

My stroke—*mens sana in corpore non sano*

It happened at six o'clock in the morning. As I got out of bed I felt lop-sided. My speech had not yet gone, so I managed to call my friend who was asleep in another room: 'I think I am having a stroke'.

My recollections of the rest of the day are fragmentary: I remember being stripped of my sodden night-dress; and I can still see the face of the young doctor who said 'What do you think is happening to you?' 'I think I am having a stroke.' 'You may well be right.' Those were the last words I exchanged before I lost the power to speak.

There are flashes of recollection: of the soles of my feet being scraped; the back of my throat being tickled but without the customary retching reflex; pencils being waved, 'Look to the right, to the left, up, down'; and of bright lights being shone into my eyes. I could hear the doctors consulting: 'It has to be brain-stem, hasn't it?' They did not seem to realise that in my moments of consciousness, inside the motionless hulk I had become, I was sharply aware of what was going on.

At one point I found the ceiling was only inches from my nose and guessed that I was in a brain-scan tunnel. Then I was in bed in a ward, surrounded by anxious friends. 'You see that eye, it's watching us. Do you think she can hear and understand what we are saying?'

My legs were uncomfortable, but I could not say so. 'What do you think she means, waving her arm round like that?' 'Why is she pointing to her feet?' They understood in the end, and my paralysed leg was moved to a new position, where it felt reasonably comfortable for about two minutes.

Then it was night-time and the nurses had changed over, the lights dimmed. I lay as I was put, quite unable to move. Now and again I had to be turned. I was unable to call out for attention, and did not know I had a bell-push—it was out of reach anyway. The solution was to tap my ring on the bedrail. This brought one or more figures to my bedside, emerging like benign ghosts from the darkness. Circular waving with my right hand told them I needed to be turned. It took three or four of them to do this—the whole of the night shift contingent, in fact. It was deft and, for me, rather pleasant, despite the complications of urinary catheters and intravenous glucose drips.

In moments of wakefulness I pondered my situation. A little arithmetic and similar mental gymnastics reassured me that my mind was clear. I could note and understand what was being said and done. My left side was completely paralysed, I could not speak or swallow,

and I saw everything double and out of focus. One difficulty I did not at first identify: now and again I was disturbed by the noise of some unpleasant loud breathing—rapid, shallow, and rattly. It took some time for me to realise that I was the culprit. Clearly, I had problems.

For the first three days I hoped it was all just a nightmare and I tried now and again to wake from it. When I finally had to realise that it was real, I made a vow that if I survived I would one day walk out of the hospital unaided.

The first essential was to regain my speech. I cannot describe the unutterable agony of a sound mind trapped inside a mute body. The inability to communicate was torture. 'If only I can speak again, I will settle for just that.' So I started to say the alphabet in my mind, over and over again. Suddenly, one night, I got to 'g' and said it out loud; 'h' was a problem, but eventually I got to the end of the alphabet, stumbling at 'x', and went through it again. A tap with my ring, and I said it through again to a sympathetic nurse; and wept for joy.

The next problem was to regain my ability to swallow. After five or six days of having to have my saliva mopped up I realised that I had managed to swallow it. The 'Nil by mouth' notice meant what it said, so I proved the point to the staff by drinking my mouthwash! Also, I was beginning to be more aware of other patients, more especially of the notices over their beds on the opposite side of the ward, giving the names of their consultants. At times, I managed to bring these notices into clear enough focus for reading, and fairly soon the ward and the world stayed in normal sharp focus, only slipping a little with tiredness or early morning drowsiness.

Early on, I was got out of bed and put in a chair. This was a humiliating procedure, rather like a hippo being loaded into a crate. It involved a canvas sling which was wrapped round me, still in bed, and attached to strong hooks on a hoist. The hooks were then raised by a ratchet handle on the hoist and my bulk was duly deposited in the chair, all the loose bits propped up with cushions.

About a week after the stroke I felt I could move the paralysed leg a couple of inches. A kindly nurse had a look and confirmed that there was a slight movement. More joyful tears. And, of course, I moved the goal posts: 'If only I can walk again . . .'

The following day I asked about physiotherapy. The doctor thought 'in a few days time, when you are stronger'. 'I think I'm ready for it now. What about tomorrow?' 'Well, if you feel that way, why not?'

During these early days the medical aspects had not been neglected. I did not worry that the consultant

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charged with my case passed me by on his rounds. There seemed little need for bedside chats. I judged that the various printouts were telling him what he needed to know. However, after five weeks, I felt it would be nice just to establish contact and at least say 'hello'. So I said so, and thereafter he always gave me a cheerful greeting as he passed by. One of the adjustments I needed to make, but in which I did not really succeed, was to accept that I was talked *about* (not only by the doctors) much more than I was spoken *to*. At one point, in exasperation at hearing 'Does she need a beaker?', I interrupted with 'Does she take sugar?' It had a temporary effect. However, I did manage to have some conversation with the senior ward doctor; he was pleasant and attractive and made me feel I was a person again.

My best chats, though, were with the night nurses. The day staff were far too busy, being constantly interrupted in their duties by patients calling for attention. Although the night staff, too, were often on the go all night, there were lovely little periods when we could talk. It was a night nurse who confirmed the first sign of movement in my leg, and another who talked me out of a terrible feeling of entrapment. One night an overwhelmingly claustrophobic sense of my physical limitations flooded over me—the fact that I could only lie as I was placed, immobile, and wholly reliant on others for any movement, any escape. I was stuck, glued to the bed, and terrified. It was this nurse who told me of the stroke patient, as badly afflicted as I was, whose determination had helped him towards walking out of the hospital after two months. The glimmer of hope this provided broke through my panic and gave me the courage to remember my own resolve and see my predicament as a temporary situation to be endured. I shall never cease to be grateful to her for saying 'Of course you will walk again. You have the motivation'.

There is, of course, a great deal of fear to which one has to adjust. Fear of permanent disablement, of one's future life being hideously circumscribed, fear of pity, and fear of another stroke. This last is said never to leave one, so it just has to be lived with.

From the beginning I was consumed with admiration of the physiotherapist's skills. Self-help also came into it. To begin with, my head did not even know when it was vertical, so I slid my glasses down my nose and lined up the frames with the horizontal curtain rail round my bed. Then the occupational therapists taught me how to wash and dress. The problem was not so much having to cope using only one hand, but more the fact that the useless arm was still there and in

the way. In the ward I was encouraged to wash and dress myself to the partial extent I was capable of. The daily therapy sessions continued and gradually I regained my basic sense of balance and my back felt stronger. But I was wary of the glowing praise of the physiotherapists, judging from watching them with other patients that they had a whole thesaurus of encouraging phrases. So I applied a conversion factor to their ecstasies.

There was also another element. To me, I was a busy, happy woman cut down overnight from a full and enjoyable life to a passive vegetative state. Now I was a patient. So what the staff saw as remarkable progress had a baseline of great affliction. On the other hand, my yardstick was myself as I had been, the *real* me, and I still am a long way from that. In spite of all my fears, I could, however, measure progress: each achievement was proudly displayed to my visitors, who were also regaled with accounts of heroic feats in the gym.

Then came the day when I could walk with a stick on my own. It was a long way from my previous quick step, but walking it was. Since I could now also wash and dress, it was time for a home visit to see to what extent I could manage and what help I might need. I was exhilarated and nervous at the prospect.

I am at home now. For a time I went back to the hospital twice a week for physiotherapy, while slowly catching up with everyday life. After the first thrill the return had been a shock. Home was familiar and normal, and I was used to being normal within it. The change in my circumstances was thereby sharply highlighted and for one dreadful day of exhaustion and despair my spirits plummeted for the first time and hit rock bottom. But I do, as they said I would, detect small improvements and these should continue. I had a temporary set-back when an aortic valve had to be replaced, but despite the hazards of open heart surgery my mind was unaffected. I am now driving again, having been cognitively and psychologically assessed to a degree that would keep many able-bodied people off the road; and I am playing the piano, too, first playing and recording the left hand score with the right hand, and then using the recording as half of a sort of duet to accompany the right hand.

Meeting the challenge of adjustments can be fun, or at least a source of satisfaction. Letters, cards and visitors continue to come. Social engagements are lined up, with good friends seeing to the arrangements. There is a lot to live for.

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