a pioneer in the field of Occupational Therapy in the State of U.P. He also has bagged many prestigious Awards in recent years like Manav Sewa Award (93), Professional Excellence Award of AIOTA (93), State Award of Govt. of Delhi (93-94), Ram Krishna Jaidayal Harmony Award (92) and others. He is constantly making all efforts to make society aware of the spirit behind F.O.D.'s motto Look first at my strength not at my weaknesses.

Mr. Johar, who formerly was heading the Occupational Therapy Deptt. of Rehabilitation and Artificial Limb Center at K.G's Med. College Lucknow, is a past member of AIOTA and is qualified from Institute for Physically Handicapped, New Delhi in 68. He met with a tragic accident in 86 and developed Quadriplegia. In spite of being 100% disabled he has become a symbol of hope and motivation for the physically challenged persons. Members of AIOTA are proud of his admirable efforts and commendable achievements through Family of Disabled (FOD) and its biannual publication The Voice of FOD.

Medical literature is replete with the havoc that quadriplegia inflicts upon an individual and robs him of many body functions. In contrast, Rajinder Johar traces a few advantages he experienced after he sustained spinal cord injury resulting into quadriplegia.

Editor, IJOT

Sound mental and physical health is nature's most precious gift to the mankind. Its loss, temporary or permanent, may affect an individual, making him partially or completely dependent in performing his activities of daily living (ADL), such as eating, drinking, talking, personal hygiene, walking and so on. Certain gadgets may also have to be prescribed to make these tasks easy.

There are numerous diseases/ condition, which may lead to absence or impaired functioning of any of the body segments. Here, I shall confine myself to quadriplegia. Injury, disease or any pathology of spinal cord in the cervical (neck) region that interferes with its functioning results in quadriplegia. In complete lesion, the paralysis affects all the four limbs accompanied with sensory loss. Control over bowel and bladder is also lost. The person forever leads a wheelchair or bedridden life. The only remedy known is rehabilitation through various modalities of physical medicine. Considering the complications associated with quadriplegia, it has gained notoriety as a disastrous tragedy to strike.

Over sixteen years ago, in an accident, I sustained an injury to my cervical spine resulting in complete paralysis below chest level and also of both hands. Shock, depression, grief, agony, misery, frustration and anxiety in addition to physical symptoms, which a patient with quadriplegia normally encounters were more pronounced in my case. The reason was my being cognizant of the poor recovery of people with spinal cord injuries. This was in my capacity as incharge of the occupational therapy department at King George's Medical College, Lucknow, where I was engaged in rehabilitating a multitude of physically incapacitated people.

It took me five long years to realize the worthlessness of a negative attitude that had enveloped me. Eventually when I was able to pull

myself out of this web, to my pleasant surprise I found that a few of my defunct faculties could still be advantageous to me. I agree with Richard Bach's view, "There is no blessing that cannot become a disaster, and there is no disaster that cannot become a blessing." And when I tried to locate the blessing in the disaster (quadriplegia), astonishingly, I found not one but many!

Overnight, I became the focus of everybody's extra attention, care and comfort. My smallest need and demand was immediately met, like that of some Nawab or an Infant. The best part was, no one had any expectations from me – a rarity otherwise.

Like Rai Sahibs and Khan Bahadurs were the titles conferred in the days of Raj, society has now bestowed upon me a new title 'quadriplegia'. Though it may be wrong ethically and morally but we Indians somehow prefer to address a disabled person by the disability she/he has.

I've been able to cultivate a new set of friends and well-wishers comprising non-disabled and disabled people. This group enables me to discuss the common needs, solution of the problems faced by 'differently able' people.

Doctors exhibiting their calculative skills issued me a certificate showing hundred percent disability. Citing this as a cent percent performance, I motivate my children to secure full marks in their studies, like their father, who has achieved perfection in disability.

I feel proud to be serving the national cause of a 'small family', i.e. Family of Disabled Acquiring quadriplegia at 37, brought an unceremonious and abrupt end to my sex life, thereby restricting my family to two children and mind you, that too without any surgery, pill or device.

My spouse and I have swapped roles. As she is a working woman, I have taken over the homemaker's job. She runs outdoor errands while I look after the children, guests, servant, pets and other domestic chores. My sexual identity appears to have changed without a surgeon's help.

Correspondence : Rajinder Johar

Founder Co-ordinator: Family of Disabled

Editor: The Voice of FOD

B-1/500, Janakpuri, New Delhi - 110 058

Phone : 25597328 E-Mail : fod_delhi@yahoo.com / fod@vsnl.net

Quadriplegia has enabled me to join that privileged class whose welfare is always on the mind of everyone in society, right from the Prime Minister(he gives away Awards on Dec 3, The World Disabled Day) to the peon. When everybody seems to be so concerned about disabled people there is no reason why they should be dubbed as underprivileged. While attending public functions as a participant/ guest, I have observed that the usual protocol is waived off, just for me. As the chief guest and his entourage have to step down the dais to my stretcher-trolley, all customs are put aside. When norms are deviated, exclusiveness gets extra defined. While going out to a movie / play or social gathering I need not bother to locate a vacant seat. I carry my furniture with me. Before coming on to the trolley I spent a few months in a wheelchair, which encourage my friends to call me a chairperson for all occasions and seasons. The credit of course goes to quadriplegia.

Perhaps my professional knowledge and experience with the patients of quadriplegia and its complications made me a difficult patient who took unusually long period of five years to get rid of the negative feelings associated with quadriplegia. But it was again my profession and qualification as an occupational therapist which eventually helped me getting over the negativity of the situation I had lead myself into. Thinking in retrospection while working in K.G's Medical College, Lucknow, helping patients with spinal injury, advising them to face the eventuality with courage and determination, I gave the same advise and therapy to myself as an occupational therapist. Though labelled by doctors as hundred percent disbled person I thought of giving a trial to the intact faculties left with me. It was time to extract the best out of the worst. I decided to do something in the field of disability, for which I was trained, than just lying back and doing nothing at all. Thus Family of Disabled (FOD) was born in March 1991. Perhaps it is the first organisation in the country working for the people with disabilities established by an occupational therapist.

My personal needs have dwindled immensely. Wardrobe, shoes, toiletries, cosmetics, and transport expenses, you name it and I need them no more. Hence, no necessity for economy drives.

Mosquito/ insect bites, cuts and bruises do not scare me – thanks to the absence of sensation of touch, pain and temperature associated with quadriplegia. Pressure sores and any ailment of the abdominal viscera goes unnoticed by me but may cause concern to my doctors.

Continuous non-usage of muscles dispossessed me of my treasured musculature and has left not much flesh between my skin and bones which has made my bony contours markedly prominent, thus converting me into an ideal specimen for medical student to study surface anatomy. Fresh medical graduates too can hone their skills, knowledge and art of therapy through the multi-dimensional scope my body offers. In addition, affliction of various systems like neuromuscular, urinary, respiratory, skin and skeletal in one single individual offer ample scope to different specialists to practice under one roof.

When employed, I had been responsible in raising the country's largest occupational therapy department at KGMC, yet my bosses

preferred to be indifferent to my sincere and disciplined endeavours. Now that I am totally dependent on others, my smallest accomplishment is noticed, appreciated and recognized. The point is that after acquiring quadriplegia, even my little achievement gets observed. A few 'Awards' have also come my way.

Being home bound and bedridden has made me available to others round the clock. Friends, relatives, neighbours and acquaintances take it as their right to phone or walk in whenever they like, to narrate and off-load their grievances, woes and seldom their joys. When the catharsis is complete they are relieved. Thus, quadriplegia has made me accessible all the time to all people for their emotional sustenance.

I have taken upon myself to introduce to my lay visitors the various aspects of quadriplegia like its aetiology, symptomology, treatment, management, complications and prognosis. By the time they leave, they are aware of what quadriplegia/ c is.

Like any pretty woman, I too get abundant side glances from every possible angle when taken out in a trolley-stretcher(my present mode of movement). Being the center of attraction, I thoroughly enjoy the curious but impersonal reaction of the onlookers. One of the biggest advantage has been that now young ladies feel absolutely safe in my company. They consider me the most harmless creature!

The above findings are entirely my own and cannot be generalized. No two persons suffering from the same condition react in a similar way. The ill effects of quadriplegia cannot be minimized. The damaged incurred is invariably irreversible and mostly leaves the patient tremendously shattered. All rehabilitation procedures would be futile if the incumbent fails to involve himself and participate actively, to fight the disability. Brooding, cursing and weeping leads to self-pity, which certainly signals doom. Realizing the nature of paralysis where done cannot be undone, the only course left is to salvage the best out of the worst. The optimum use of the remaining faculties would result in a more productive and enjoyable life. It not only helps the incumbent but also the people around.

Today, I feel satisfied to be able, to whatever extent I am capable of, to coordinate the activities of Family of Disabled. I think my schooling at St. Joseph's Academy, Dehradun, my professional training at Physio-Occupational Therapy Institute (Now IPH), New Delhi and over seventeen years of clinical and professional experience as an occupational therapist at the country's biggest Medical College, KGMC Lucknow, enabled and equipped me to fight my disability and also to manage the affairs of a registered voluntary organisation with the help of so many like minded people.

What matters is how you live your life- fighting disability bravely or surrendering to it meekly? Society would do a great service if it starts looking at the strengths a disabled person has, than at his/ her weakness.

Reprinted from Vol.XI, No.1, Jan.-June issue of 'The Voice of FOD', a publication of Family of Disabled.