

What is Transverse Myelitis?

By Mary Bergin_ - RGN,

Group Leader Poole/Bournemouth Transverse Myelitis Support Group

What is Transverse Myelitis? A question I asked myself when I was diagnosed in 2007. It had started with a few pins and needles in my leg and within 12 days I was paralysed from my chest to my toes.

TM is a rare neuro-immunologic disorder with an inflammatory attack on the central nervous system. This can occur anywhere along the spinal cord causing a lesion visible on an MRI scan, this also rules out other causes such as a herniated discs or spinal tumours. Viral screening of blood and urine and cerebral spinal fluid from lumbar puncture for analysis are essential in ruling out other primary auto immune disorders such as Multiple Sclerosis, Systemic Lupus, Lyme's Disease or H.I.V.

It affected me in the acute phase with tingling/burning sensation from the chest to my toes; a T4 lesion was visible in my spinal cord and two lesions on the brain MRI. A complete loss of sensation from chest to my toes over a period of days, resulting in me being unable to stand or walk. Together with the muscle weakness I developed complete bladder and bowel incontinence. This is a common symptom with TM as the demyelination has occurred to the central nervous system. Other patients experience urge, retention or overflow of urine. Sensory loss to the bladder and perineum simply allows the bladder to fill up and overflow. Some patients are therefore urethrally catheterised if appropriate. Common bowel problems are urgency and constipation due to the blocked nerve impulses caused by the spinal cord lesion.

Treatment

I received 3 doses of 1gram IV Methyl Prednisalone followed by oral prednisalone, reducing over a few weeks. To reduce inflammation of the lesion. If this treatment is unsuccessful plasma exchange or more radical immune suppressant therapy may be used. In turn rapid Neuro Physiotherapy can commence. I learned to walk again over a period of weeks. Fatigue was a major problem and the smallest of task would induce lots of sleep. With Neuro Occupational Therapy I adapted and learned to manage this.

My bladder problems had also improved following return of sensation starting with my toes and working up to my chest level (level of the lesion). I was commenced on anti-cholinergic medication which helped the bladder urgency. My bowel problems were then managed with a healthy diet and two tablespoons of dark linseed daily. I also drink up to three litres of water a day and avoid caffeine.

In general the recovery is most rapid in the first 6-8 weeks but can take up to 2 years following an attack. The rule of thirds applied to TM with a third making a full recovery a third making some recovery but living with some disability and a third making no recovery. For the majority of patients the attack is monophasic and idiopathic in origin. However it can be secondary to another auto-immune disease, a recent viral infection or post vaccine. However the research into TM post vaccine is inconclusive. Stress can also be a contributing factor. I had been completely well prior to TM but had been under a lot of stress at work as a Community Staff Nurse.

Ongoing rehabilitation and support is essential for mobility, continence, pain and fatigue management. I stick to a regime of Pilates for core stability, walking my dog daily and swimming. Management of my continence was only by medication. I had no formal assessment or referral to a Continence Nurse Specialist or Urologist until I highlighted to my GP I felt I needed more input. I was then assessed and bladder scanned at home to establish that I had no retention but urgency. I was then referred to a uro-gynae physio for a pelvic floor exercise regime, assessment with bio-feedback and electrical stimulation program for bladder urgency. This has all helped me tremendously not just by me taking some control over my continence but my dignity and self esteem has improved, however self motivation to follow this program is essential for it to be successful.

I relapsed in 2008 and was re diagnosed with relapsing remitting Multiple Sclerosis. I am now the Group Leader and Chair for the Transverse Myelitis Societies Poole and Bournemouth TM Support Group. With over 70 members we cover a geographical area between Tonbridge Wells and Berkshire. The group supports members with a variety of rare neurological disorders from TM, Neuro Myelitis Optica and Acute Disseminated Endocephalomyelitis and Multiple Sclerosis. This allows me to not only support others but is cathartic in my ongoing therapy.

I manage my disability by keeping a positive outlook on life I now ride a motorbike and keep a sense of humour whenever possible, coupled this keeps me strong minded and sane!

See www.myelitis.org.uk (support groups).

Published in the Royal College of Nursing Continence Forum Newsletter January 2010.

