

Health Condition Insight Report into Transverse Myelitis

This report was completed by the Transverse Myelitis Society in October 2013 for use by assessors at ATOS and CAPITA when assessing people living with Transverse Myelitis for the Personal Independence Payment (PIP). PIP helps with some of the extra costs caused by long-term ill-health or a disability for UK citizens aged 16 to 64.)

This report consists of four sections:

- 1. The condition explained- An overview of Transverse Myelitis*
- 2. Areas of daily life where restriction occurs - How Transverse Myelitis impacts an individual's daily life*
- 3. Recommended communication approach to claimant with this condition at PIP assessment*
- 4. Misconceptions about the condition*

Although the information in section 2 aligns to the PIP criteria and in section 3 it aligns to how the PIP assessors work, the information is useful to anyone living with TM whether they are applying for PIP or not.

1. The condition explained

Transverse Myelitis (TM) is a rare auto-immune neurological condition where there is an inflammatory attack to the myelin sheath surrounding the spinal cord. Inflammation can occur anywhere on the spinal cord and the person affected can experience symptoms of neuropathic pain, muscle weakness, paralysis, bladder/bowel dysfunction and other symptoms from the point of attack downwards in their body. If the cervical region of the spinal cord is affected, the person may experience problems in their arms and hands as well. If the thoracic region is affected, the person tends to experience problems from the chest downwards. If the lumbar region is affected, the waist downwards including bladder and bowel is affected.

TM is typically a one-off attack (a small percentage may experience recurrent attacks) that results in people experiencing on-going residual symptoms that can be life-changing: partial or total paralysis or muscle weakness and hence mobility issues, bladder/bowel dysfunction, sexual dysfunction, chronic neuropathic pain, intermittent muscle spasms or constant stiffness known as 'spasticity', fatigue, and/or depression. Neuropathic pain is different from nociceptive pain. It results from the injury to the spinal cord and comes from problems with signals from the nerves. Neuropathic pain is often associated with abnormal sensations such as a stabbing, pins and needles, buzzing, numbness, itching, burning, coldness or heaviness. Neuropathic pain can also be caused by non-painful stimuli such as hot and cold water, when a person is touched by someone or even wearing clothes.

Steroids are often given to reduce inflammation. Plasma exchange or more radical immunosuppressant therapies may be used if steroids do not work. Neuro-physiotherapy is given to help regain muscle strength, reduce stiffness and spasticity, improve sensation, and manage pain, balance and gait issues. However, neuro-physiotherapy is not always available and may not always have these outcomes.

There is no set pattern to the recovery process from TM; it is uncertain and the prognosis is unpredictable. Everyone recovers differently and at different rates. Some people who get TM make a full or nearly full recovery with a few residual symptoms. Others make a partial recovery and may have mobility issues. Other make no recovery and have to use a wheelchair for part or all of the time. They can also experience

on-going residual symptoms that can be debilitating such as fatigue, chronic neuropathic pain, bowel/bladder dysfunction, spasticity, and/or depression. There is currently no cure for TM.

TM is a variable condition. The experience and impact of TM can vary from one individual to another, and can change from day to day and fluctuate during the day. Some may experience all or some of the above mentioned on-going residual symptoms to varying levels of degree over a period of time and even during the day. Changes in the weather can also have an impact on the severity of symptoms on a daily basis. However, some symptoms do not fluctuate such as paralysis and bladder/bowel issues. If a person has recurrent TM, there will be variation in how one is affected from episode to episode.

The daily problems encountered by people living with TM differ greatly. The main problem being that the messages going to the affected spinal cord from the brain become slow or distorted. An idea of how it can impact on the life of someone living with TM is outlined below.

2. Areas of daily life where restriction occurs

The following describes the impact of TM including on-going residual symptoms a person may live with and how that affects a person's life.

People living with TM often struggle with balance. In the kitchen some people may have a perching stool, however this does not help with tasks such as lifting food out of an oven or carrying full/heavy pans they may also struggle reaching for things out of low or high cupboards. For the people left in a wheelchair cooking can be difficult because appliances may have been installed and built for everyone else in the house or there may not be enough room for suitable adaptations. People with TM who have lost core strength may not be able to sit for long periods without pain and so cannot use perching stools, as these chairs do not offer enough support for the back and sides and the seat may not be large enough. People with TM often struggle carrying drinks due to balance as they can become 'wobbly'. People with TM often use a shower chair because they cannot stand and balance for long. They may also need someone to watch over them to ensure they do not slip and to wash feet/hair.

Many people living with TM have limited mobility – often they use aids such as poles, wheelchairs, crutches and walkers to get about. They also tend to walk slower than the average person and can easily get distracted by others walking in front of them or moving objects such as cars – this can make crossing a road difficult. Balance, gait and spasticity issues means that some people living with TM walk with a staggered motion. This makes it difficult to walk on the slightest of inclines and stepping up or down from the kerb can require a lot of concentration. Navigating steps can also be an issue.

There are two types of fatigue – neuro fatigue and task driven fatigue. People living with TM are often affected by both types fatigue and this requires the individual to make changes to their lifestyle, work and family schedules.

A person living with TM has a certain amount of energy to spend in a day and once that is spent, the person needs to rest. Due to TM, it costs the person more energy to do basic daily tasks like walking, bathing, dressing, making meals, reading, etc. This point in the day can come at any time with no warning. So people cannot always stick to plans or appointments they have made and have to cancel at short notice.

Often people have to complete all tasks early in the day which means that tasks that need to be completed later in the day, like cooking an evening meal, becomes extremely difficult. Some find that after the morning routine of washing and dressing, there is no energy left for anything else including cooking.

Task-driven fatigue makes things like walking far, physiotherapy and dressing/undressing harder and slower. The body has to work harder due to the damage done to the spinal cord. As more tasks get completed through the day, fatigue makes the tasks slower and more difficult.

People living with TM need to figure out how to do daily tasks much more efficiently and get help in doing them so as not to spend their energy levels too quickly. Fatigue can also negatively impact cognitive function.

People living with TM can suffer a loss of sensation. This makes it difficult to distinguish between hot and cold water – so the person would need supervision to ensure bath/shower water is the right temperature. Loss of sensation also means that the people living with TM that can walk find it difficult walking over different surfaces and makes walking from one surface to another extremely problematic. Muscle weakness and loss of sensation means that the individual has to find alternative ways of doing things. If the person has lost sensation and strength in their hands, they will have to look at what they are carrying so they do not drop it. They can also lose the ability distinguish between sharp and blunt objects, and are at risk when preparing food.

A person may experience an ‘autonomic disturbance’ resulting in poor regulation of body temperature. The person may experience hot flushes or extreme sweating, which can be embarrassing. The person may also sweat yet feel goose bumps at the same time or feel heat on one side of their body and cold on the other.

Some people living with TM often have a lot of pain or nerve spasms. This can make day to day tasks extremely difficult and affect coordination. Bending can be especially difficult – people living with TM would need help putting on shoes, socks and even underwear, and also help with everyday tasks such as loading/unloading the dishwasher/washing machine, and getting into and out of the bath. People with TM may have difficulty with fine motor movements, such as using a pen or typing, due to spasticity and lack of control and strength in their hands and fingers. Activities and jobs that require fine motor control of the hands may no longer be possible for the person to do. Some people may experience their legs ‘jumping’ and toes ‘flicking’ uncontrollably and this can be visible to others. Others experience a band-like sensation and when this occurs around a person’s middle, it feels like one’s breathing is being compromised. For some, standing for any length of time is not possible due to the pain.

People living with TM also tend to suffer bladder and bowel incontinence as well as constipation and bladder/bowel retention, which can cause infections. For some people, the message from the bladder to the brain is so slow that it gives a very short time to get to the toilet and this mixed with mobility problems can cause incontinence. Even after a person has learned how best to work with these bladder and bowel issues, accidents still occur, which is very embarrassing whether the person is at home and requires help in cleaning up after him/herself, or in public. For others, the person may feel they need to make frequent trips to the toilet with no relief. Some people need to self-catheterise several times a day to empty the bladder. This can be done independently by the individual. But for people who have loss strength and dexterity in their hands, help may be needed. Self-catheterisation can result in urinary tract infections at times. Planning journeys, errands and activities outside the home can be difficult as one has to ensure there is an appropriate place to self –catheterise. For those people who cannot control bodily functions, for example flatulence, leaving the home can be distressing.

Medication is given to reduce neuropathic and nociceptive pain, and manage symptoms such as muscle spasms, fatigue, bladder/bowel issues and sexual dysfunction. However, neuropathic pain and fatigue are not easily treatable by medication. Medications are often given on a trial to see if they help the individual. Sometimes the medications do not work and it can take a long time to find the right medication or combination of medications that help an individual. The medications may work effectively one day and not

the next and this can affect what the person is capable of doing. Some of the medications have a marked side effect profile causing tiredness during the day, a feeling like one is living in a fog, nausea, headaches, dizziness and even type 2 diabetes and a fatty liver. The individual may then have to take additional medication to manage the primary medications' side effects. Some medications can be immunosuppressive and that may make people more susceptible to contracting common illnesses like cold or flu, which can severely affect their ability to do their usual daily tasks.

With TM, an individual's spinal cord is working at maximum capacity so it is easily compromised, when the person overdoes it one day or contracts a common infection such as a cold, flu, ear infection, etc. These exacerbate TM symptoms and it takes the person longer to recover than someone who does not have TM. For example, a common cold can result in someone with TM losing function, such as not being able to walk, for several weeks.

TM can also cause additional health issues. For example, if someone's gait is compromised or one side of their body is stronger than the other, the person will compensate for this which results in secondary problems.

Due to the often sudden and debilitating nature of TM, many people suffer feelings of isolation and loss of self-esteem as they and their families/friends haven't had a chance to prepare for the challenges that now present themselves. People with TM may get depression and anxiety, as activities that were once taken for granted as "normal" - daily activities of washing, cleaning and cooking as well as social activities - now need planning and adjustments. Often the planning itself brings on fatigue which means the activity cannot then be completed. For some people living with TM, a social activity or journey may require them to rest for several days in advance of and afterwards.

People with TM may also have emotional issues, as they find it frustrating to not be able to physically do things that their minds think they should be able to do. The person with TM has to put themselves in a lot of "try it and see" situations, and it can be demoralising each time they find something else that they can't do. The nature of friendships changes too, with the friend either having to play the role of a carer when with the person with TM or with a separate carer being involved in personal relationships to support the person with TM. Sometimes trying to cope with everything can feel very overwhelming.

3. Recommended communication approach to claimant with this condition at assessment

Some will be unable to drive, or use public transport, and may therefore require a home visit.

If a person living with TM has bladder or bowel issues, s/he might be embarrassed to talk about it.

As TM is a fluctuating condition, how the individual appears on the day of assessment may not be an accurate reflection of how their condition affects them over the course of the day or a longer period of time. Instead of discussing a typical day, they should be asked about how TM affects them on a bad day and how their condition might fluctuate during the course of a day.

Some of the on-going residual symptoms, which can be debilitating, may not be visible to the naked eye such as fatigue, neuropathic pain and bladder/bowel dysfunction. A person may look well on the outside but feel very poorly on the inside.

4. Misconceptions about the condition

Due to some of TM symptoms being invisible as described, members of the public (including family members and friends), sometimes do not understand the limitations and changes to the individual's capabilities as the individual looks healthy.

Some people also think that because the person looks healthy, s/he will get better with time, which may not be the case.

The person with TM may not like to dwell on their condition, and may have got used to underemphasizing the effect it has on them as a coping strategy.