

EXCERPTS FROM THE DIARY OF A TETRA

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## INTRODUCTION

Many people have been asking me to write of my experiences after my riding accident in 1988, in which I broke my neck, and the subsequent treatment and rehabilitation to enable others in the same plight to benefit by and get some ideas from my experiences, both good and bad. Since I have been making graphic notes of all this from the day of my accident, I have taken extracts from my more detailed diary and compiled it together as best I could.

I was both lucky and unlucky in the events that befell me after my frightening and horrible accident. What was immediately apparent was the almost total lack of knowledge and experience amongst ancillary medical personnel (starting from transferring me into the ambulance) and thereon in dealing with spinal cord injuries in my immediate surroundings and in India. I was fortunate in being able to be flown to England (for treatment and rehabilitation) almost immediately after languishing uselessly for a week in a hospital in Bombay and I was immensely lucky in having a wonderful family (both immediate and extended) as well as a lot of supportive and gorgeous friends who moved heaven and earth for my survival.

So to summarize, I have given a lot of details to the events that took place prior to my rehab, because I want to highlight the awful conditions of hospitalisation in India for people with severed spinal cords, *where there is no specialised unit or institution (with specially trained auxiliary staff) for spinally injured persons.* I have tried to show the comparison with U.K. hospitals and Rehab centres for the Spinally injured, so that perhaps people who read this article, may try to improve facilities in India for such injuries. Even transferring an accident victim in an ambulance here is so primitive, in comparison to the West, as I have pointed out in my 'story'.

Another aspect I have kept harping upon in my article, is the solid family support which is so essential for an injured accident victim. I was lucky. In 'Third World' countries we are better off than in the 'Developed' countries where the nuclear family system prevails, which isolates people and patients; because of this their spirit becomes low and discouraged. It's so important for spinal cord injured persons (SCIs) to have constant emotional support, to be able to get stronger and maintain their dignity. It will be noticeable that I have emphasised the importance of this throughout in my 'diary excerpts'. I have also briefly touched upon both the financial and sexual predicaments that SCIs could come across, and how this was so openly and freely discussed in the 'lectures' given to us at the Rehab centres abroad, but never is spoken of here in India.

The main reason for this article is to highlight and bring to awareness the dearth of facilities for paralysed and wheelchair bound people in India such as the total lack of wheelchair accessibility in public and private buildings as well as very little recognition in our society to both the proper treatment and the needs

Shanoor Forbes.

### EXCERPTS FROM THE DIARY OF A TETRA

I fell on 28th February, 1988. I was forty-four years old at the time. It was like any other morning ride - pleasurable as all my riding had been, since I was a little girl, up until this moment. However, this time when I took the toss from my horse, I thought to myself, "This is the beginning of the end". I have been maintaining a diary from the day I toppled and making notes of all that I have undergone since my accident, and I think the following may be of interest and help to other tetraplegics and paraplegics in reorganising their lives after becoming paralysed, since a problem shared, is a problem halved:-

"I am only one, but still I am one. I cannot do everything, but still I can do something; and because I cannot do everything, I will not refuse to do the something that I can do."

These words of Helen Keller have been an inspiration to me, after my riding accident at Mahalaxmi Race course, Bombay. The moment I was thrown from my horse Romanique when she tripped, I fell straight on my head, and snapped my spinal cord at the C6/7 level. I was immediately paralysed.

The minute I fell, on my head which was protected by my riding hat, I recollect being on the ground in a crouched position - not able to move. There was no pain at all and the only thing I felt myself doing was fighting for breath, my whole body concentrating instinctively on that one fierce activity - breathing hard, in out, in out, and not being able to do that easily seemed strange. Nor could I move from that crouched position.

My friend Mini, who was riding with me at the time, and other joggers and walkers on the track quickly summoned an ambulance which is always standing by at the race course. The driver and his assistant pulled me on the stretcher without protecting my neck or head as is customarily done in the West these days. In India there are no properly trained ambulance personnel, like the

trained Paramedics abroad, who are always on the ready, when called, to treat accident victims. I can never be sure, but my fractured vertebrae could been further damaged and greater injury done to my spinal cord due to the movement of shifting and lifting me without proper support to my neck and back. I was then taken to a hospital near the race course, and after taking X rays of my whole body, they said my neck seemed to be broken and summoned my husband Sarosh and my son Reshad (aged twenty at the time), my mother and other close family members, informing them of my poorly state. (My daughter Simonil aged twenty-one at the time was studying in America and had to be informed by telephone). Needless to say they were all completely shattered and distraught. My Myelogram and C.A.T. Scan had also to be taken but the present hospital had not the facilities, so they took me off to another bigger hospital, which had the equipment. Being a Sunday the department for this was closed! So I had to remain in agony with my broken neck and without treatment. But all my close family members and lots of my friends constantly came in and out visiting me and giving me a lot of support and encouragement.

I remember my mother Freny sitting by my side night and day, shoos away visitors when she felt I needed my sleep more than conversation! Being her only child, she and I have always had an almost symbiotically close relationship and it doesn't bear thinking what agonies of hell she must have been going through, not sure whether I'd survive or not. But the outwardly calm exterior she kept certainly kept my spirits up. My timid sweet mother-in-law, Dolly, with whom I had a pricelessly superb friendship, seemed withdrawn and frightened and in deep shock, unable to speak or do anything much when she was around me. We just had an unspoken communication which forged a bond between us in those terrible days. Being a gregarious person, despite all my agony and pain both mental and physical, I remember feeling very cheered and happy that so many people were concerned and helping me in every way they could.



The next day after the Myelogram was taken the consulting surgeon seemed to be of the opinion that a very major and critical operation of the vertebrae would be necessary, since the fractured portion was in bits and pieces, the shards of which had severed my spinal cord. This news filled us firstly with dismay and then fear, so on being advised by many well wishers that the conditions for the proper treatment of this immense problem, were totally lacking in India, Sarosh my husband, made a snap decision to fly me to England where we knew the facilities to treat me did exist as we at one time had lived in England. There I could be operated on and my rehabilitation commenced if the operation proved successful.

Not being wealthy business people we did not possess the huge amount of money that would be required, so there began an immediate search for funds; loans, grants and liquidation of any stocks, shares and capital owned by us then, in the shortest possible time. This was an enormous task and would not have been possible without the help of our very kind family members and friends who ran around together with Sarosh, who was near break-down point himself with this horror that had happened to me, and whose life too had been smashed just like my vertebrae, in a split second. Sarosh contacted one of his best friends, Manek, who lived in England and set the ball rolling. Hundreds of phone calls were made back and forth liaising with friends and doctors all over the world. It was eventually arranged to fly a Neuro Surgeon from England to Bombay and for him to return to England accompanying me on a stretcher along with Sarosh and Reshad. All these arrangements had the deadline of a week and till then I lay, my neck broken and in agonising pain at every turn of my head. There were no neck collars which could give me comfort. My comfort was my mother and friends and relatives who were constantly at my side together with private nurses feeding me, changing me, turning me and giving me courage. I was totally paralysed and in complete depression. Both my husband and son

could not, at the time, physically sit with me all the while, for they were running around completing all formalities in and out of the hospital.

They then decided to do a tracheotomy to my throat since I seemed to have a little bit of difficulty in breathing and talking and it was after this operation that my real nightmare started. It was apparently not properly performed and I was put in the I.C.U. which was full of moaning and groaning patients who were seriously ill. The physiotherapist who came routinely on her rounds appeared to me a young haughty and unsympathetic girl who seemed to be raw at her work. She seemed to have to overcompensate for her lack of knowledge by trying to terrorize her patients. She forced me to breath in and out on a breathing apparatus which choked me and when I pleaded with her to stop and remove the tube she had inserted in my mouth, she snapped at me in anger and forced it down. I heard my private nurse who was a gentle and kindly woman urging her to stop since I was obviously choking. But she snapped at the nurse telling her to mind her own business.

Just then I saw one of my aunts, Nergis, who is a doctor, come in and exclaim that I seemed to be completely out of breath and turning blue and that in her opinion these exercises ought to be stopped immediately. To this the young physiotherapist angrily retorted that my aunt had no business being in the room and to leave immediately. By now I was in a state of panic and turning and twisting my head this way and that, regardless of the sharp, shooting pains this resulted in, and then finally with a superhuman effort I feebly lifted my arms and somehow managed to push out the tubes that the physio had been forcibly holding down into my mouth. Ah! the relief of being able to breath again, immediately and freely! The physiotherapist left in a huff. I was so terrified she'd reappear the next day to once again "do her duty" as she put it, that later in the day I begged another of my aunts, Feroza, a formidable lady, to explain to the authorities and press them not to allow this physio to come anywhere near me! She obviously succeeded in convincing the physio not to "force" herself on

a patient who was so frightened of her, because she never bothered me again, and another kinder and more competent physiotherapist treated me for breathing exercises the following day.

A couple of days later, the cut on my throat started bleeding and when this was pointed out to the hospital doctors and nurses they brushed it aside as being of little consequence. However the bleeding would not stop and finally with great difficulty a house-surgeon was located by one of my family members. He breezily stopped by for a while and said it was not an urgent enough matter to inform the surgeon who had operated, but he did try to stop the bleeding by pressing down on the spot where the blood was gushing, counting the seconds on his stop-watch, saying this was the 'three minute technique' of applying a so-called tourniquet on the area which was bleeding, and in ninety per cent of cases it usually worked. However he did mention that just sometimes this technique did not work, and a clot may form instead. I must have been amongst the ten per cent of cases where this technique did not work, because slowly slowly the blood which was oozing outwards in the beginning, started to flow internally down into my gullet, where it finally clotted. The consequences of this, we were to later realise, nearly cost me my life.

Perhaps it may have been best if it had, for indeed life just then felt horrible. It was a nightmare. It was like being a new-born infant - utterly helpless and at the mercy of others, having to be looked after twenty-four hours a day. What kept me going in those early days of shock, fear and horror was the tremendous surge of love and compassion I could sense was emanating from all those caring people, both friends and relatives, surrounding me and supporting Sarosh, Reshad and my mum by extending every sort of help they could possibly give us. There was a round-the-clock vigil by my bedside and they dropped their work, their daily routine, their other personal commitments and rushed around from morning till night helping us get things organised in the short time available before our imminent departure for England. (Thank heavens for their

constant vigilance at my side because the nursing staff at the hospital were sadly lacking in attentiveness).

I suffered from horrific nightmares when I slept. I would suddenly hear loud screeching noises in my dreams and feel that my body was being ripped into two pieces. This nightmare recurred again and again and I would wake up trembling with fear. I felt and said in my moments of utter despair that life was a bitch and kept wishing I had died instead of living on as a 'cripple' - completely dependent on others and without any movement except a feeble one in the biceps of my arms, neck and head. However my friends kept assuring me that my mind was sharp and urged me to refrain from expressing such dark thoughts but to think ahead of the future and my imminent departure to England and getting my neck and back straightened out with operations and then a rehabilitation to learn to live life as independently as possible. A part of me accepted this - knowing that my mind had remained razor sharp, despite my 'mangled' body, and it was slightly comforting to think that I'd be able to continue to move around in mind - both in the written and spoken word - despite the intense frustration of being confined in body.

I remember the one who thought of explaining my condition to me with honesty and directness. It was my uncle Ruzbeh, who is a doctor and he explained to me that my spinal cord injury was complete. The cord within the vertebrae being as delicate as marrow within a bone could never be pieced together again, so sadly I would never be able to walk again, nor regain my continence. Needless to say I'd guessed that already, but he explained the truth of it so well and knowing my personality, he was confident I'd not be drowned by this daunting thought, but would, with the rehabilitation I'd be getting in England learn to live constructively and joyfully once more. He said he knew I had the grit to face up to living in a wheelchair, with the same grace and courage that I'd shown in my living until this period of time. This he said he had seen from the day he'd set eyes on me as a new born infant! His words fortified me as

no other words uttered by well meaning friends and visitors, who assured me this was only a temporary state and that they were sure I'd walk (and ride) again one day. Being the realist that I am, I preferred his straight talk and blunt kindly honesty. I knew I'd survive - in a wheelchair. Being an extrovert by nature, I come alive in the company of people and wither away when left to my own devices. Even in the miserable state that I was, I appreciated having so many of those I loved, always around me. There were others behind the scenes like my sister-in-law Bapsy, who was doing all the outside leg-work, organising and orchestrating with many other well-wishers many of the technical details and making arrangements for Reserve Bank loans to enable me to travel abroad as fast as possible. She shone out like a beacon with her great zeal in so many different ways, and in her tremendous support to us at that time.

Then finally the neurosurgeon from England, Michael Powell arrived by my bedside and relief of reliefs, he speedily fitted me with a neck collar which was different from all those collars I'd been forced to wear, which had been hard and inhuman contraptions of absolute torture! He strapped me up in this collar which eased my pain and extreme discomfort instantly. He examined me and asked me questions, my replies of which he lip-read as I couldn't speak. Indeed I had become quite adept at exaggeratedly mouthing what I wanted to say and Reshad (who was also accompanying me to England along with Sarosh) was the most adept of all in interpreting what I wanted to say!

Michael (with whom I was already on a first name basis, so friendly was he), was taken home to have lunch and refresh himself whilst I was resting. My nurse said she would like to have a half hour lunch break and I remember my cousin Dinaz sitting by my bedside, munching sandwiches and keeping vigil. It was a quiet, peaceful afternoon and I was mildly dozing when suddenly I felt short of breath, a sort of choking sensation. (This had become a fairly common occurrence ever since my tracheotomy, because saliva and liquids flowing into my trachea caused me much discomfort and breathlessness, relieved only after

the saliva had been suctioned out of the trachea by one of the nurses or doctors). The nurses when alerted, tried suctioning the fluids out of my trachea, but this time it failed to work. Things were going badly wrong. I fought for breath. I felt I was losing my hold on life.

Two or three hospital doctors and assistants had materialised by this time and they all tried hard (apparently with different instruments, called bellows) to clear my lungs which seemed to be collapsing. I gasped for breath and as my breathing grew more and more shallow I felt myself sinking. There came a point when I had almost stopped breathing. I could hear myself rattling and wheezing. (I was told later that I had turned blue). I seemed to be in two worlds. One, fighting for my last breath, with a terrible heavy feeling on my chest, knowing that these seemed to be the last bits of breath I would be drawing on this earth. Another part of me was in a dream world of thoughts. I thought of my daughter Simonil, who was away in university in America and who I hadn't seen in many months, but who I'd been told, was on her way to England to meet me there on our arrival. I remember thinking I must somehow hang on and survive this nightmare or I would never see her again. I kept instinctively struggling for my last bit of breath even though my breathing had turned absolutely shallow and it had become a pain to keep trying to stretch out the tiny gasps of breath I was still managing to get into my lungs, but still I struggled on. I thought of Sarosh and Reshad and my mum, and fought on, thinking of them. I was told later by my doctor friend Furrokh, who was present at the time, that the persistent use of the bellows, by him and a very competent hospital doctor, forcibly pumping air into my lungs, apparently helped keep me going. Without this desperate action on their part, I would not have survived as long as I did before help came in the form of Michael Powell. A fierce battle for the life and death struggle was going on within me. One of my thoughts during this ebbing and flowing of my life was, "I don't think I'll make it. So now I won't be flying to England for life-giving treatment - but I'll just die a sordid little death in this

crummy little hospital in Bombay." Later I was told that they had hastily summoned Sarosh and Reshad, who had dragged Michael out of his shower at home, and in the meanwhile everyone had gathered round my bedside, many of who were weeping, thinking I was past saving.

Whilst I was fighting for my breath and my life, insidious thoughts kept creeping into my head. On the one hand I was grimly and instinctively fighting for survival but on the other hand I recollect saying to myself, "This is your chance to give up the ghost gracefully and instantaneously. Stop struggling for breath. Give it up and die in peace, because if you survive this there will be great hardship in store ahead. You will be paralysed for life and undergo great suffering. So just give up. This is your one chance to slip into death easily. Later you will never get this chance again, so give up, give up, give up." Another thought that kept coming to me was that I'd led such a full and happy life so far, packed with so much travel and adventure and pleasure with my family, that should I die right now, I would not regret having missed out on life's experiences and joys. However another part of me fought on, disregarding these tempting thoughts, and saying to myself, "If I give in, I will never again see Sarosh, Simonil and Reshad, or be able to do things together with them. That is unbearable!"

So the struggle within me went on, seemingly endlessly and painfully, till I lost all consciousness - when suddenly I surfaced once more, slowly coming back to the present and to the living and I remember I felt myself smiling and calling for Sarosh. My breathing had started easing ever so slightly. I returned to the present world extremely gradually and saw faces around me, anxiously looking at my inert body. Michael was looking down on me with X-Ray machines and gadgets of all sorts surrounding us with bright and blinding lights overhead, shining fiercely upon me. He was bending over me, pressing suction tubes down in to my trachea and throat, and I knew I was over the crisis since my breathing had eased and the terrible weight on my chest had lightened. I feebly called for



Sarosh once again and Michael moved away telling Sarosh, "Your wife is asking for you." I saw Sarosh standing by, looking rather dazed, I thought. (What agony of spirit he must have just gone through, only his tormented soul would really know. And I knew - because given the reverse circumstances I'd have felt the same torments and agonies of hell, that only two people who loved each other as we did could ever feel). He came up to me, and pressed my hand and smiled reassuringly at me.

We later discovered that it was Michael virtually, who had saved my life as he had brought along with him an extremely thin variety of suction tubes which the hospital in Bombay apparently did not possess. Thus it was that Michael, on seeing my condition, pulled out the thinnest of suction tubes from his paraphernalia, like a magician pulling out rabbits from a hat, and swiftly and efficiently worked down my gullet and trachea suctioning out all the matter that had congested there, and I was told later that only when a huge clot of blood shot out, splattering all over my hospital gown and midriff area, that my breathing started up again. Later I often wondered in my despair of paralysis, immobility and helplessness whether it would have been better if the thin suction tubes had never been brought to India.....

The time for our departure to England finally arrived. I saw my mum's face looking small and pinched and very very troubled. I realised then what a brick she'd been in her own quiet way, seeing to my care and well being with such loving devotion and attention, regardless of her age and herself. Being a mother myself, I could empathise with her anguish at having to see her carefree, vibrant, willful and life-loving daughter (she usually described me as such) so pathetically down and under.

I was frightened and awed and suddenly a thought occurred which surprised me, and that was that I hadn't wept a tear since my accident, despite my dark despair and wish for death. The tears had just not flowed. Presumably my body was in such a state of shock, all tears had dried up.



The ride in the ambulance to the airport was very rough as the Bombay roads, true to type were full of hideous pot holes and the rather primitive ambulance (the stretcher on which I had been put was laid out on the floor of the ambulance) was in pitch darkness and seemed to be moving at snail's pace particularly since I was in great discomfort and pain with the bumpy ride. It seemed to take forever to reach the airport where they lifted my stretcher up in to the plane by a fork lift. The stretcher was then placed on one side of the plane which had been curtained off and isolated from the rest of the passengers.

Whilst dozing in the plane, though I was heavily sedated, my mind was whirring non-stop and it helped when Reshad who was constantly attentive, and didn't sleep a wink, read out a letter (which I have kept) written by my Uncle Ruzbeh, for me. I remember he wrote, "You have met with an accident and got hurt. Now what is the next step? It's to give you all the best possible available medical help to get you up once again as you were. Because you are vivacious, active, courageous, honest, gutsy, never afraid to speak out, sincere and above all always ready to try and give a helping hand to those in need. So I say Shanoor, "fight" against all odds, and reflect on the spirit of Zarathushtra, from who you have descended.

One of the things he said was, "The mind is the most important part of the body. Develop it. Sort out the good from the evil and follow the path of goodness, and at the same time expose the evil. Fight the evil and destroy it." - Shanoor, you and I often fight with words. Sometimes harsh, but it is a loving fight. But now you have to fight the enemy. Your disease. Defeat him and destroy him. It will require courage, patience, will, determination and all you've got, to defeat paralysis, but I am absolutely confident you shall succeed because you have inherited all that is required to defeat this disease. So resolve and you will succeed. What if you have no power in your body below the level of the chest? You have the brain, strong shoulders, a fiery tongue, sound eye sight, excellent hearing, knowledge, intelligence, character and culture. You shall be

of tremendous help to many - and an inspiration to all when they see you helping others in your own way. Your father Porus, who was poor and worked hard because he hated poverty and did not spend on himself but left it all to you so that you may never be in want as he was in his young age. So make use of the inheritance he has left you and do not feel that you are a burden to anyone because you are not, since it is yours and for you, as it is clear from his Will..... I shall always think of you and feel proud when I see you back with excellent results achieved by your own effort and helping others with your experience and knowledge in spite of your disability....."

Reshad seeing that his reading aloud of this letter soothed me, continued to read to me a poem a friend of his had given him for me and which comforted me in its own way. Something called Footsteps in the Sand:

"One night a man had a dream. He dreamt he was walking along the beach with the Lord. Across the sky flashed scenes from his life. For each scene he noticed two sets of footprints in the sand. One belonged to him, and the other to the Lord.

When the last scene of his life flashed before him, he looked back at the footprints in the sand. He noticed that many times along the path of his life there was only one set of footprints. He also noticed that it happened at the very lowest and saddest times in his life.

This really bothered him and he questioned the Lord about it. "Lord, you said that once I decided to follow you, you'd walk with me all the way. But I have noticed that during the most troublesome times of my life, there is only one set of footprints. I don't know why, when I needed you most, you would leave me."

The Lord replied, "My precious precious child, I love you, and would never leave you. During your times of trial and suffering, when you see only one set of footprints, it was then that I carried you."

I recollect that after Reshad finished reciting these lines out loud to me, I thought to myself rather wryly, I'm an atheist- humanist, yet I feel so comforted and soothed by these words. I do not personally believe in the 'conventional' God or the Lord as a great King with shaggy beard and eyebrows, holding court in the sky that determines your fate or grants you your wishes when you 'pray' to him. However I do believe, in GOD with a double O. Good - The goodness in people, the goodness in animals, in birds and plants and trees and to be in tune with nature and not get out of synch with it. I'm firmly against bigotry, fundamentalism, superstition and dogmatic beliefs, rituals and doctrines. From my learning and interpretation of Zoroastrian thought I believe one should be non-judgmental, kind to others and compassionate towards people and ideas differing from ones own, and my faith (from Zoroastrian origins and beliefs) is a religion only of the living, by the living, and for the living. Life is a fight for existence. Enjoy it! Relish it! Zarathustra the man, (not the deified god that men have made him into), Zarathustra loved life. His was an immense affirmation of life. So is mine. I have faith in the universal GOOD that is in the Human Spirit, which is unquenchable. - And my interpretation of this little moving poem read out to me by Reshad fit in perfectly with my way of thinking. That all these wonderful loving people around me - one by one in turn - had lifted me up and carried me out of my worst despair and horror, and into their care and help and the God that is spoken of, is the Good in each 'human' one of us, ever ready to come forward and perform super-human efforts to help ones fellow man. THAT is the essence of all existence and all of Nature. And I felt I was in the best of hands. The most loving and the most kind. That of the Human Race.

Whilst lying there dozing on the stretcher in the plane I thought of all the sacrifices my family was making for me. Albeit we have always been an extremely close-knit family unit, and they did not, I am sure even think of the word sacrifice whilst they were instinctively and automatically performing their

hundred acts of love for me. Sarosh, being a Psychoanalyst, just giving up his practice at the drop of a hat. Reshad by coming with us to England was giving up his studies and final B.A. preliminary exams with the probability of having to sacrifice a year of his academic career. And Simonil, dropping her studies in America, even though she was under great economic pressure, and flying over to London to meet us there. A lot of friends and family generously chipped in with large sums of money and even larger sums as loans to help contribute towards all the horrendous expenses we were undergoing for this life saving venture. Many others ran around, frantically urging Trusts and getting contributions from them to help boost our financial recourses, without which all this would not have been possible. It was like embarking on a downhill slide without brakes. Something that just had to be done without thought. Everyone around me had given up so much of their time and work to ease matters for me. It was all a labour of love and in the midst of my helplessness and wooziness, I felt warmed and touched by the wonder that is mankind and of the proof of the heights of which he is capable of reaching. It felt good to be loved. And I did believe at this moment that though there was much to live on for, I still was not afraid of death if it should strike me now, for I really had no regrets but plenty of rich and lovely experiences stored up.....

Then suddenly the weather became rough and awakened me from my dreamy state with an unbearable pain in my neck. Reshad immediately held my head steady with Sarosh stroking my forehead to try and ease my discomfort. Michael stood by, checking on things and reassuring me that there was nothing to worry about.

It was rather an uncomfortable flight but we finally arrived at London Heathrow Airport and I was whizzed through immigration and custom's formalities without a hitch and as fast as everyone could possibly manage. My cousin Meher, a resident doctor in England had been permitted to come right up

to the tarmac and greeted me warmly and lovingly, and helped in shifting me to a waiting ambulance.

Then I heard swift running footsteps and was delighted to feel the arms of my daughter Simonil round me, kissing me and saying, "Hi! Momma" in her loving cheery voice. I had been waiting for this for so long since I hadn't met her for some months and I noted with pride that she was looking very chic in her blue beret and light make-up. My darling daughter, my pride and joy.

When all the formalities were completed we were ready to move on to the Humana Wellington Hospital to where we had a smooth ride in the ambulance (a far cry from my ride to the Bombay Airport on the floor of the bumpy ambulance and rough roads of India). I was taken to the Intensive Care unit straight away and washed and cleaned and made comfortable in the very capable hands of the nurse in charge and I remember feeling at this point a little easing of the spirit and a bit less on the precipice between life and death ever since my existence had been taken over by the accident. Sarosh, Simonil and Reshad stayed glued to my bedside, patting and comforting me and trying to ease my pain and discomfort as best they could. The three people I loved best in the world. Their very presence was my comfort and solace.

The next day Michael performed a major six hour surgery on me whereby the dislocation and fracture of my cervical sixth and seventh vertebrae was set and fused by inserting steel tubes around my spinal column. I remember emerging from the effects of the anesthesia in an extremely irascible and depressed mood. I had this horrible angry feeling of being completely abandoned. I scolded Sarosh and my two children for nothing at all and they felt quite bewildered at my unjustified lashing out at them like this. Emotions of such intense rage and subsequent sulking (specially over such piffling matters) are usually so alien to me, I must have really been awfully traumatised by the operation to have come out of it feeling and expressing myself like this. They all understood and sympathised with the obvious strain I was under and gently

cajoled me out of the terrible state I was in. Sarosh said I was not myself at all and was raving and rambling, speaking incoherently most of the time. I was also suffering from terrible nightmares of huge inanimate objects, like giant-wheels and immense gigantic watermelons and colossal statues of Donald Duck being split into two with jarring noises and I would feel that like these gargantuan things, I too was being cleaved into two at the same time.

Two days later Michael performed yet another four hour operation whereby bone was grafted from my hip onto the vertebrae of my upper back so as to stabilise and firm my neck further so that I need not rely only on the steel braces, which without this fusion of bone, had a likelihood of coming loose at a later date and may have necessitated another operation. I remember emerging from the haze of anesthesia and seeing a jubilant Michael triumphantly showing me the X-Rays and telling me with immense pride and pleasure what a perfect success the operation had been and what a fine fusion it was. I smiled at him gratefully and thanked him for all his personal interest and care and thought to myself, "How 'human' he is, and what a lovely man." He had virtually saved my life by his timely intervention in my life-and-death struggle in that frightful hospital in Bombay and fortunately for me (and because of Sarosh's burning one-track thought and action of sending for him) had been in the right place at the right time, or else I'd have been a dead duck. It was he who had given me my second chance of life, and at the time I was not sure I even appreciated it, I felt so miserable and downtrodden.

The Humana hospital had very flexible visiting hours and I was lucky to have tons of friends and cousins (who luckily for me lived in London) dropping in on me the whole day through. Even in my half comatose state of those first few post operative days, I enjoyed the sense of having plenty of close family and friends flitting around me. On the fourth day Michael said I must be put in a wheelchair and go for walks in it. So my enthusiastic husband and children trundled me off in a wheelchair (with my neck hanging down on my chest

horribly, because the muscles around it had become weak and traumatised). I gingerly started returning to the land of the living. When in bed I had to be turned from side to back to side every three hours to prevent bed sores. The nurses kept a watch at night and it was quite a ceremony each time I had to be turned as I was dead weight and it took two nurses to physically lift me and expertly turn me into the proper position.

After this ritual was completed, I was always made to sip a glassful of water or juice to get me into the habit of continually drinking liquids since this was another important thing for me to do round the clock, for prevention of kidney stones which could cause immense damage since the twenty-four hour catheter inserted into me, could easily create kidney problems if enough fluids were not imbibed by me continually. So practically from day one these two directives became a part of my future existence. As important for my survival as breathing, which in fact was the third house-rule for the present and future. Keeping my lungs as clear as possible without any chance of infection - and avoiding getting colds and coughs as much as possible. (In fact a major part of my physio-therapy at the Humana was breathing into some complicated looking apparatus rolled into my room twice a day, so as to clear my lungs completely of phlegm, which in the beginning used to keep plaguing me for long periods of time. My chest muscles being paralysed, I couldn't bring it up and out on my own and had to be assisted in coughing by the nurses and my family all the time).

My cousin Joy, a doctor in Los Angeles, specially flew down to London to be with me for a week or so. I was so touched by this thoughtful action of hers. I was at my most crumbly state during those days. I kept feeling life wasn't worth living and very morbid thoughts kept whisking round my head. And I just wanted to die. Everyone tried cajoling me out of these blue moods. They told me it would be abnormal for me not to be feeling so at this early stage of my injury and that depression was the first step in the healing process and that I would get through it and overcome it, as they felt I was strong willed enough to



do so. One day Sarosh found me lying prone in bed and staring into space. He stroked my cheek lovingly and tenderly and that whispery brush of his touch, broke all the dams within me, and suddenly I wept - the first tears since my accident. The strange thing is that despite my horror, terror and depression since my fall, up until this moment I had not wept at all. I cannot explain this but I was unable to weep for myself - even though I did feel very sorry for myself.

My first physiotherapy session (at the Humana) started when a bright and cheerful voice greeted me one morning saying she was the physio assigned to me and would be attending to me one hour every morning and the same in the evening. Her name was Pippa and she moved my arms and legs around, got me sitting up properly in a wheelchair and showed me a few exercises to do daily. I found I enjoyed the diversion of these exercises and would force myself to make that extra effort to do them even on the days when I was feeling particularly unwell and I found I was well rewarded for my instinctive determination, for never once did I fail to feel the better for that extra push I'd given myself.

The next step was that Michael contacted Dr. Hans Frankel who was one of the Senior Neuro-physicians at Stoke Mandeville hospital which was world famous for its spinal injuries unit and was known to be the last word in rehabilitation of paraplegics and tetraplegics. He examined me thoroughly for about two hours asking me many pertinent questions. After the examination was over he looked me straight in the eye and told me he felt that one day I would be able to lead a fairly independent life - be able to swim, use a word processor, write, probably drive a car and even ride if I wanted to! I must have looked extremely skeptical because he then told me, "I can see it in your eyes - you'll make it." And somehow I suddenly believed him.

So it was decided by all of them that I would be moved to Aylesbury where the Spinal Injuries Rehabilitation Nursing Home run by a very enterprising businessman called Dr. Clarke, was situated, many miles away from London, right in the heart of the most beautiful English countryside. I felt like a leaf



being helplessly tossed hither and thither at the will of the wind, unable to take charge of my destiny any more. I felt this was my fate ever since the accident.

This small cosy Nursing Home cum Rehab Centre had a very cheerful atmosphere and the nurses who came in to attend to me were extremely friendly and cheery and comforting.

I was still too frightened to stay alone in my room at night specially since my flailing arms were so uncontrollable and because of which I could not press the call button for the nurse however hard I tried, so Sarosh and Simonil decided to sleep alternate nights in my room. (My first few nights were extremely restless and stressful and I woke them up several times to call the night nurse to turn me and ease my pain and fright).

The next day I remained in my room and several of the other patients breezed in on their wheelchairs, introduced themselves, and told me I wasn't alone in this, and must keep courage. What felt very good about being here was that this place was only for spinal injured persons, all in wheelchairs and all rehabilitating together. Thus living day in and day out with tetras and paras all in the same Rehab Nursing Home together gave great emotional support to me and my family who were with me all the time. All the patients and their few family members who lived here, ate together, exercised together, shared each others' experiences together, moaned and wept together, and laughed together. The emotional acceptance of my ghastly condition, became a little easier, since I started feeling, "I am not alone in this". We would chat and tell our stories to each other. There were many who'd had worse accidents than mine. Some had been in car accidents and had survived with broken backs, only to be told that their spouses and children had died on the spot with the impact of the accident. Not only had they to cope with their own paralysed helpless states, but also with the deaths of their loved ones. They were utterly alone. At least I had my husband and family who supported me. I felt I was so much better off than many of them.

After a couple of days I was taken to the Physiotherapy room where there seemed to be quite a lot of activity going on. I was introduced to the head physiotherapist called Ruth. She was very plump, but seemed strong and vital. Then there was Elizabeth, tall and smiling and serene; and Heather, jocular and full of life jumping around excitedly demonstrating some movement on the floor on a mat beside a very reluctant Arab man who was shaking his head woefully. They were conducting a physiotherapy session instructing the patients, animatedly performing various exercises, some of whose arms and legs were strung up with various types of gadgets hanging from the ceiling and against the walls. Ruth immediately took me under her wing and started me off on a few mild exercises, never pushing me beyond the impossible but encouraging me to stretch myself to the fullest limit.

Sarosh and Simonil joined in, sat around, and encouraged me, also sharing the coffee and biscuits handed around to us all by the physiotherapists during the coffee break. I felt helpless and frightened by the strangeness of it all, and very thankful to have my husband and daughter within sight and calling distance! It was a very friendly informal atmosphere and I was introduced to the other patients who I hadn't met before. Hashmet and Hussain. Hashmet was a young lad of twenty-one and was from the border area of Pakistan. He told me he was working in the customs department and had been shot in the spine during a raid and a subsequent shoot-out, a week before his marriage day. A partial paraplegic, he was always in great pain and later I found out he had a drinking problem. He would smuggle in whiskey with the connivance of taxi drivers, after a night out at the pub near by, and get roaring drunk, and for this reason he could not be given pain killers and would scream and bang against the walls of his room, in great agony. Because of this he was constantly under the vigilance of the nurses who would try and squirrel out all the whiskey bottles he'd hidden under his mattress and pillows!

Hussain was from Jeddah and had been climbing a palm tree, from which he fell, shattering his spine. He kept repeating he was much too young (at twenty-five) and in the prime of his life to have this terrible fate befall him.

They were all paraplegics and I envied them the use and strength of their arms, shoulders and fingers and their full upper bodies above the waist. I was so much more helpless than they were, being a tetraplegic and having no strength in my arms, hands and fingers, which were lifeless, although my thumb and first finger had some sensation. My chest muscles also being paralyzed, I could only breathe through my diaphragm.

And so began a routine whereby I would be woken up at 8 a.m. and for the first few days be sponged by the morning nurses, but some days later, I was lifted in to my shower chair which was wheeled in to the bathroom and showered there. In the beginning I felt terribly dizzy so I was then given a pill one hour before the shower which succeeded in stopping the world going round and round every time they tried to sit me up from my reclining position. After the nurse had showered me in the bathroom I was wheeled back in to my bedroom, lifted in to the bed where I would be given a bladder wash as I had a suprapubic catheter inserted in to my tummy area (which had entailed a minor operation at the Wellington hospital a few days before I was moved here. A catheter had been attached to my bladder after making a tiny hole below my navel). This also meant a dressing having to be put on that hole every morning for ever after!

Then the nurses got me in to my track suit which was the regular 'uniform' of all the patients. Followed by breakfast in bed, fed to me by Sarosh and Simonil, since I could hardly lift my arms and had no grip what so ever in my fingers to grasp my spoon and fork. I was then hoisted back in to my wheelchair and rolled in to the physiotherapy room where I remained from ten in the morning until one'o clock in the afternoon. Lunch was fed to me between one and two, and then back to physiotherapy until four-thirty. For the afternoon

physiotherapy sessions I was always put on an upright stretcher like table, which could be raised or lowered, called the Standing Table.

The purpose of this was to stretch my legs and allow my blood to flow down in to them. Once I was strapped firmly in to it, the physios would gradually jack it up to go higher but if it was raised too up-right, I always felt dizzy and the physio in charge would lower it once more. Whilst I was stretched up right on the Standing Table, Ruth, Elizabeth, Heather (and Sally who came in the afternoons, part-time), would be attending to other patients and giving them individual exercises, chattering and kidding around all the while, making us laugh and talk and forget our depressions over our helpless bodies. They made physiotherapy sessions such fun and so interesting, that the time just flew!

At four-thirty I would be wheeled in to my room and in to bed to rest there for a while with Simonil or Sarosh either reading to me or writing letters for me which I dictated to them at a fast speed! I received at least five letters a day from friends and relatives from all over the world, the majority being from Bombay. I would avidly have them read to me as I could not hold them up in my own hands, and then would slowly reply to them, on an average of one or two a day.

Fridays was Swimming day and my friend Perin had come visiting. So Ruth, Heather and Elizabeth took us all in our wheelchairs to Stoke Mandeville Hospital, where there was a special swimming pool for the disabled. Simonil came along with me in the very large van which had a fork lift attached and which would heave up all our wheelchairs one by one. It was very early days for me to start swimming but I wanted to see the famous Stoke Mandeville hospital and have an outing. My very first outing since I'd entered the Spinal Injuries unit.

Stoke Mandeville appeared to be a huge hospital on very large grounds and the Spinal Injuries Unit there seemed extremely posh and had been sponsored by Jimmy Saville, a well known T.V. personality who took a keen interest in its functioning. The swimming pool was in a very large enclosed area with beds in curtained cubicles. The patients were changed by the physios into their swimming costumes in these beds, then wheeled to a fork lift gadget by the side of the swimming pool, lifted in to this hoist like contraption, and then let down gradually into the pool. The patients always had rubber rings and arm bands and different types of chest floats to keep them well afloat. I was petrified at the thought of the day when I would have to swim as I felt so weak and vulnerable at that moment, even though I used to swim very regularly and be very fond of it before my accident.

Whilst the other patients were swimming with the help of the three physios, Simonil and Perin wheeled me around the hospital, the three of us taking a keen interest in every thing around us, since I would be moving there one day when a vacancy came up as Dr. Frankel had promised. It seemed to me like a giant factory of patients, wheelchairs, rooms, corridors and wards. I felt overwhelmed by the hugeness of it and what to me at that time felt like the 'impersonality' of it in comparison to my safe little Nursing Home with only around six inmates in it where very personal attention and time was given to us by the nurses and physiotherapists. At that moment I reached the pits of despair at my weakness, and at the hopeless vulnerability of my existence. Perin saw my distress, and I recollect, she threw her arms around me and hugged me long and hard, saying, "You will never be alone. You will always have loving people around you. Don't be afraid."

I felt like this because this was no more the safe little nursing home where I was rehabilitating but a huge impersonal hospital which symbolised that one day I would have to move out of this safe little cocoon I was in, into the real world. Dr. Frankel had conveyed to me that after a couple of months it may be beneficial for my progress to move into Stoke-Mandeville Hospital so as to become more independent in a larger more impersonal setting which would get me ready for the "outside world".

Thus the days of my routine-of rehabilitation continued at my nursing home. My body flopped like a rag doll when lifted and I felt utterly dehumanised because of this but everyone assured me that after six months with the intensive physiotherapy programme I was receiving, I would be a different person. At the time I did not have much faith in what they said but because the nurses and physios were so encouraging and dedicated, and coaxed me to give my all, I was most regular about going to my physio and swimming sessions. I enjoyed them thoroughly because it meant exercising my body which I had always done before my accident, being a very sporty person. So this sudden breakdown of my body and lack of control over it was very humiliating for me, having been so independent before.

Then started the shivering fits. I would start shivering from early morning and continue throughout the day at intervals. (No doubt England in March was colder than the climatic conditions in Bombay). This shivering was a disorder of the temperature control in my body due to my shattered spinal cord and the very weak, tense and anxious state I was in. Incidentally I was told by the doctors that this condition of shivering was very common to all tetraplegics for the first six months to one year of this injury. My teeth would chatter and my body shake uncontrollably no matter how many sweaters I wore. This would drive me mad and I would think that this was worse than the paralysis. The shivering would only stop during physiotherapy sessions. Presumably because of the vigorous exercises, my blood flowed freely and warmed me.

Slowly, slowly I gathered strength and the physios and nurses suggested we buy a second hand electric wheelchair so that I could step out together with Sarosh for walks on the beautifully paved streets of Aylesbury. Very often friends and cousins would come visiting in the evenings and walk with me beside my wheelchair and we would go to parks and pubs and enjoy ourselves.

Once on our way home from the pub, I got a bit cocky, and got so exhilarated with the speed of my wheelchair, I must have been going too fast and hit a stone, for I was thrown out onto the pavement. Everyone panicked and I was terrified but they bodily lifted me up and heaved me up back again into my wheelchair. It taught me to be more careful next time.

Days rolled by in all these different activities and I was slowly but surely absorbing from the whole atmosphere of nursing and physiotherapy and patients and swimming and outings and picnics arranged by the physios, to start coping to live as a tetraplegic, wheelchair bound for life. The nurses taught me and my family how to deal with incontinence which also is a part of tetraplegia. They taught me with great compassion and personal interest, that I should not feel helpless and undignified because of my incontinence. In my daily routine they taught me to cope so well with incontinence problems, that it practically caused no inconvenience of bowel and urinary accidents, and no one would ever suspect that I was incontinent. They instilled into me and my family the utter and absolute importance of hygiene so that no infection could occur, since having a catheter makes one prone to infection. They taught us to how to clean the urinary leg bags every night and morning in disinfectant solutions, and to have regular bladder washes which they trained Sarosh to give me twice a week. They also taught him how to change my supra-pubic catheter once a month. They saw to it that I was forced to drink three to four litres of liquid per day, to prevent infections. They told me I should never let up on this but relentlessly keep drinking every one hour.



of my life. This has stood me in good stead in enabling me to lead a very active working and social life now, even though confined to a wheelchair for life.

Another thing that they drummed into me which was vital to my care management was to avoid very close contact with people who had heavy colds since it was vital for me not to catch colds and coughs as my chest muscles were paralysed and I could not cough up any phlegm which would then slip in to my lungs and lead to pneumonia. In fact the physios taught Sarosh how to press my chest and abdomen and help me cough up and out if ever I needed to do so, since otherwise I would choke. This method is called the Heimlich Maneuver which is basically an "abdominal thrust". Prevention of coughs, colds and flu is also helped along by the vaccine which is available only in England and U.S., which I try to take once every year so that I am relatively free from chest infections.

The physios and nurses then began encouraging me and Sarosh to step out a bit on our own, so Sarosh hired an old car and Ruth gave us demonstrations of "The Standing Transfer" which enabled Sarosh to lift me up and out of my wheelchair into the front car seat, entirely by himself without straining his back muscles. It took a lot of practice sessions for Sarosh to learn to do this the correct way, because it wasn't easy! Sarosh's niece Havovi, had kindly flown over to England to be with us at that time and we all took plenty of outings, together with my mother who had also come to spend time with me, and despite her age and 'frailing' health remained with us giving us all moral support, till the very end of our stay there. We made many trips into the countryside with my wheelchair stowed away in the dicky. We even went to the movies together and to restaurants. In fact, earlier, since my fingers were paralysed and the arm muscles very weak and uncoordinated due to the trauma of the accident and operations, I had to be spoon fed which was very ignominious for me. However Ruth encouraged and pushed me to start trying to eat myself by equipping me with leather palm straps which had slits in them to fit in the spoon in one palm and the fork in the other and slowly, with immense practice and



determination, I started feeding myself. I also could not grip a glass in my hand so they insisted I hook a thumb in the handle of an insulated mug, which they provided (which would prevent my skin from burns when I drank hot coffee or soup). This paid dividends when we visited restaurants and friends' homes for dinner in the evenings.

As the days went by, I started absorbing new ideas from the actions of the other patients who were also an inspiration to me. I was getting stronger and stronger and every small thing I used to do was an achievement, such as reading a book by myself, by supporting the book against the table and clumsily holding it down with my hands and with great difficulty turning the pages. They also brought me a wheelchair which was extra light and made me practice daily to push the wheels by myself.

They drummed into me the fact that I must "stand" (propped up in a Standing Frame) for one or two hours every day, three-sixty-five days a year, if possible. Dr. Frankel who visited me once in fifteen days and also who liaised with the physios, gave me lectures about the importance of standing propped up in the Frame every single day. He said this would enable the blood to flow freely down into my legs, through the kidneys, and the weight of standing on my legs would keep the calf muscles toned. I have never forgotten this lesson and even though I now lead a very full and busy life, I still make time to stand every day in the Standing Frame; either watching T.V., or reading a book, or chatting with friends or running my household.

Having been an active and "physical" person, this enforced paralysis was practically impossible to accept, though the more I fought it, the worse I felt. Everyone around me, told me that it would be easier with the passing of time and Ruth said it was like grieving over the death of a loved one and it would take about two years for acceptance to come because it was a kind of death of my limbs and major parts of my body. She always encouraged Sarosh to hold me and hug me, forbidding him to treat me like delicate china! She said people

didn't realise, but being wheelchair bound, one could get so easily isolated from the 'human touch' of others.

Then came the call for moving me to Stoke-Mandeville Hospital since there was a vacancy there and both Dr. Frankel and Sarosh felt that graduating to larger more impersonal surroundings might toughen me up a bit and thus make me fitter for the "real world." I was immediately thrust from a small nursing home of eight patients into three floors of hundreds of patients in wheelchairs, bustling all over the place. Although the staff here was very motivated also, they obviously did not have the one to one relationship or huge amounts of time for each individual patient. It was like graduating from my safe little K.G. class into senior school. Very scary but very necessary for progress! This place taught me DISCIPLINE and PATIENCE. Very often I found I had to wait for the nurses to come to my assistance, since they had to attend to many other patients as well. I used to gnash my teeth in frustration and rage but these are the frustrations which are necessary for a tetraplegic to learn to control as fast as possible for her own good. I learnt very early on here, that impatience with helpers and attendants would get me nowhere; instead a smile and a polite "please" and "thank you" would make them move mountains for me. My motto became "Laugh and the world laughs with you, Cry and you cry alone."

Here, each of the patients was given a timetable (like a school timetable). We had to be ready and wheel ourselves to the correct "classes" at the correct time. There was a huge Occupational Therapy Department which I revelled in. Since I'd been a secretary all my life, I opted to learn typing and attended my typing classes religiously, where I had to learn everything from scratch from the Pitman's Typing Book. The occupational therapist equipped me with straps and sticks bound to the palms of my hands which enabled me to tap the keys. I then progressed to the computers and since I love writing, took to it like a duck to water. This class would be in the mornings from ten to eleven and then I would wheel myself to the Physiotherapy Gymnasium, where the Physios were efficient

but had no time to give us their undivided individual attention. I did not feel the same warmth and interest emanating from them as I had felt in the previous place, but I soldiered on. From twelve to one was the lunch break, when my family would troop in and we would eat together in the huge dining room. Though my life was full of compromises now and though in one day I would go through intense swings of mood of frustration, anger, rage and despair, I would however also derive great joy at having my family constantly around me and we did have a lot of fun together.

When I looked around me at the other patients I noticed that most of them had visitors only about once a week. In fact I remember an incident when one of the head social workers came up to me whilst I was sitting with my family and said "You are a very lucky person you know". I looked up very startled and wondered how she could call a "tetra" lucky. She turned around meaningfully, smiled and said, "You must know that you have such a wonderful family always surrounding you". At that I agreed with her and I thought that I was indeed lucky despite my ghastly disability to have such a loving and caring husband, mother and children, with me.

Stoke-Mandeville Hospital had other good facilities such as programmed lectures to be conducted at three in the afternoon every day by different specialists in the field of paraplegia. The formal lectures consisted of bladder and bowel care, pressure sore care, rehabilitation ideas on returning home and how to cope with life in home surroundings and relationships with family members, as well as lectures on sexual relationships with spouses. These were very interesting and full of lively group discussions. Part of this lecture programme also consisted of ex-patients who spoke to us of how they were coping with life after their accidents and the success of their own rehabilitation programmes.

One of the patients who impressed me a lot, was Barry a tetraplegic like myself, who came along with his wife who used to be his nurse in the hospital. They spoke to us about how after Barry's accident when he was rehabilitating in

the hospital, they fell in love got married and were now trying hard to conceive a baby. We were told that the sperm count of men with paraplegia, for some odd reason, tended to become very low and thus it was hard for wives of paraplegics to conceive. Barry said they were leading an active sexual and working life together and he was working with the Spinal Injuries Association. I noticed how freely everyone was discussing with him and his wife about how they were able to have sexual relations.

He told us that there was more to a sexual relationship than just having an orgasm. A loving relationship between partners even if one of them is paralysed, also naturally consists of foreplay and touching and stroking and kissing and hugging. He told us that at first when you are paralysed it seems unlikely that you'll be able to have a sexual relationship with any one. It's not unusual to be preoccupied with this thought and it's a distressing and worrying one. However, although you may have to modify or change some of your sexual activities, you can still have a meaningful sex life and continue to be a sexually active human being.

Another very helpful programme was the "Family Day". A full day was set aside for families of patients who had a day of lectures and slides on care of patients with spinal disorders as well as talks with other ex-patients. This proved a great support system to my family and set many of their apprehensions to rest about how they would take care of me when we went home. There were practical demonstrations of bowel evacuation, bladder wash outs, catheter changes etc, which the family had to practice under the supervision of the nurses and doctors.

Another wonderful idea and facility that the Hospital provided was a cottage in the grounds of the Hospital, called a "Half Way Home" with a hot line straight to the wards, should we require emergency assistance at any time of day or night. It was a lovely little cottage, decorated with pine furniture and had all the facilities of a home, complete with a fully equipped kitchen, T.V. and two bedrooms. Sarosh and I shared one bedroom, and Simonil and Reshad, the

other. We lounged around together, for the first time alone as a family, since my accident, watching T.V. and chatting and feeling just fantastic! On retiring to bed it felt good to have private moments with Sarosh and sharing close intimacies, for the first time after my accident. It was lovely lying in bed with our arms around each other and sharing moments that we could not have in the hospital surroundings with no privacy at all. It was sweet indeed to taste the pleasures of preliminary sex and I egged Sarosh on to greater intimacies than he felt we could manage, as he was prone to treat me like China glass ever since my accident.

After this experience in Half Way House, I moved out of Stoke-Mandeville Hospital as an in-patient, on the advice of Dr. Frankel and decided that we would rent a small house near Stoke-Mandeville Hospital as well near to the previous Spinal Injuries Unit where I had been first rehabilitated. I would be taken by Sarosh to the latter place as an out-patient where I would spend the whole day doing physiotherapy and practice typing and writing with an excellent gadget they had provided me with. Dr. Frankel felt that this would be the next step in 'supervised independent living.' This made us feel more and more confident as the days went by, and since my rehabilitation had been such a success Dr. Frankel felt it was time for us to return home to India.

Sarosh and I flew back to Bombay together and this time I was sitting upright in my wheelchair and had to be transferred on to the plane seat. I had a urinary leg bag attached with straps under my skirt and Sarosh discreetly drained it into a plastic urinary bottle which he then flushed into the plane toilet. He bent me forward from time to time to see that the pressure on my bottom was lightened for the prevention of pressure sores on this long eight hour journey. By a huge coincidence, one of the air hostess who had been on my flight out to England happened to be on to this return flight and suddenly approached me telling me she was amazed to find I was actually sitting upright and looking so hale and hearty!

Back in India, I am putting to full use all that I have learnt and absorbed from my rehabilitation experience in England. So far, sadly there has been no such grand hospital facility in this country for other Spinally injured victims. In fact if this had not been a permanent injury, this whole experience of rehabilitation (together with my family of course) was a life experience I would not have missed for anything, since I think it was a very full and gaining experience. The good time of sharing and caring with the other patients, nurses and physios was great fun and a learning experience which I was fortunate enough to have undergone.

Here in Bombay I am lucky to have a close family friend, Percy Chibber, who is an Urologist. I am constantly asking him about any problems that occur regarding my catheter or kidneys, or anything else that goes wrong - since he has had a lot of experience in dealing with paraplegics, both abroad and in India.

Fortunately the entrance to my building, and the areas in my apartment didn't need any modifications for wheelchair access.

I was lucky enough to have been re-employed on a part time basis by my employers, Messrs. Gulf Air who have been very sympathetic and kind. I love going to work five times a week in the Reservations Department working on the computers and the telephones. I have a wonderful set of colleagues who are most supportive and fun to work with. I feel it is vital for "paras" and "tetras" to have employment on a regular basis so as to be part of the mainstream of life's activities and be constructive individuals in society. This enhances ones self respect and gains respect from others. Just as another lesson I learned, which was to always dress smartly and be well groomed. It is also very important to lead an active life - and at home, in my spare time, I am always at my computer since I am fond of writing and correspondence being one of my hobbies, I communicate with friends and relatives all over the world. This helps me reach out and to be in touch with people which again is so important for a wheelchair bound person to be able to do. It is so tempting in this condition, to take the easy

way out, be in the grip of despair, and isolate oneself because of the huge difficulties in day to day living that this affliction creates.

I have to employ servants and maids to assist me in bathing, dressing, toilet routines and transfers. We have to employ a chauffeur who drives me to work. We have modified a Maruti Bubble top van with collapsible ramps which come in and out from the back door. The driver wheels me and straps me in with seat belts in the wheelchair itself. This mobility enables me to be independent and burdens the family members less. I get about a lot in this van visiting my friends, going for lunches and dinners, movies and the theater and we all often go out of Bombay on holidays together.

To highlight a slice of a day in my present life, I wake up early around six-thirty in the morning. A tetraplegic has much to cram into her day, because everything takes ten times longer to do than it would for an able bodied person. So there is no hanging about!

"Today is "Bowels Day" and my attendant has inserted the suppositories and now I shall be lifted into my Shower Wheelchair and wheeled into the bathroom for my ablutions and shower. This is slow going and takes about two hours. Now back to bed, not to sleep but to commence my daily routine. I have to be dressed, which is done lying down. Then still on the bed I do the exercises and my attendant helps with the passive movements taught me by my physiotherapists, after which I am lifted into my normal wheelchair and rolled to the breakfast table. Whilst I eat I read the newspapers and any letters awaiting and I give the servants instructions for the day's household running and for the care of my mother who is now eighty-seven years old and has been suffering from Alzheimer's disease since the last three years. (Her condition creates a constant ongoing sadness in me which is a heavy burden of grief to bear).



Once weekly my physiotherapist Marukh, with whom I have built up an excellent rapport, comes to give me a good two hour work out which is extremely essential to prevent my body becoming stiff.

I also spend a lot of time playing with and attending to my dog Cal, who is a Beagle and very sprightly, who constantly demands attention and is a joy to have around for all the family!

I often sit on my computer and complete my correspondence and other writing since this is my hobby and gives me great joy. Any phone calls are now made, after which when my husband Sarosh comes home from work for lunch I snatch a bite with him and am ready to go to my office, Gulf Air, where I work in the Reservations Department. My driver wheels me into my specially adapted van, and off we go!

I enjoy my work immensely. Having worked in the airlines industry since the last twenty years, there's nothing else I'd rather do. I have my computer terminal and with headphones on and typing gadgets attached to my hands I handle telephone sales, make bookings and discuss flight details with clients. My employers and colleagues are extremely kind, understanding and wonderful people to work with. They give me a lot of respect and affection and that feels good.

My work day ends and I reach home at six-thirty in the evening. I have a short rest on my balcony couch, to ease the pressure on my bottom through sitting so long in my wheel chair. I am then heaved into my Standing Frame where I watch T.V., read, chat with visiting friends or deal with several things that may need attending to.

Sarosh comes home from work and we relax together with Simonil and Reshad (if they are around at the time, and not out with their friends) for a short while. Sometimes we have dinner at home and sometimes we go out to friends' homes or to a restaurant. (Sometimes in the evenings, we also go to the theatre or to concerts of which we are very fond).



Back home at around elevenish, I am undressed, put into my sleeping attire and lying on my side, propped up with pillows, I unwind and chit-chat a bit with Sarosh. During the night he turns me in our bed just once to change my position, to avoid the risk of pressure sores and hopefully the remainder of the night is passed in peaceful slumber. (Strangely whenever I have dreamt since my accident, it has always been of myself as a 'normal' person, running or walking or standing. It is only recently, in the ninth year after I became paralysed, that my dreams have started registering me as wheelchair bound! I have only now started dreaming of myself in a wheelchair - often trying to get up and walk, stumblingly and clumsily).

Also, it is just recently that I have begun feeling more 'comfortable' with my own body, paralysed chest down and permanently in my wheelchair. Very often earlier, at numerous moments of the day, I'd feel awkward and almost apologetic both at home or in public, about my condition. Fortunately I am blessed with abundant self confidence which has seen me through these inner flashes of awkwardness!

With the help and encouragement of those around me I live a similar life to most other people. Proof that one can have a good life even in a wheelchair".

However to keep up with the quality of life for a tetra, is horrendously expensive. I have to order Supra-pubic catheters, urine bags, and many other medical requirements on a permanent basis, as they are vital for my existence. The money goes down as though into a bottomless well, and we often worry about it and feel that this quality of life, to maintain my body physically, will last only as long as the money does. There is a great necessity for government funds to be made available for people with spinal injuries in India, since there are very few facilities in terms of financial support.

I find that the facilities for wheelchair access in private and public places, all over India, is abysmal. This is a major stumbling block in the practicality and

comfort of day to day mobility for tetras. I know of many wheelchair bound people who just give up going out, in despair. Every where in the West it is mandatory, by law, to have wheelchair access, in all public buildings, hotels, restaurants, theaters, as well as parking facilities for the disabled, not to mention special wheelchair accessible toilets. There is a great need for a lobby to fight for this in India.

Another aspect of my care management is the obsession I have to maintain over regularly being lifted out of my wheelchair, so as to prevent pressure sores, to compulsively drink four litres of liquids a day and stand regularly (strapped up) in my Standing Frame for one or two hours daily. It needs a lot of drill and discipline and proper training of my servants and care-attendants. Luckily I am a very vocal person and I had made up my mind long ago, that since my hands and legs are grounded, I would need to sharpen my mind and tongue which would fly instead! This seems to have worked very well for me, as I often have to talk others through situations for my care, gently cajoling with tact and humour, as far as possible.

The active and full life that I manage to lead with my family, in the household, also in the office as well as socially, helps to keep me cheerful and at peace with myself. Though I do not think the frustration and depression I feel at times can ever be abated; it will always be a part of me and a demon to be kept at bay. I believe the most important thing to bear in mind for people in my condition is not to keep seeking cures to enable them to "walk" again, but to accept that this will be a permanent disability. Once this acceptance comes, life can be lived to the full.

"Nothing in life is to be feared,  
It is only to be understood."

(Mrs). Shanoor Forbes.

C. 6/7

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