Perspectives of a patient and a physiatrist on neuralgic amyotrophy

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A patient's perspective

The pain in both shoulders started around midnight and got worse as the night went on. It felt like someone was stabbing me. No matter what position I was in, I couldn't sleep. In the morning, I went to work. The pain was bearable, but when I picked up something a little bit heavy, it felt like somebody was trying to pull my arm out of the socket. At that point, I realized, "Okay, this isn't just aches and pains."

At the first hospital, they didn't really know what was wrong with me. The doctor was thinking maybe shingles. They gave me some steroids and Tylenol 3s and sent me home. The pain got worse throughout the day. Again, I couldn't sleep. In the morning, I called my family doctor. Because of COVID-19 restrictions, he just talked to me over the phone and suggested I go to another hospital. They did x-rays in emerg and the doctor tried to get hold of a specialist, but they weren't around. They released me and within a couple of days, I got a call from the specialist's office.

Within a week of the pain starting, I noticed I had weakness, especially in my right lower forearm. I couldn't lift anything. My fingers and thumb felt paralyzed. I've always had a good grip, but I just had nothing there. That was scary. I ended up quitting my job in a stockyard because I couldn't do it. I became self-employed. I had no insurance, so I was worrying about money. I wanted someone to tell me what was wrong. The specialist thought I had something called Parsonage–Turner syndrome. He said this thing could heal itself, or it might not, but it's a long process. And I was just like, "Well … ?" A few months later, he did a nerve test and realized the nerves weren't connected in my arm.

When you break your hand, you know how you broke it and how to fix it. But with this ... is it going to heal? Is it going to be like this forever? It feels like you're in a cloud and you would just like some clarity. I've gone from the sudden pain 10 months ago to nerve transfer surgery to now. My arm is still not normal. I'm thankful that I got in and that all these people took time to see me, but I still don't really know where I'm at. — Interviewee who wished to remain anonymous

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A physiatrist's perspective

Patients with neuralgic amyotrophy often have acute and severe pain. Multifocal weakness follows hours to days later. The pain is in the shoulder or arm, and patients typically rate it as 7 out of 10 or worse. Being woken up from sleep at the onset is highly characteristic for neuralgic amyotrophy and would be unusual in other painful shoulder conditions like radiculopathy or a musculoskeletal problem. With those conditions, people may find relief by holding the arm in different positions or holding it still. In neuralgic amyotrophy, the pain is constant, there are no relieving positions and it is severe at rest.

The weakness can be in muscles supplied by different nerves. If you are seeing a patient early on, there is a chance that the weakness has not developed yet or is not recognized by the patient. Checking for scapular winging or scapular dyskinesia is a high-yield manoeuvre in this setting. Even when there is no frank winging when pushing against a wall, ask the patient to slowly abduct and then lower their arms to watch how the scapulae are moving. You may see asymmetry or jerkiness in one of the scapulae, which is an early sign of weakness. Also, remember that when patients are having severe pain, they may not be aware of other neurologic deficits. If you look closely, you may find subtle weakness and sensory loss the patient has not previously noticed. Sometimes these are the only findings suggesting a multifocal process. Although it's rare for a patient to present with a sensory symptom, a high percentage will have sensory loss in a peripheral nerve distribution.

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The patient described in our case had improved pain with steroids. However, the pain of neuralgic amyotrophy can be difficult to manage because there are not many great options. Neuropathic pain medications take too long to work. When a classic presentation occurs, starting steroid treatment early is important. In the long term, we're starting to recognize that after the acute pain improves, muscle imbalances sometimes lead to a persistently painful shoulder. Even when strength returns, rehab can help correct imbalances.

Early prognostication can be difficult. From an electrodiagnostic perspective, we can give a more accurate prognosis after 12 weeks. If we can see some nerve signal getting through to a muscle, there is a better likelihood that muscle will regain strength. After a few months, if there is no sign of nerve recovery, we begin to explore surgical options. — Nicholas Miller MD, Department of Physical Medicine and Rehabilitation, University of Manitoba, Winnipeg, Man.

As told to Andreas Laupacis MD MSc
Deputy editor, *CMAJ*

This article has not been peer reviewed.

Consent has been given for these perspectives to be shared.

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