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## Multiple Sclerosis

### **MS is an incurable disease affecting the central nervous system**

My sister had MS. She was aware of some symptoms earlier on in her life and I recall her saying that she was unable to understand why it took years before the disease was actually diagnosed. Apparently, the problem was that the initial symptoms came and went quite quickly, and many of them could have been attributed to other medical conditions. These were the ones specialists targeted first. When all of the other possibilities had been exhausted, it was finally agreed that MS was the cause of my sister's debility. The diagnosis was a shock, but she came to terms with it: and I believe her greatest motivation was family. For her they had always come first, and she was determined not to let some disease interfere with what she did for them; nor cause them to suffer too. She proved, to me at least, that where there's a will, there is a way.

Multiple Sclerosis (MS) cannot presently be cured, only managed. One of the most commonly acquired neurological diseases, it affects the central nervous system and can impact the brain, spinal cord and optic nerve. The problem occurs when the body's immune system mistakenly attacks the myelin, a fatty substance which insulates the nerves. As myelin is lost, electrical impulses sent to various parts of the body are slower and disrupted; so arm, leg and other movements normally performed without thinking become increasingly uncoordinated. The loss of myelin results in scarring; hence the name multiple sclerosis which means many scars.

There are no hard and fast rules regarding who is likely to be diagnosed with MS. Statistically, people between the ages of 20 to 40 are most at risk, although young and old outside of this demographic can be affected. It seems up to 10% of people may experience symptoms even before the age of 16. Unfortunately, no two cases are the same, and as a consequence, treatment is unique to the individual. The progression of the disease can be either slow or fast; some people experiencing episodes in stages that come and go, whereas for others there may be a gradual decline of function. And, apparently, there will be some diagnosed with MS who do not have a disability at all. Two things would seem to be certain: MS is not contagious, so cannot be passed on to someone else; and although the disease itself is lifelong, it is not terminal.

As already mentioned, the treatment of MS is personalised and varied depending on the individual patient. Medication can be a juggling act when other existing medical conditions have to be considered; and this is best left in the hands of an experienced MS healthcare team. Physical therapy too is an aspect that should be handled by professionals, rather than left to personal choice or suggestions from well-meaning friends and relatives. For these reasons I won't go into how MS is medically treated, but will focus on experiences I enjoyed with my sister over the years. Yes, I did mean

enjoyed; because, despite the problems associated with the disease, to me she was the same person I had known all my life – caring, happy and always up for a good laugh.

When first diagnosed with MS she confided that she had met a young, 23 year old woman who also had Multiple Sclerosis. It upset my sister that someone so much younger than her should be suffering what she had assumed to be an old person's ailment. The young lady's type of MS was also different, it being the faster-progressing kind; and even in the early stages she was losing many of her motor skills. This motivated my sister to continue doing whatever she had done before, no matter how hard it might become. Neither was she prepared to sit back and let MS gradually diminish pleasures she enjoyed; and, if there was something she fancied doing that she had never tried before, she was determined to give it a go. So she took up golf.

Aside from their medical teams, sufferers of MS need the support and understanding of those around them; and this is often not as forthcoming as it ought to be. Some are unable to handle the changes happening to a long-time friend who has suddenly become a patient with a disease that eventually progresses to a stage that they simply don't want to witness anymore. They don't know what to say or do that won't cause offence or upset their friend; so they stop visiting. My sister had one or two so-called friends like this; but fortunately there were many more who rallied round, and that included family.

Sons, daughters and grandchildren accepted how she was from day to day and week to week; and they were always there to help and encourage whenever she needed them. She loved cooking and insisted on making the traditional Sunday cooked breakfast for the family, despite it being rather awkward from a wheelchair. Losing the use of her right hand was another issue that made life difficult; but she found ways to use the left hand for writing, making pastry and so on. Refusing to let MS get the better, her attitude was definitely: never give up.

People with MS will have professional teams to guide them through the various stages of treatment; but the understanding of others is so important. For anyone who needs to know more about MS, I highly recommend a read of the Understanding Multiple Sclerosis Introductory Guide available from MS Research Advocacy Cure Australia.

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