The Transverse Myelitis Association

couldn't be, someone from our family helped.

Jesse will be seven years old in three months and is in the first grade. When we look back at those first six years, we can honestly say they were hard, at times frustrating and exhausting, but they have been the most fulfilling. This will be the third year in a row I have gone to Jesse's class to share with the children about who his mama is and all about being in a wheelchair. It wasn't until recently that we realized Jesse had given little thought to the fact that I am in this chair, when he asked me where all the other mama's wheelchairs were. He's very proud of his mom and loves it when I come to his class. In turn, Myk and I are extremely proud of our son, especially when we see how easily he interacts with anyone who is different in any way. He is a constant reminder of what a good decision we made seven years ago.

Member Questions and Answers from Joanne Lynn, MD

Joanne Lynn, MD is an Assistant Professor of Neurology at The Ohio State University. She is currently on the staff of The Ohio State University Multiple Sclerosis Center and has special interests in clinical research on the treatment of MS. Dr. Lynn serves on the Medical Advisory Board of The Transverse Myelitis Association. If you have questions for Dr. Lynn regarding the Transverse Myelitis condition, please send those to Sandy Siegel; we will attempt to have your questions addressed in the next newsletter.

The following information is offered as a

general response to questions related to Transverse Myelitis and is not to be construed as a specific medical recommendation for any individual. This information is based on the information provided in a brief question and is without the benefit of a complete history or an examination. Any decisions regarding diagnosis or treatment should be made in consultation with your personal physician who is best suited to make appropriate medical recommendations for you.

What is a lesion? What are doctors describing when they explain that they have identified a lesion or lesions at particular levels of the spinal cord in regard to TM? Why are people effected in one place on the spinal cord and others over larger areas of their spinal cord, and still yet others in non-contiguous areas - is that possible? Why do some people with TM have lesions and others do not?

The dictionary definition of the word *lesion* is an abnormal change in the structure of an organ or tissue due to injury or disease. Most patients with TM undergo examination of the spinal cord by MRI (magnetic resonance imaging). Often this type of imaging will display an area of abnormal signal within the cord. which is circumscribed and well defined; this is a detectable lesion. Lesion is a very nonspecific word meaning any abnormality of structure. In TM, the abnormality may be the result of inflammation, swelling or destruction of cord tissue.

Sometimes there is tissue damage that does not show up on a MRI of the cord. In this case, a microscopic lesion or area of inflammation or tissue injury is presumed to have occurred at a certain level of the cord based on findings on neurologic examination, but the MRI was not able to pick it up. One would assume that if a biopsy was done of the injured area of the cord, abnormalities such as inflammation would show up on microscopic examination of the tissue.

It is true that the lesion may be small, limited to one level of the cord, and well localized. Other people with TM have a lesion that spans many inches of the spinal cord. And yet others can have multiple lesions at different levels of the cord. We do not know the reasons for this variation at this time. However, if one assumes that TM is caused by inflammation of the cord caused by the immune system reaction to various infections, etc., then it is understandable that the white cells of the immune system can come to any level of the cord through the bloodstream.

People are told they can resume all of their physical activities, but sometimes when they have completed these activities (running, walking, weight lifting, swimming, aerobic exercise, golf), their symptoms are intensified for a while afterward. Are these people hurting themselves from a healing standpoint? Are they causing any damage to the nerves that have been injured? How should a person evaluate the type and amount of exercise they are doing? What factors need to be considered?

There is more information about exercise in multiple sclerosis than in transverse myelitis. However, the basic principles regarding exercise in MS also apply to TM and other spinal cord injuries. An interesting phenomenon can occur when a person with MS experiences an increase in body temperature either by exercise, hot external temperatures or fever. Weakness or other neurologic symptoms may worsen. This is attributed to the fact that electrical

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nerve signals do not travel through demyelinated nerve tracts as well as through normal nerves at hot temperatures. (Myelin is the insulation around nerve fibers; it is destroyed in MS). Some people with TM also have demyelination of parts of their spinal cord and may also experience worsening of neurologic symptoms such as weakness, numbness, tingling or other abnormal sensations when they exercise and raise their core body temperature. This transient worsening does not mean that another attack of multiple sclerosis or transverse myelitis will occur with exercise.

Because of this worsening of function with elevated temperature, neurologists used to warn against exercise in MS. However, there is more understanding now of this phenomenon and most neurologists would recommend exercise for people with MS and TM if certain principles are observed. A proper exercise program designed for a particular individual should include type of exercise, duration, frequency, and intensity of exercise.

Stretching is an important part of any exercise workout but is especially important for people with spinal cord injury who may have abnormally increased muscle tone (called spasticity). Muscles and tendons should be stretched gently before starting on an exercise routine. It takes more energy to exercise when there is significant spasticity.

For those who have significant weakness in the legs, it is best to start with gentle aerobic exercises such as walking if possible, propelling a wheelchair, swimming, water aerobics, bicycling. The goal should be to gradually increase endurance and stamina. As Randall Schapiro, MD has written, the "no pain, no gain" approach to exercise is exactly wrong for people with MS and other spinal disorders. If there is partial weakness, trying exercises that require too much resistance or doing too many fatiguing repetitions may lead to injuries such as sprained ankles, etc. Exercise programs must be individualized according to the person's level of training and type of underlying neurologic problems. However, exercise is strongly recommended for people with MS and should be for people with TM also.

In fact, a recent study of 46 patients with mild to moderate disability from MS who could all walk, some showed that an aerobic exercise program of three supervised training sessions per week for 15 weeks had significant benefits including improved fitness and strength and reduced body fat. A 5-minute warmup period was included and care was taken to control the air temperature and to prevent overheating by fans. In addition to the obvious benefits. the exercise group also showed some benefits in bowel and bladder function, fatigue and depression. This study was reported in the April 1996 issue of Annals of Neurology.

You may find it useful to read about the stretching exercises described in Dr. Schapiro's book or to ask your physician for a referral to see a physical therapist to help design an individual exercise program. Obviously, you should consult with your personal physician for recommendations regarding exercise. However, I would say that people with TM should not be scared away from exercise by worsening of tingling in the legs, etc. It is unwise to exercise to the point of significant pain as your body is probably trying to tell you that you are injuring it. The guide here is "start slow, and go slow."

Could you speculate as to why TM impacts one particular area of the spine and not another? Is it a random process? Could there be any influence from a physical episode such as a strain or a blow to that area?

I don't think that I can speculate in any meaningful way about why one area of the spine is affected in TM and not another. It has been noted that the thoracic spine is most frequently affected, followed by the cervical and then lower levels. There have been attempts to link many neurologic illnesses to trauma including multiple sclerosis, amyotrophic lateral sclerosis (Lou Gherig's disease), Parkinson's disease, etc. However, there has never been good evidence to back up these proposals and trauma would seem to be an unlikely cause for most episodes of TM. It should be noted that the spinal cord can suffer injury from trauma with resultant high signal lesion in the cord which could mimick TM. Preexisting canal stenosis (not enough room in the canal for the spinal cord) could also predispose to spinal injury with trauma.

Is there a causal relationship between TM and seizures - any relationship?

By definition, TM normally affects only the spinal cord. Seizures are caused by abnormal discharges in the brain. Therefore, TM should not be a cause of seizures. However, there are processes of inflammation that may affect both the brain and the spinal cord at the same time. In those cases, the TM would be caused by inflammation of the spinal cord and the seizures by inflammation or injury to the cerebrum (part of the brain). Reference: Randall T. Schapiro, MD. Symptom Management in Multiple Sclerosis. New York: Demos Medical Publishing Co., Inc., 1998.

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