

TM Conference April 2011

A wide range of experts addressed the conference. Below are notes taken at this event. They are written as notes, which hopefully will make sense to the reader.

Doug Kerr

Neurons are the electrical circuits

Axon - the wire connection needs insulating, as the insulation has slipped and left the axon bare, which short circuits

Movement, strength, and sensory are all affected.

Sensory function goes up to the brain. Symptoms – pain, numbness, pins and needles, burning, lack of balance

Motor function starts in brain and goes out, leading to weakness and paraplegia, stiffness, cramps, spasticity

In 2002, Interleukin 6 (IL6) was added to the diagnostic criteria as it has been found to be elevated in acute episode, as TM is a neuro-inflammatory disorder.

TM - motor, sensory (parasthesias, dysthesias), autonomic, monophasic, monofocal

(Parasthesias - abnormal skin sensations (as tingling or tickling or itching or burning) usually associated with peripheral nerve damage; Dysthesias - an unpleasant, abnormal sense of touch, and it may be, or not be, considered as a kind of pain)

TM 1 phase, 1 region, whereas MS is multiphasic, multifocal, ADEM is monophasic, multifocal and NMO is oligophasic

TM occurrence - 15% through vaccination within 30 days for onset of TM, 35% had preceding illness characterised by fever, 20% trauma with direct impact on the back

During acute phase, motor (stiff [increased tone], normal or floppy [decreased tone]), sensory, autonomic, pain

Longer term there is increased tone

Sensory – parasthesis (pins and needles), numbness (absence of sensation), warmth. Sensory system just giving wrong information – this shows signs of pathway intact.

Autonomic – urinary urgency, urinary retention, bowel urgency/retention, sexual dysfunction

Pain – burning, banding (activation of sensory pain fibres) –

Numbness 91%, sensory 97%, pain 68%, bladder 64% catheterisation in acute stage

In acute stage, IV steroids given to 65%, oral steroids 52%, IVIG 6%

MRI 88% abnormal, lumbar puncture abnormal in about 50%

Recurrent TM must have a return to abnormal MRI and/or CSF (10% of people with TM); relapse – more injury uses up reserves, which doesn't come back

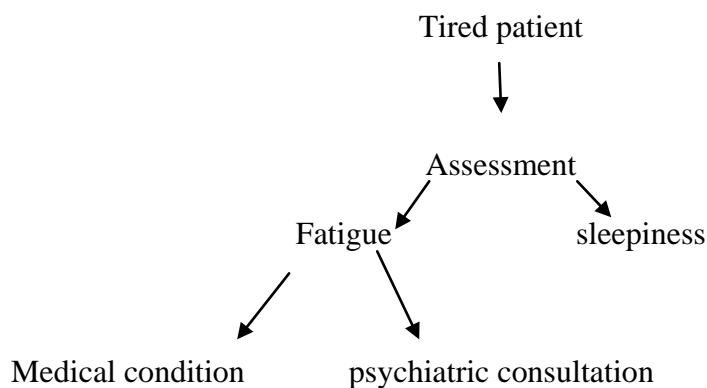
Vitamin D deficiency – vitamin D helps to regulate the immune system and synthesise iron in the body. Calcium, vitamin D and high fibre are all essential for the patient with TM

Dr Charles Ffrench (University of Edinburgh Regeneration Medicine in Neurology)

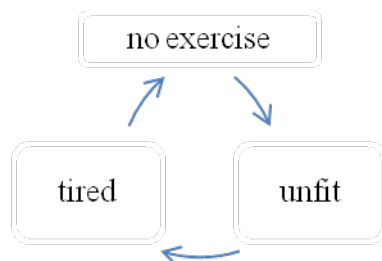
Research is ongoing. There is a new research facility near the Edinburgh Infirmary. JK Rowling, who lost her mother to MS aged 43, has donated £10,000,000.

Carolyn Young - Fatigue and TM

It is common and bothersome



Is the fatigue to do with the TM, or to lifestyle and condition?



Vicious circle

Health promoting behaviours to reduce fatigue and TM - exercise, nutrition, adequate fluids, monitor weight, keep sleep wake cycles, avoid long naps in day (20 mins), if a poor sleeper, maintain bed time routine – observe sleep hygiene

Factors relating to TM which cause fatigue – depression, anxiety, bladder problems, pain, other causes of poor sleep, spasticity (3 x more energy used for walking) and spasms, weakness, deconditioning

Energy conservation – OT – basic principles – where do I expend energy, could I conserve energy, achieve the same result in different way, use of labour saving devices, use the energy for something else, pacing

How symptoms relate to a medical condition (like TM) –

Primary – directly caused, eg nerve damage causing weakness, numbness

Secondary – level separated to cause, eg weakness, numbness causing impaired mobility, falling, loss of confidence

Tertiary – 2 levels separated – deconditioning, depression, obesity

Sleep 7.5 hours, set sleep and rise time. Experiment with 20 min nap or 30 min rest (lying down); 3 meals, experiment with snacks; ensure hydration; exercise in 5 min bursts and build up stamina and strength; minimise painkillers; avoid sleeping pills; caffeine once a day; alcohol is neurotoxic; some fatigue is normal

Dr Anu Jacob – NMO and update on TM Research in UK

NMO_- A relapsing condition, of either TM or ON, multiple spinal cord lesions

NMO – Long term immunosuppressant treatment

Azothiaprין Plasma Exchange

Rituzimab Steroids

National NMO Service based at NHS Liverpool at the Walton Centre and at John Radcliffe, and Aberdeen

UK – TM RESEARCH

324 TM patients used from TM records 2003-2009

222 patients had other autoimmune conditions

TM = 30, MS = 59, NMO = 11, OTHER = 2

60% women, Median age 46

19/30 TM patients had had steroids, 1 patient plasma exchange. 66% were transferred for rehab

93% had some residual symptoms – 60% pain, 53% bladder problems, 72% need some medication, 24% spasms

TM can be the first sign of other conditions

Residual disability in the vast majority.

Dr Anu Jacobs's research is now currently suspended until he finds more patients with an idiopathic TM – our money from the sponsored walk 2010 is still earmarked to continue phase 2 of his research.

Carolyn Young - Bladder Management

Cervical – neck, arms, hands, diaphragm

T – torso

L – hips, legs

S – groins. Toes

TM generally occurs at thoracic level

Weakness of legs and arms, pain – visceral from bladder, sensory alteration, bladder and bowel dysfunction (bladder increased frequency or urge, incontinence, difficulty voiding – hesitancy, sensation of incomplete emptying, reservoir of urine). The bladder needs to contract to empty efficiently – set times under voluntary control. If it is unable to relax completely, then frequent urination occurs; if it is unable to contract completely, and remains partially full, then frequent urination occurs as there is less room. Stagnant urine can lead to infection, increased fatigue, spasticity, and can worsen pain.

Incontinence – genuine stress incontinence, detrusor instability, mixed (GSI and DI) are common, resulting in overflow and fistulae

Bladder instability thus can lead to frequency, nocturia, urgency, urge incontinence, stress incontinence

Assessment is often general, but ultrasound may be used. Micturition will be tested, looking for residual volume, flow studies, dipstick, abdominal pelvic volume/frequency chart, renal function blood test, cystoscopy and video urodynamics are the range of tests which may be carried out.

Treatment – change of medication, pharmacological, self-management (adequate water intake 1500mls day), decrease dietary irritants (coffee, tea, alcohol), constipation worsens bladder.

Who can help – GP, neurologist, urologist, specialist nurse, uro-neurology, nurses funded by industry

Joan Hesther – neuropathic pain

Pain is an unpleasant sensory or emotional experience

Nociceptive – any part of body not nerve (Nociceptive pain is pain detected in either the body's soft tissues (such as muscles and skin) or organs by specialized sensory nerves, known as nociceptors. Nociceptors detect painful stimuli, sending information to the spinal cord and brain for interpretation and response)

Inflammatory – body putting out

Above level of injury, cold & hot in different nerves

Neuropathic – anywhere along nervous system; at level, above or below

Above – sensitive to touch

At level affected – inflammation, ischemic, nerve root involvement

Below – throbbing, burning, stabbing pain; numbness, weakness; muscle spasms; made worse by infection

Depression – pain can be a presentation

Pain is rarely psychological in origin

Severe – anything which affects spinal cord; affects all activities; sleep; mood; work; relationships

Why – chemical neurotransmitters released; change in response to injury; winds up the brain.
Injury is like a computer virus

Management of pain – assessment of pain, mood, impact of pain in function, rehabilitation.
Set goals, but make them small ones

Medication used - Gabapentin, Pregabalin, intravenous Lignocaine (Australia), Amitriptyline, Nortriptyline, Duloxetine, Ketamine (unpleasant side effects), other anti-epileptic drugs, opioids – morphine suppresses immune system; long term suppress hormones; Tapentadol; Clonidine, Baclofen, cannabis

Psychological – relaxation, biofeedback, counselling, mindfulness, imagery, CBT, development of pain coping strategies, TENS and acupuncture, spinal cord stimulation, deep pain stimulation. Difficult to control – multidisciplinary team

Question Time with Guest Speakers

Alcohol – neuro toxic effects on the immune system

Lesions at T6 and above are susceptible to Autonomic Dysreflexia. Treat the cause before the problem. Can present in A+E with very high blood pressure and pulse and sweating and clammy. Causes are often constipation, very full bladder, or an ingrown toenail. Example of one member with recurrent night sweats and high blood pressure had been wrongly treated for the menopause with HRT no improvement. Cause was her TM and symptom of bladder problems.