

## Dealing With Charcot-Marie-Tooth Syndrome

Edgar Romero, DC, DACNB

Chiropractic neurology has given me the great privilege of seeing many patients with complex conditions and varied symptoms. Just recently, I treated a patient with Charcot-Marie-Tooth syndrome, a genetically progressive, peripheral neuropathy with motor loss of the extremities and some sensory loss of the hands and feet. To be perfectly honest, when the patient (who is an MD, to boot!) presented and gave his clinical diagnosis, I nodded appreciatively at the gravity of his situation and tried to remember the board question and the distinguishing characteristics of his particular disease. I tried to seem sympathetic, hopefully all the while not giving away that my mind was working furiously to figure out what the heck the disease was and how it was supposed to present.

Yes, my fellow physicians, even a board-certified neurologist does not remember all the obscure names of diseases that were once known and well-studied for board exams. In fact, they inconveniently leave our neurons once the frequency of firing of "Charcot-Marie Tooth syndrome" is decreased to the extent that permanent plasticity of our temporal lobe is not achieved. I, for one, do not have one of those encyclopedic memories (although it is not too bad, I'd like to think), and I am very glad to have the reference books at hand to look up the interesting cases that often come into my office.

The point is this: Who cares about the name, anyway? Give someone a label, and we are basically giving them a diagnosis to "call their own" and tell everyone about, as well as a *name* to go with the suffering. There is no doubt that having a firm diagnosis brings a level of comfort. I, for one, would rather know what is wrong with me than to have some clueless physician guess and say, "Let's see what happens when we try this!"

Hopefully, we are all in this profession to get sick people well. In my experience, it is a great deal more important (and I believe one of the brilliant aspects of my neurological training) to know how to help something than to give it a name. In the end, it doesn't matter if we call it Charcot-Marie-Tooth syndrome, a herniated disc, the ever-elusive "pinched nerve" or a decreased cerebellum with concomitant hemisphericity complicated by vascular dyscrasias. My training was focused on seeing what was there. Who cares what the name is if you don't know what to do with it? On the other hand, avoid the names and we are left with what is there. Do they have sensory loss along one dermatome or is it across various innervations? Is there weakness in a pyramidal pattern or is there generalized hypotonia? Are there autonomic signs related to vascular abnormalities or are we seeing hormonal signs that may be related to neurological disorders? Are the cranial nerves intact? Do the emotions correspond with the hemisphericity we think is present or are there conflicting signs that may mean transneuronal degeneration of the opposite side?

Our value as physicians - as doctors of chiropractic - is not in naming a condition, but in treating the patient who *manifests* with the condition; is it not? In that case, it really doesn't matter what we call the cause of the malady - just what we do with it. Of course, there is a responsibility inherent to that notion. It means we better darn well know what we are looking at, or how in the world can we treat it? I have seen numerous cases of "pinched nerves" come into the office, diagnosed by everyone and anyone with a degree. Yet, when examined, there are no signs of

atrophy of musculature; there are no atrophic skin changes, no signs of sensory loss. Based on neurophysiological principles, the probability is not very great that these signs and "pinched nerves" are the same. In those cases, I do not care what name was given, who thought what, or what an MRI may say. All that matters is what the patient's nervous system is telling you and if you are listening.

Another patient came in recently with a diagnosis of arachnoiditis. Arachnoiditis is another progressive disease, whose hallmark is scarring and inflammation in the dura, leading to complex neurological sensory syndromes, constant, unremitting pain and the use of heavy medications just to function on a daily basis. Another earnest nod from me and another search in my memory for what it was. Had I ever even heard of that one? I wasn't sure. This wonderful patient, very informed and educated, actually had a text with her, the whole of which was on arachnoiditis. I didn't even know that it was common enough to have its own text.

Having moved past my blank expression, we proceeded to examine this poor lady's years of debilitating pain, two spinal surgeries, an electrical stimulator placed directly into her back so she could stimulate herself as needed, sleepless nights, miserable days, and a life nearly centered on her suffering. We proceeded to find weakness of both the anterior and posterior musculature of the right side of her body in a non-pyramidal distribution. Sensory examination revealed decreased sensation to vibration and pain of the upper extremity on the right side, decreased vibratory sensation of the right lower extremity, but increased pain sensation to the point of allodynia of the right lower extremity. Hemispheric evaluation revealed left cortical signs consistent with her right cerebellar signs. The hypersensitivity reaction of the lower extremity was a possible sign of TND of the left cortex at the saggital cortex, but more likely a vascular compromise into the right lower extremity secondary to the cerebellar-pontine lesion. Further evaluation of the lower leg revealed atrophic changes to the right lower extremity, with skin changes.

The treatment: Increase the frequency of firing of her right cerebellum and left cortex in a progressive manner, limited to her metabolic rate of firing and based on her ability to process the changes. Like exercise, we start her easy (no adjusting that first visit, only indirect stimuli) and build into a beautiful symphony promoting neurological stability. Interestingly enough, her surgically implanted electrical stimulator had been placed on the wrong side. It was implanted to help alleviate her pain only, with no consideration for the neurology involved with her condition. Not a malicious oversight, but a serious enough mistake that this poor patient worsened her own neuraxis every time she used the stimulator. She would further imbalance an already imbalanced nervous system, all for a very short-lived improvement in her pain. We educated her on her nervous system, explained the complicating factor of the stimulator in her ability to be stabilized and fired up her system carefully but progressively. In three weeks and three visits, she had been without pain for three days; the first time in 15 years that she can remember. She is increasing stability every day and is as grateful as can be. Who cares what the name of the diagnosis was?

And what about my good friend, the MD with Charcot-Marie-Tooth syndrome? At the end of care, he still had Charcot-Marie-Tooth syndrome, of course. He still has sensory loss and still has rather severe motor atrophy and weakness. How-ever, he has seen improvement with strength in both hands. This was surprising, since he was under the impression that his changes were permanent and irreversible. He was also pain-free, which was his much-hoped-for result.

Not everything is changeable, not everything is known and there are a million things I have yet to figure out. Still, I would rather have a suffering patient with a "communicating" neuraxis than a board-question diagnosis where my first reaction would be "Refer!" Forget the names, focus on what is there, and treat what you find. You may be surprised by the results, as I often am.

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