Multiple sclerosis: a patient’s perspective

Laurel C. is a 48-year-old mother of two teenaged children. She has been taking an immunomodulating drug for five years.

AP: When did you find out you had multiple sclerosis?
LC: I woke up one morning in 1997 with numbness and tingling in my left foot. Over the next week, this spread to the whole left side of my body. I lost balance and was dragging my leg and bumping into things. My general practitioner organised a urgent appointment with a neurologist. An MRI scan showed I had multiple sclerosis.

Looking back I had probably had attacks before. In 1992 I developed Bell’s palsy and I remember other attacks.


Conflict of interest: none declared

Self-test questions

The following statements are either true or false (answers on page 47)

3. Interferon beta significantly slows the deterioration of patients with progressive multiple sclerosis.
4. Patients whose disability increases while they are taking interferon beta should have their dose increased.
times when I had tingling in my hands and feet. I had also lined the pockets of naturopaths trying to find a remedy for my fatigue.

AP: How did you react to the diagnosis?
LC: There was a mixture of shock and relief. While there was relief that somebody knew what was wrong with me, I was horrified because my aunt had been disabled by multiple sclerosis and died at a young age.

AP: What treatment did you have?
LC: I was given cortisone tablets. The attack lasted three months and then I started on interferon injections. I was told these may help slow the progression of the multiple sclerosis.

AP: How did you find the treatment?
LC: I have a phobia about needles. Having to inject myself was one of my greatest fears. I could not even watch the video which showed you how to inject. I would sit for half an hour before I could insert the needle. Although I now inject myself every other day I still need to call on my internal strength to do it.

AP: Were there any adverse reactions?
LC: At first the side effects were horrendous. I wondered what I was doing to myself. There was redness, swelling and tenderness at the injection site. I often would wake up at 2.00 a.m., after an injection, with severe pain in my legs. I would be shaking and felt like I had a bad dose of the flu. Sometimes I had to stay in bed all day to recover.

After about a month the side effects reduced. They are less of a problem now, so I would encourage other people to persevere with their treatment as the initial severe side effects should not be long-term.

AP: Have you used any complementary therapies?
LC: I have tried them all, including high doses of intravenous vitamins. While some therapists say they can cure you, none of the therapies worked for me. I did find a mixture of Chinese medicine and massage improved my general well-being.

Changing my lifestyle has also helped. I exercise and have a good diet. High stress levels have an adverse effect on my condition, so I made the decision to retire from full-time work three years ago.

AP: Has the treatment worked?
LC: I have constant tingling, numbness and aches, but I do not let them restrict me. I am able to play golf and I have not had a serious attack since 1997. I see my neurologist once or twice a year and have a check of my blood tests. I would like to have another MRI to see if things have improved.

AP: Is there anything you would like to say to doctors treating other patients with multiple sclerosis?
LC: General practitioners are only going to have a couple of patients with multiple sclerosis, so they cannot be expected to know everything about the disease. They should encourage patients to have a positive attitude to the illness, and to maybe re-evaluate their lifestyle.

When you have multiple sclerosis you have to be prepared to take control and help yourself. General practitioners, therefore, need to be aware that most of their patients will be trying alternative therapies.

Patient support organisations

**MS Australia**

There are MS Societies in all States of Australia. These State Societies provide information and education for people with MS, families, carers and health professionals as well as the general community. They promote awareness of MS, and raise funds for research and service provision. They also provide support services such as the Immunotherapy Support Programs whereby MS Society nurses give information regarding the immune-modulating drugs, teach self-injection techniques, and offer ongoing support and advice in the management of any side effects.

MS Australia represents the national interests of people with MS, promotes and funds research and produces the quarterly magazine ’MS Life’.

**Contacts**

Tel: 1800 2873 67 (1800 CURE MS)
E-mail: public@mssociety.com.au
Web site: www.msaustralia.org.au

Australian Capital Territory
Gloria McKerrow House
117 Denison Street
DEAKIN ACT 2600
Tel: (02) 6285 2999, Freecall: 1800 356 354
Fax: (02) 6281 0817