

Medical Practice

A Case of "Frayed Nerves" – My Experience with Miller-Fisher Syndrome

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A friend put his finger on it exactly. I was telling him on the phone how I was feeling and what had happened to me that morning: it sounds, he said, like being drunk without having the pleasure of the drink. The hospital doctors, too, it seemed to me, didn't quite believe my protestations that I hadn't been drinking the night before. True, I couldn't walk a straight line for them, either, and was finding the situation rather amusing and faintly ludicrous, in a giddy sort of way. They'd sent me home and told me to lie down for the rest of the day.

I'd woken up feeling a bit groggy, light in the head rather than dizzy. Looking out the window, I noticed the ship moored in the harbour below seemed to have sprouted a double, and on the distant highway all the cars and trucks and buses appeared to be moving along in pairs, identical pairs. Something was not quite right; but, I thought, it'll pass over. It didn't. So, a little later, I thought I'd better go and see a doctor. I found myself walking quite ponderously towards my car, giddily bemused at my deliberateness and slowness of gait. However, the effort of keeping carefully to the left of both of the diverging white lines in the middle of the road (surely there should only be one?) soon changed amusement into something more like anxiety. The doctor of course was horrified that I'd tried to drive at all. She examined me but then thought best to send for an ambulance to take me off to the nearby hospital. There they asked me questions, tested reflexes, examined my eyes, made polite enquiries about personal habits, but finally still couldn't say what was wrong.

Three days later I was back at the hospital, now needing assistance just to stand up straight, never mind walking a straight line. After more tests and examinations they admitted me this time, still undiagnosed. During the intervening days I'd got progressively more tired, though lying down most of the time; trying to read was a strain, and looking at the TV set obliquely with one eye closed became so too. Eating was no problem except that getting to the table required the support of convenient chairs, walls, doors, cupboards, anything to hold on to. I also noticed, first in my palms and then on hands and forearms, a gentle sensation of something like a mild version of pins-and-needles; not exactly a numbness or tingling but a feeling as if wearing an extremely fine and delicate glove. By the third morning even to sit up and reach for the bedside telephone was an exhausting effort. Speaking also now seemed a bit difficult, and to my own ears at least, I sounded slightly

slurred... a good imitation of a mild case of alcoholic over-indulgence.

Through my torporous doze in the hospital bed I learned that they wanted the E.N.T. people to have a look at me, and also the neurologist. I found it strange having to move my head a little to see each of any two or three people standing nearby. Even to keep my eyelids from drooping was an effort, not always successful. And I had no energy now to face the job of eating. The E.N.T. people were kindness itself. They made all sorts of tests but by then it was clear even to myself that my eyes just didn't move no matter how hard I tried to follow extended forefingers moving to and fro and upwards and downwards. By the time the neurologist came I'd convinced myself that he was my one remaining hope of finding out what was wrong with me. He asked some questions, did a few checks and tests, made a couple of observations and, finally, said he thought he knew what my problem was. And then for the first time in my life I heard the name Miller-Fisher, and about his syndrome. Putting a name on the mystery was, that afternoon, the return of hope.

Curiously enough I felt both reassured and yet not at all surprised when the neurologist explained that though he was reasonably certain of his diagnosis, there was still a possibility that my problem might be a tumour or a slight stroke. He thought both unlikely, in fact, since I hadn't at any stage complained of any pain or headache, and my motor loss and loss of balance was equal on both left and right. However, he would have checks made, and arranged for an immediate C.A.T. scan of my head and a lumbar puncture to follow. Confirming his diagnosis later, the doctor cheerfully explained that Miller-Fisher is a very rare condition and not usually fatal. The treatment, however, he described as being the most difficult of all – nothing: no medications, no drugs, nothing for me to do but stay lying down in complete bed rest. The malady had to run its course, though certain cautions would be needed. The immediate need was to monitor my deterioration because there was no way of knowing when or at what stage it would reach its lowest point before natural recuperation took over. There was a possibility of wider paralysis, and the progressive loss of nerve action could become dangerous.

After all the hi-tech scans, x-rays and laboratory work, a simple exercise that was more like a children's game was all that the doctor ordered. Apart from being an effective medical check it gave me as the patient a direct involvement in monitoring my own progress and a welcome regular break in the monotony of "complete bed rest". It also gave some amusement to the nurses who, I suspected, carried out their instructions with particular gusto during the night

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hours. Every half an hour, day and night, I was to sit up, take as deep a breath as possible, then count out loud as far and as fast as I could. A record was to be kept of what number I reached each time, and if there was a drop in the number I could reach to or if my counting slowed down or became unarticulated this would be a bad sign and the doctor should be called at once. Happily this never happened, and after a couple of days and nights of regular counting (my lowest "score" was around 40) the exercise was relaxed to only once an hour, as it seemed no further disimprovement was anticipated.

"Frayed nerves", it seemed, was all that was wrong with me, a disorder in the brain-stem nerve system. My symptoms of ataxia and reflex losses were a classic case of the condition pin-pointed some 30 years ago, by a chap called Miller-Fisher, as a variant of the more well-known Guillain-Barre syndrome. That latter name, at least, was one that my friends could find in their popular medical encyclopedias, and that bit of knowledge lessened the mystery of what was afflicting me. My neurologist's description of the "frayed nerves" in terms of an analogy with the fraying of electric wiring and subsequent short-circuiting provided a usefully graphic image for my own comfort and the enlightenment of enquiring friends and wellwishers. Unlike electric wiring, though, which can be simply replaced with a new piece, renewing and healing of frayed nerves requires time and rest. How much time, nobody could say; nor even how bad it might get before it got better. A couple of well-known personalities were quoted to me as people who'd had this Miller-Fisher syndrome and fully recovered even after long and serious paralysis: comforting news at least. And the cause of the overload on my nervous system also came to light: a bad "sore throat" about ten days before my symptoms appeared was evidently a virus infection that I hadn't treated with sufficient respect but had foolishly tried to fight on my feet.

At the age of 52 it felt faintly ridiculous having to learn how to walk again, first with a walking-frame, then with sticks and finally on my own but with the physiotherapist or a nurse at hand all the time. Just to walk down the ward and back was quite exhausting at first, and tacking a flight of

stairs for the first few times was actually very painful on the knees for a while afterwards. I found I had to try and keep my eyes fixed on a spot straight ahead of me in order to keep balance, and had literally to stop in order to look around; looking at anything that moved made me feel dizzy. Having got used to shaving by feel while sitting up in bed, it was quite a disorienting experience when they moved me into a room where there was a mirror and wash-basin I could sit at; trying to shave, I just could not focus my eyes at all on the side of my face! My cheeks I could see alright, and my chin and forehead and (by this time) a little beyond those points, but it took another week or more before just the edge of my ears came into focus and then some time longer again until I could really see my whole head in the mirror: most odd.

At my age, one of the professors of medicine said just before I left the hospital, he thought I should make an almost full recovery, 95% perhaps or up to 98%. But there wasn't enough data or experience of the syndrome to predict with any certainty how long a full recovery might take: another three weeks, perhaps, or maybe three months, or possibly up to three years. Out of hospital, gradually my walking improved, and I began to resume normal life, but the side-to-side movement of the eyes only imperceptibly returned, and it remained difficult for a while to focus onto any moving object. It was disturbing not to have the accustomed peripheral vision, not being able to see someone walking beside you but having to stop and turn in order to talk to them.

For quite a while even after I began to read and write again and to watch TV I did not use either my normal or my reading glasses; they were just uncomfortable and not really helpful. Then one day I found myself putting on my glasses because it was uncomfortable without them, and a few days later I felt ready to drive into the city and was able to do so without discomfort: it was almost three months to the day since I'd undrunkenly lurched my way to the car and, keeping to the correct side of those non-existent double white lines painted on the road, driven most carefully to the clinic at the start of my encounter with Mr Miller-Fisher and his syndrome.