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‘Mr Nodding, I think you’ve got motor neurone disease.’

These were the devastating words that my doctor uttered as we sat in his consulting room. This was just an ordinary doctor-patient consultation like so many before it – but now it had been completely transformed by the introduction of an absolute nightmare.

I said nothing but my reply to myself was abundantly clear, the words resonating within my head:

‘NO! HE’S GOT THAT ALL WRONG.’

In fairness to my doctor, his words were a necessary response to a direct question of mine. Before this crucial exchange, I had heard the results of all the tests I had undergone in the weeks before. These were tests arranged as a result of a previous visit to the medical practice. The Computed Tomography (CT) scan had revealed nothing untoward, I had just been told. The same was true of the other x-ray images that had been taken. And, finally, none of the battery of tests that had been carried out on my blood samples had revealed any abnormal values.

‘All is fine here’, had been my doctor’s welcome message. Sweet music to my ears!

However, it was in response to all this positive information that I had asked the fateful question:

‘So why is my voice changing?’ In previous weeks, I had become aware that my voice was weaker and distinctly more husky; also, I noticed that I was having occasional articulation difficulties with more complex words. In the past, I had never suffered from such problems.

My presence in the doctor’s consulting room was the culmination of unfocussed feelings that something was not quite right. Even nine months before, family members had commented that I had “changed”. These comments had been made by my son, Paul and also by our lifelong family friend, Diane. Both said that I seemed to have “slowed down” to some degree; furthermore, these comments continued to be made with increasing frequency in the subsequent months.

‘Well, what do you expect?’ My rejoinder was made with bravado and a certain degree of irritation, ‘I’m 69 now, so I’m bound to be changing to some degree.’

In fact, I knew I had already changed in another fundamental, physical way. For many years, my weight had been steady at around 85 kilograms (kg). Now it had altered. For some time, my weight had been falling steadily and I had become increasingly aware of my changing body shape – perhaps something to be welcomed at first! However, when I eventually visited my doctor, I recognised that I had lost around 14kg, without any change in diet or lifestyle.

There was another significant event. In March 2014, I had a rather nasty accident – a rather dramatic and injurious fall. I was in the pleasant but very hilly city of Birmingham, (in the Midlands area of England) carrying out some financial duties at the Museum and Art Gallery, where I had been engaged to do some accountancy work.

The Birmingham Museum and Art Gallery is at the top of a majestic hill in the city and I was making rapid progress down one of the rather steep roads towards the railway station when I tripped and fell heavily, suffering serious bruising and acquiring a nasty wound on my forehead. People, including a passing doctor, were very kind and rushed to help me. An ambulance was called and I soon found myself in the Accident and Emergency Department of one of the city's hospitals. Although my accident was very unpleasant, with painful consequences for several weeks after, I blamed myself for not taking enough care.

'In the future, I'll watch out for uneven and ridged pavements,' I thought, 'and I'll try to remember I'm not a teenager! There's always the next train to catch. All this was all my own fault.'

So the evidence was mounting but we all have a tendency to minimise problems – I know I do, anyway! Even when we begin to suspect that something may be wrong with us, we refute it. 'It's just my imagination,' we cry. 'It's advancing age (though we don't believe that for a moment!) It's something I've eaten or drunk. Maybe I been overdoing things, etc., etc.' Then there comes a time when we decide we should act and seek advice. The spur for this can occur in many ways – in my case it was when I was approached by one of the nursing staff at the excellent "Heartcare" gym that I attend. She took me aside and told me that she was worried about me. She said she had noted my weight loss, my "slowing down" and the change to my voice. She thought I should consult my doctor about these changes.

This was the stimulus I had been waiting for. I decided to take her advice.

As I left the doctor's surgery after the consultation, I felt very shocked and disquieted – but I retained my staunch conviction that his suggested diagnosis was completely wrong. 'After all, they do get it wrong at times, don't they?

I've heard about wrong diagnoses many times ...' However, try as I might, I couldn't think of a single example at that time!

Of course, the doctor's "bombshell" diagnosis had not been the end of the consultation. He went on to advise me that the next step was to be examined by a consultant neurologist, a specialist in such conditions. The necessary paperwork would be completed immediately, he said, so that the visit to the specialist would happen as soon as possible. In the event, I was able to arrange an early appointment with the designated consultant neurologist. 'The sooner the better,' I decided. 'Let's have this diagnosis of motor neurone disease (MND) quashed! Let's get me started on treatment for whatever problem my sixty-nine year-old body has developed.' I remained resolute and convinced that my problem was likely to be caused by some minor imbalance.

My visit to the consultant neurologist involved a very thorough examination during which I had to undress almost completely and have most parts of my anatomy poked, prodded and twisted. In addition, I was required to demonstrate the extent of my strength, flexibility and coordination by carrying out various physical movements while he watched me carefully. It was not a pleasant experience but I knew it had to be done. He asked very many questions about my lifestyle, past and present. On hearing about the accident in Birmingham, he opined that it was very likely to be part of the range of symptoms associated with the medical problem he was now investigating.

At the end of the examination, the neurologist advised me that more tests were required and that he wanted me to have a Magnetic Resonance Imaging (MRI) brain and neck scan. He also told me he was referring me to another consultant for nerve conduction studies; this would involve special reaction tests on a range of nerves and muscles, using electrodes and needles. This specialist, a clinical

neurophysiologist, was one of only a handful of doctors in the UK who carried out such tests, he told me. This would provide valuable information for the diagnosis, he said. I understood that the purpose of the tests was to discover the extent of nerve injury and to assess the degree of possible recovery that could be expected.

The visit to the second specialist proved to be an even more uncomfortable experience. As explained by the neurologist, the stimulation of my nerves and muscles was either by electric current or sharp needles. When this was being done, every time I reacted to the stimulations (as I often did), I noted that the consultant apologised: ‘Sorry!’ he said each time.

‘Why do you say “sorry” every time I react?’ I asked him.

‘Well,’ he replied, ‘I know that I’m hurting you, and I’m sorry for that. However, it’s the only way we have of discovering the truth.’

THE TRUTH. These two words were welcome, indeed. ‘Ah yes,’ I remember thinking, ‘that’s why I’m here; to discover THE TRUTH. To get rid of this MND suggestion and to discover the solution to whatever problem is responsible for my symptoms. I certainly look forward to returning to full health and strength.’ That thought made me feel happy and filled me with a surge of welcome optimism! Eventually, the examination was over. Now I concentrated upon this man who was setting aside the various instruments he had been using on me. My gaze was fixed directly upon him. Here was the man who would tell me “the truth”. I waited. And waited. The silence in the room lengthened but, still, he said nothing. His head was down as he examined the various readings that his equipment had presented to him. Eventually, I felt it was appropriate to break the silence; to move things forward:

‘So am I all right?’ This was my brief, direct question. I felt quite upbeat as I spoke these words.

‘No,’ he replied immediately, his voice quiet and flat.

I froze, recognising in that moment that my world, my life, had changed. That was the moment that I said to myself: 'I really have got MND.' I couldn't refute it any longer.

On my return visit to the first specialist, I was informed that the MRI scan had not revealed anything of significance and the report of the nerve conduction studies from the second specialist had ruled out several possible diseases and disorders. Crucially, however, it did not rule out MND and it was the neurophysiologist's opinion, and the opinion of my neurologist, that MND was indeed the diagnosis of my condition. The neurologist communicated this diagnosis to me carefully and comprehensively; then, in his follow-up letter to my doctor (copied to me), he wrote:

"I have explained to Mr Nodding that I do consider he has motor neurone disease."

An unequivocal statement indeed. Now it was confirmed positively that my status had changed irrevocably. My neurologist advised me that I would be referred, as an MND sufferer, to the New Queen Elizabeth Hospital at Edgbaston, Birmingham. This is an ultra-modern, premier hospital known to be in the forefront of many present day medical techniques. It is also well known across the UK as the hospital that treats the serious casualties of war who return from conflict, often with devastating injuries. Within the Department of Neurosciences of this hospital, there is a Motor Neurone Disease Care Centre, led by leading specialists in the disease.

Until now, everything had been happening very quickly, almost at breakneck speed. The diagnosis of MND had been established very quickly, despite the range of consultations that I needed to have with different specialists.

Consequently, I was disappointed that a nine-week delay now occurred before contact with the MND Care Centre team was established. This was very worrying, because I noted that my condition continued to deteriorate.

However, when action began to happen, it was like the deployment of the support troops! Firstly, I was visited in my home by a delightful specialist nurse from the MND Care Centre. The nurse painted for me a very detailed picture of MND, explaining that it is a progressive disease that attacks the “motor neurones” (nerves) of the brain and those within the spinal cord. The result is progressive weakness and wasting. At present, there is no cure but symptoms are managed so that the best quality of life may be achieved for each sufferer. She emphasised that the course of the disease is different for each patient; it is impossible to predict how it will run its course in any individual, she said. This was an excellent introduction to how my life would change in the future and I was very grateful for all the information that was given to me during the specialist nurse’s visit.

Soon after, I was also visited by an expert from the MND Association, which is a charity organisation operating across England, Wales and Northern Ireland. This organisation funds MND research, campaigns to raise awareness of the disease and has thousands of trained staff and volunteers in many centres to support the sufferers of MND and their families. In Birmingham, the MND Association staff work with the MND Care Centre at the Queen Elizabeth Hospital. During this visit, I received expert advice on how I might change my house, specifically how to change the downstairs bathroom into a “wet room” and transfer all my living quarters to be solely on the ground floor. I was advised that the Association has practical contacts with specialist companies who can carry out conversion work at favourable rates to the client. There was also a medical discussion about the provision of an external feeding tube to the stomach if food cannot be taken via the throat.

I was also briefed on other aspects of MND care in the area. There is a team from a local hospice (the John Taylor Hospice, who have been offering end-of-life care for over 100 years) who concentrate on MND patients, providing various therapies, including advice and treatment on nutrition and physiotherapy aspects of care. Furthermore, a Speech and Language Therapist is available within the Birmingham Community Healthcare system, while advice on respiratory care is available within another function at the Queen Elizabeth hospital. All this information was very helpful and I am most grateful that so many comprehensive services are available to help me.

At time of writing this account, work is being done to convert my house, so that it will be suitable for my physical state in the future and make me as comfortable as possible. Friends and family are helping with this. Items that I will soon need (e.g. a wheelchair) will be delivered to me in due course.

Meanwhile, I am still losing weight through the wasting of my muscles and consequently becoming weaker. I find I have little energy and stamina. This also affects my mind and I am finding it more and more difficult to concentrate.

My world is changing; where I have been helping others, people are now helping me.

Three months have passed. Now it is November and I think back about my life; about the good and the not-so-good things that have happened to me during my seventy years in this wonderful world. I think about the great joys there have been in my life and I think about the sorrows, too.

That's what the rest of this book is about.