

Adjusting to a Diagnosis of Multiple Sclerosis

Diagnosis

If I was to offer one piece of advice for those newly diagnosed with multiple sclerosis (MS) it would be avoid the internet. 'Knowledge is Power' as one national MS Society website proclaims. However, for someone with 24/7 access to the internet, and a research-based job, researching the disease had become somewhat of an obsession since my diagnosis.

I was diagnosed with MS in May 2004 age 39. Unlike many who are diagnosed there were no earlier signs of anything wrong. Indeed, in 2001 following my office medical, the doctor congratulated me for being a "model patient". However, in March 2004, I noticed that I wasn't shaving properly with my right hand and that I had become 'de-sensitised' from the waist down. I went to my GP practice three or four times in the following weeks and was eventually referred to a neurologist. Having medical insurance proved a mixed blessing; I saw a neurologist privately within a week; had an MRI the next week; and was told that I had MS the next week. Too much to take in too quickly!

What's MS really about?

Following my diagnosis, I wanted to find out more about the disease and to find an answer to the "why me?" question. I started searching the internet for answers, starting first with the national MS Society websites. Initially, I was quite upbeat as many of the national MS society websites appeared very positive about the future. Most reported that, for relapsing remitting MS, there were now treatments that could reduce relapses and the number of lesions with better ones in the pipeline. The aims of the various national MS societies also appeared impressive – "a world without MS"; "to end the devastating effects of MS"; "to find a cure" etc.

But my searching of the national MS society websites also uncovered a much more serious side to this disease. I knew that MS could involve pins and needles, and loss of feeling, but the list of symptoms on these websites were something I had not been prepared for: visual impairment / blindness; paralysis; mobility problems; bladder and bowel problems; speech problems; sexual problems; depression; and something called cognitive problems (including memory problems). Also, for the first time, I came across the term 'near normal lifespan'. I also encountered terms such as respite care, and reference to your partner becoming your 'carer'.

As my research increased, the disease seemed to get worse and worse. Many of the websites were visited by patients with more 'advanced' MS, or carers of such patients. Adverts for mobility aids, hoists, adapted cars began to play on my mind as I started to think of a future I never believed could be mine. How long could I work for? Why am I saving for a retirement? Would I see my young children grow up? The prospect of mobility problems were a particular concern – not only because I loved playing sport, but because mobility problems would end my career (my commute

involves: walking to the station; overground trains; underground trains; lots of steps etc).

I was also reminded constantly about the disease through: (i) family members / friends posting me articles about miracle treatments such as Goat's serum, and a stem cell cure available in Holland; (ii) news reports of someone being prosecuted for growing cannabis for MS pain / spasticity; (iii) news reports of the 'loving husband' who helped his wife with MS commit suicide to end her suffering. Everywhere I looked there seemed to be an article about MS, or a celebrity with or affected by MS: Alan Osmond; Richard Pryor; Jacqueline du Pre; JK Rowling.

In the three years since my diagnosis the way the disease is viewed appears (to me) to have changed - MS is now often described as a neuro-degenerative disease in addition to being an inflammatory disease (the chicken and egg issue of what comes first has still to be pinned down). Many research articles have highlighted the involvement of grey matter damage in addition to white matter (myelin).

unsafe stem cell treatments have been offered in countries where appropriate testing does not appear to be an issue. My father offered me the £15,000 to go to Holland. Thankfully, I didn't accept this!

In terms of my own treatment, I was given steroids at the time of my diagnosis and for subsequent relapses. I started my disease-modifying drug in February 2006. Unfortunately, I had further relapses in June 2006 and a very bad one at the start of October 2006. An aim of the current disease-modifying drugs is to 'slow down' the disease. But my research could not identify what bit of the disease the treatment was 'modifying' and whether it was working for me. In October I came off my disease-modifying drug as, in late November 2006, I was given the chance to be given a more powerful treatment currently being trialed – which I had come across through my internet searching! So far I am doing very well following this treatment. Mentally I feel better as I consider that I have given the disease as big a 'whack' as I could.

While the internet can provide hope...it can also expose a patient to the realities of a disease

Rather than being a focal disease based on lesions, MS is now considered to be a global disease of the CNS. A recent piece of research using a very powerful scanner (8 Tesla) showed that there were lots more lesions which could not be seen by normal scanners. Urgh! My research also introduced me to the world of axonal degeneration. Gone are the days when MS was just a disease where myelin was damaged. Loss of neurons and axons are now seen as the cause of irreversible disability.

Treatments

My research on treatments also left me confused. The national MS websites refer to 100+ MS drugs in trial. These include those targeting T-cells, B-cells and drugs used for other diseases such as cancer. Minocycline seems to have been examined as a possible MS treatment for some time. Then there are a host of other agents: statins; Low Dose Naltrexone (LDN); Vitamin D supplements; heavy duty antibiotics (on the basis that MS is caused by chlamydia pneumoniae); and anti-virals. Neuro-protective agents are also being examined.

Stem cells are considered by many as a possible future "cure"/ repair strategy for degenerative disease such as MS. While I'm glad to see that the UK's leading lights in Cambridge and Bristol are pushing forward in this area, there would appear to be many more years' research before such a treatment makes it to market. Of course, unproven and potentially

So in my experience, it has taken almost three years to adjust to the diagnosis. I am still working full time and am now beginning to cut down on the time I spend looking at MS websites. I'm not sure how 'normal' my response has been. But, at the end of the day, an MS patient is being asked to take on board a huge range of major changes to their lives: having a disease for the rest of one's life; possibly watching yourself deteriorate (quickly or slowly); possibly having a shorter life than the 'norm'; dealing with potentially major changes to your employment, family life, and interests (be they diving, running, hill-walking etc).

Like many with MS, I keep my fingers crossed that the big breakthroughs in understanding the disease are not too far away and that the drugs companies can develop treatments that can shut the disease down (and perhaps promote some repair!). I will, no doubt, check the web to see what comes out of this year's ECTRIMS and ACTRIMS meetings. Clinicians may wish to suggest to those newly diagnosed with MS that they do not spend too long undertaking 'research' on the internet. While the internet can provide hope, in terms of highlighting future treatments in the pipeline, it can also expose a patient to the realities of a disease (a hard one for me has been the issue of 'brain atrophy') which can be very difficult to adjust to.

Mr Ian Rogers