Personal Paper

Motor neurone disease: a demeaning illness

ROGER CARUS

I wish with all my heart and soul that I had not written this paper; for then I should still be where I spent five years' training to be, and where I planned to spend these years of my life, at work as a civil engineer, looking forward to coming home and playing football with my son. It would also mean, of course, that I would not have had to endure this agonising and devastating illness, motor neurone disease.

Neither use nor ornament

A second point I want to emphasise early on is that I now spend my time in the wheelchair—I, who have fallen down so many times that I've forgotten (and that is *not* supposed to be a pun). I have fallen down in every room in my house: in the bath-room, the bedroom, the kitchen, the dining room, the lavatory, down the stairs and up the stairs. Every time, it is I who has had to get up and carry on. And I have to rely on somebody to wash me, dress me, take me to the lavatory, and to do even the most meaningless task for me—blow my nose or scratch my ear if it itches. I cannot do even a simple thing like wear a watch. So do not believe you understand—any more than I can understand what it is like to be blind: imagine, yes, but only for a few minutes at a time.

The illness has continuously and relentlessly hammered me into the ground over the past four years, without ceasing. Now I have become what I consider doctors are to me in their professional capacity: neither use nor ornament. All the drugs, creams, and lotions that are used for my illness I could buy for myself over the chemist's counter, or find a substitute for at the off-licence.

More important, there are only two people in the world who know how to look after me to my satisfaction and comfort: one is me and the other is my wife. Families know more about the illness and caring for the patient than any professional.

Lack of knowledge

It has been my unfortunate discovery that what most GPs know about my illness can be written on a postage stamp. This is not only my opinion but the opinion of many others who suffer from motor neurone disease—and, from recent surveys carried out, there are about 4000 sufferers at any one time in Britain, with a death rate of around 1000 a year.

Motor neurone disease has a high incidence in the Kei Peninsula of Japan, and, for some unknown reason, 10% of the population on the island of Guam suffer from it. This is where

most of the research has been carried out by the World Health Organisation. Every mechanism that might start the disease has been investigated thoroughly—every one, that is, except the right one. So anyone reading this article who wants fame or cares to win the Nobel Prize has only to discover what starts this terrible disease and, I assure you, will spare a lot of people from one of the most demeaning of all illnesses.

My own case

My father suffered from and died of multiple sclerosis, though I never knew him. My mother divorced him when I was 2. I was brought up in an unhappy family by my mother and stepfather and vowed mine would not be the same. I left home when I was 15 and in 1967 found myself penniless and on the dole without a qualification to my name. By 1974 I had a nice home in Farnsfield, Nottinghamshire, and had gained a senior officer's position with Rushcliffe Borough Council as a civil engineer. I had a wife, a son, and a daughter. In 1975 motor neurone disease was diagnosed. How about that for a success story?

So we come to what was done in my case. The short answer is *nothing*.

In November 1975 I went to see my own general practitioner, who realised that there was something very wrong with my central nervous system. He diagnosed multiple sclerosis, chiefly because of my age. Not a bad guess under the circumstances. To his credit he sent me to the right neurologist, whom I saw in December 1975.

I have the highest respect for my consultant neurologist as a man who can label and diagnose neurological illnesses, but, in the context of my illness, he is no more use to me than the milkman.

While I was in hospital during December 1975 I saw many things that made an impression on me; but none more so than the woman bedridden with multiple sclerosis. She had a 6-year-old son, and her husband was divorcing her. I can well remember the little boy standing by her bedside with his father. I thought, "Things haven't changed at all in 20-odd years"—this was history repeating itself.

Telling the patient

For myself, I knew what was wrong with me before I left hospital. How and who told me I will not divulge. I have my own reasons for not doing so. I knew before my GP, and here is an interesting point: in the letter he received from the hospital he was told that my wife had been told the diagnosis. This was untrue. A houseman had told her that they were keeping an eye on me and that she was to take me to outpatients in three months' time.

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(Mr Carus died on 25 November 1979.)

What a wonderful situation to be in. Did she know or not? My general practitioner said the letter stated that she did but I was almost sure that she did not. I then spent two of the most agonising weeks of my life trying to find out, in the most delicate way possible, whether she knew or not. As the days passed the mental pressure became enormous. I could not live with a lie. Needless to say, she did not know; and I have never regretted telling her because we have always been able to discuss any problems and work things out together. But there was no need for me to suffer the experiences I went through during that fortnight.

My GP's mistake was to believe the hospital letter and not his patient. I believe patients should always be told the diagnosis so that they can decide what to do with the rest of their lives—jump off the nearest bridge or go on a world cruise. Personally, I wanted to do many jobs around the house while I was still physically capable. We have heard of many patients with motor neurone disease who are not told and their partners suffer agonies, living a lie and having nobody to talk to.

I gave up work in May 1978, principally because my arms were too weak to drive safely and I could not walk out of the office at night, even with the support of a young colleague. That I had been going to work for the past month or two without being able to leave my desk—not even to go to the lavatory—seemed to have escaped everyone's notice. Incredible, I can hear you say to yourself: they must have known. That is exactly what I said to myself but why did no one help, instead of leaving me in no-man's land? So much for modern management.

It took me until September of that year to recover from the physical and mental exhaustion of getting to and from work.

Loneliness and lack of understanding

Then I became bored and frustrated. I also felt unique and alone. I seemed to be the only one in the world with this illness and these problems. When I looked for help and moral support, just like all my predecessors with motor neurone disease, I found nothing.

On one of my visits to the hospital my wife asked if there was a society we could help to support. Nobody seemed to have any idea. My frustration and boredom turned to anger and resentment—even more so when I found out, for myself, that there are two large organisations for sufferers from MND in America. Why hadn't someone done something about it before in Britain?

You see, a person suffering from motor neurone disease seldom drops down dead. The disease systematically and slowly destroys the individual's physical condition until he becomes helpless. That is how I felt—helpless and deserted. Is it any wonder that patients with motor neurone disease end up ranting and raving and banging their heads against the wall? They are fully mentally alert, they see and know what to do, and yet they are physically incapable of doing a solitary thing. That goes on day after day, week after week. Frustration, boredom, and active imagination—as good a recipe for insanity as any I've heard. That is why the Motor Neurone Disease Association came into being in Nottingham.*

The association has been formed to help the patients and their families in every way possible. I have been asked many times whether I feel cheated or robbed by my illness. The truthful answer is that I do not give a damn about me, but I certainly know that my whole family have been—not only now but in the future. Instead of being an asset I am nothing more than a burden.

I am fed up with hearing the same old story from other people suffering from the disease. "No one cared. No one had heard of motor neurone disease. The doctor didn't know what to do. We were just left alone." No one told us anything about the illness or what to expect. In fact, most people had to force the diagnosis out of their doctor or consultant, and many had been

treated for the wrong illness—rheumatoid arthritis, for example.

Let me give you one example. One patient refused to go out of his house. He would not let his wife out of his sight for more than five minutes. His GP never came near as he said there was nothing he could do. In the end his wife was threatening suicide. After his death she had to readjust her whole life and establish a relationship with her 6-year-old daughter, who had been neglected since her father had needed and demanded so much attention.

Another patient was a woman who used to run a nursing home. "My God," she said, "If I'd had this illness before I had the nursing home, I would have had a different attitude towards my patients." There you have it. Attitude and understanding. Patients with motor neurone disease need understanding and an abundance of patience—and this probably applies to many other disabled people who cannot physically help themselves but are mentally alert.

Social workers should be able to do a great deal for patients with progressive illnesses. The whole family needs continuous support because the problems are ever changing. Patients need help and aids *now* and not in six months' time.

Euthanasia

Ironically, while preparing this paper I read with amazement that Plato did not believe that life should be prolonged in cases of incurable disease. My earliest memories regarding euthanasia go back to the 1960s when I was a healthy young man hearing Malcolm Muggeridge speaking out against it. The point that stuck in my mind even then was that he might change his mind if he was suffering any great pain. My own point of view is that it is a question of when and how; if a person is free to run his own life as he wants to when he is well why can't he do so when he's ill? If a man can draw up a will to say how his estate should be settled after his death, if he can authorise doctors to take organs from his body should he die, then why can't he give doctors the authority to terminate his life when everyone knows there's only suffering left?

If people want to die peacefully then why can't they? It seems to me that we show more humanity to our pets than to our fellow human beings. People do not understand—but they will when it is their turn. If I cannot join in the game of life then I want no part of it now.

Conclusions

In conclusion, I should like to draw attention to the following points. Firstly, the medical profession fails to understand the ordeal a person can go through not only while he is in a wheelchair but, more significantly, while he is still trying to stay on his feet. Secondly, preparing this paper has not made any difference to my condition. Thirdly, how do you explain to the public what this disease is? People cannot respond to the fact that I have motor neurone disease as they could if it were multiple sclerosis or Parkinson's disease, of which they have a vague understanding or awareness. Because of this problem a leaflet was printed to make the general public more aware of the disease. It may not be perfect, but anyone who can write a better one for us is welcome to do so. Fourthly, and to his eternal credit, my GP has never stopped coming to see me, no matter what the circumstances, even though he can do nothing constructive (but neither can anyone else).

Finally, a lot of people at various times have asked, "Why don't you write a book?" I don't think I will because it has all been said before but, if I ever did, I know what the title would be—*Next*.

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