Motor Neurone Disease
By Ruth Werner, LMP, NCTMB

My stepsister Robin made the decision to have no intervention in the progression of her disease. She was determined to stay at home and to die at home. She wanted no feeding tube or breathing apparatus. When Robin decided that she had had enough, it had been just one and a half years since her diagnosis. She asked the family to the house, and she asked me to give her one last full massage session. As I worked with her, family members filtered in and out of the room, visiting. Robin was making her usual groans of delight about the massage she was receiving. She died peacefully two days later with her family around her. I have now collected a group of ‘Robin’s Angels’, massage therapists who go into the homes of people with ALS to massage them. There is no greater reward in this work than to be able to help victims of ALS in this way. (As shared by Debra Roof, LMT).

General background of MND
Motor neuron disease (MND), called amyotrophic lateral sclerosis (ALS) or Lou Gehrig’s disease in the United States, is not a common disorder, but it is a dramatic, rapidly progressive, and ultimately fatal neurologic condition.

MND causes damage to two groups of motor neurons: the upper motor neurons in the descending tracts of the spinal cord, and the lower motor neurons that have their dendrites and cell bodies in the ventral horns of the spinal cord, with long axons that reach into the peripheral nervous system to supply voluntary muscle cells. When these muscle cells are deprived of neurological stimulation, they atrophy and die. MND is of special interest to massage therapists, because while motor control is progressively lost, sensation stays intact. This means that people with this serious disease can receive wonderful benefits from massage therapy, both in the way of preserved function and in relief from pain and anxiety.

MND usually affects people between forty and seventy years old. The average age at diagnosis is 55. Men get it slightly more often than women do. About 1,200 Australians have been diagnosed with MND, and about 400 new diagnoses are made each year.

Etiology of MND
MND is considered to be idiopathic, that is, a disease of unknown origin. Several contributing factors have been identified, mostly focusing on a central nervous system chemical called glutamate. Glutamate is an excitatory neurotransmitter, and prolonged exposure has been seen to cause nerve damage. Glutamate appears to collect in the synapses of people diagnosed with MND.

While the vast majority of MND diagnoses involve no recognised genetic mutation, a small percentage (about ten to twenty per
and Massage

cent) of people diagnosed with MND appear to have a familial pattern. An even smaller portion of that group has a recognised genetic profile, called an SOD1 mutation. This mutation prevents the removal of excessive glutamate from synapses, leading to motor neuron damage and eventual muscular atrophy.

Regardless of whether MND is classified as sporadic — that is, with no recognised genetic history, or familial — about one-third of the motor neurons that supply any muscle must be destroyed before atrophy is apparent.

Other contributors to ALS may include a genetic susceptibility to damage from free radicals (this has been reliably established in the case of familial ALS), autoimmune disease, mitochondrial dysfunction, exposure to some environmental toxins, and a history or repeated head trauma.

**Signs and symptoms of MND**

Symptoms of MND are sometimes classified by whether the disease affects upper motor neurons or lower motor neurons. Upper motor neuron problems manifest as progressive spasticity, exaggerated reflexes (including the gag reflex), and a positive Babinski sign (the great toe goes into extension rather than flexion when the plantar surface of the foot is stimulated). Lower motor neurons are involved when weakness, atrophy, muscle cramps, and fasciculations (uncontrolled twitching) are present.

Another way to classify MND is by whether spinal nerves or cranial nerves are affected first. The spinal form of MND is the most common, affecting about 75 per cent of all patients, and it usually shows its first symptoms in the distal parts of the extremities: problems with fine motor skills (buttoning a shirt, frequent tripping or stumbling) may be the first signs. One side is often more severely affected than the other. Gradually the loss of function moves up the limbs to the body’s core, culminating in loss of control of the diaphragm and muscles that control swallowing and eating.

About 25 per cent of MND patients have the bulbar form, which affects cranial nerves. It tends to be more aggressive, since it begins with changes to muscles involved in speech, swallowing, eating, and breathing.

The nerve damage seen with MND affects motor neurons only; sensory neurons are left intact. This can be a painful process, however, with muscle spasms, constipation, and the gradual collapse of the body as gravity puts stresses on muscles that have no power to respond.

While MND doesn’t usually affect intellectual capacity, many patients become emotionally very fragile, and the risk of anxiety, depression, and many other negative mental consequences is high.

**Treatment of MND**

Only limited options are available to treat MND. Discoveries about the effects of glutamate in CNS synapses have led to the development of some medications that can slow this process. In this way life can be preserved for several months, but the disease is not halted or reversed. More drugs to deal with the effects of glutamate are still in development.

Other treatments for MND focus on mitigating the worst symptoms. Exercise and physiotherapy may help to preserve function and boost muscle strength. Heat and hydrotherapy may help to manage painful muscle spasms. Assistive devices like braces, canes, and finally a wheelchair can prolong mobility and independence. When the disease affects muscles of the face and neck, eating may become prohibitively difficult; at this point a gastrostomy (stomach tube) may be recommended. And since this disease can have a profound affect on a person’s mental state, psychiatric counseling for anxiety and depression may be advised.

**Prognosis for MND**

This disease is usually aggressive and progressive. Once diagnosed, it usually results in death within two to ten years. Most patients succumb to pneumonia or to cachexia (extreme weight loss). Surprisingly, a few MND patients have survived for years, or even decades. It is not clear what makes these people, who include the British physicist Stephen Hawking, different from other people diagnosed with MND.

**Massage for MND**

MND is not contagious, and it doesn’t cause numbness or other sensory dysfunction. Furthermore, even though MND patients eventually become immobile and very thin, they tend not to develop bedsores. Therefore, carefully performed massage can be a safe and welcome addition to a patient’s treatment plan.

Massage will not reverse this disease process or probably even have much impact on its progression. However, the benefits massage has to offer in the way of compassionate, educated, caring touch are important. Massage therapists can ease muscle spasms, and preserve range of motion at joints that become atrophied. We can provide a brief vacation from the stress and anxiety of living with this difficult, life-threatening disease. Therapists who are invited to work with MND patients should be in communication with the rest of the healthcare team to insure the safest and most comfortable (and comforting!) interventions are offered.
For the past two years I have treated Eric for ninety minutes in his home every week. Before he lost control of his facial muscles, I could understand his slurred speech that sounded like a post-stroke patient or someone who’d had too many whiskies. Now all he can do is grunt and point, so he communicates with the aid of a small computer keyboard through which a stilted robotic male voice ‘speaks’ as he types. He can no longer walk, and moves about his home with a fancy, battery-operated wheel chair.

In these two years he has changed from being a hearty, muscular, chiseled, strong man to a man who leans on one entire side of my body as he takes slow, uneven steps from his wheelchair to the massage table.

Eric says that without the weekly massage sessions, his medication level would be much higher, he would have more muscular spasms, and the pain in his shoulder would be unbearable.

Approaching a body with ALS is more than a little tricky. Spasms occur without warning; the beginning of slow, even, medium-pressure effleurage while applying lotion to a lower extremity can result in a board-hard leg that extends as if levitating off the table of its own accord. All I can do is place my hand on the leg, and slowly coax it back down to the table. Arms that used to open wide to hug those around him would become contracted against his body were it not for the slow, sometimes painful ROM we perform of all arm joints each week. Every bit of therapy takes twice as long as working on a ‘normal’ body: if he’s not stretched, he contracts; if I go too fast, he spasms; communication is cumbersome; and creating pain, though unintended, is always a possibility.

The end of life for an ALS patient is often related to diaphragm function. It can slow down to the point that the decreased lung capacity invites pneumonia, which is the ultimate threat of any sedentary human. For this reason, aggressive (though careful) resisted breathing exercises are part of every session. This means I have to get up on the table and place my hands just at his 10th rib, while trying not to dislodge his feeding tube or the dressing around his diaphragmatic monitor. Then I encourage him to push against me with his breath, while I’m wobbling all over and trying hard not to fall off the table. This brings on a lot of laughter – therapeutic in itself for someone with limited lung capacity. I hover above him while he laughs, and tries to take a deep breath. I watch as he deems himself victorious if he can take at least one deep inhale and exhale: it’s enough to bring a strong woman to tears. The victory is so miniscule to most of us, but this effort could help extend his life.

Presently, there is no cure for this frustrating and frightening disease. But massage therapy can make a profound difference in the pain the patient experiences, and in the progression of muscular contractions. Every case is different, but the intelligent and dedicated therapist can adapt her skills to these very special patients, and help make the damnable progression of ALS more tolerable as it is accompanied by loving touch.

(As shared by Charlotte Versagi, LMT, NCTMB.)

Ruth Werner is a massage therapist, writer, and educator with a passionate interest in the role of bodywork for people who struggle with health. Her book, A Massage Therapist’s Guide to Pathology, is used in massage schools worldwide. Ruth can be contacted at wernerworkshops@ruthwerner.com.

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