

PRACTICE

A PATIENT'S JOURNEY

Thoracic outlet syndrome

After undergoing sensory tests for numbness in her left arm, this patient was diagnosed as having thoracic outlet syndrome. Despite seven operations, she is still in pain

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (lapsley@bmj.com) for guidance.

It all started around nine years ago when I was 17; I began to get a strange tingling and a dull ache in my left arm. I noticed I couldn't carry a bag over my left shoulder, as my arm seemed to go numb and achy. At the time I was training at college to be a beauty therapist. I kept getting strange electric shock sensations and stabbing pains and the feeling of a dead heavy arm, but I remember putting it down to over-working at college and at work. I ignored it for as long as possible. I mentioned it in passing while seeing my general practitioner for an unrelated matter.

I explained to my doctor the pains and symptoms I had been getting. She then carried out some sensory tests on my arm. I watched a needle being pressed on my arm and hand and knew it should be hurting or at least feeling sharp, but I couldn't feel it at all. The general practitioner pointed out that I had muscle wastage in my left hand; my palm was indented and my tendons could be felt, I had no pad of muscle under my thumb area, and the back of my hand also looked thin. I had not noticed this before.

My doctor arranged an urgent appointment for me to see a neurosurgeon. From then on I had so many tests I can't even remember the number—nerve conduction studies with needles and electrodes, vascular scans, magnetic resonance imaging, radiography, etc—and everyone seemed to be confused by the results.

Eventually I was told I had a condition called thoracic outlet syndrome and that it was rare, especially in my case as it affected my veins, arteries, and nerves. I was then told that I needed surgery to remove some ribs and fibrous bands to stop the damage to my hand, as the veins were being squashed and affecting blood flow.

I spoke to my doctor and various specialists and I did a lot of research myself, but there was not much information on thoracic outlet syndrome. I did, however, find a good website called PubMed. I also found a surgeon in America whose book I ordered. This explained everything in depth.

I could not believe it; one minute I was at college and working at my mum's salon enjoying my life and friends and the next I was being told I had to have major surgery for a rare condition. I made sure I worked hard at college and completed the course. It took my mind off things, but I couldn't ignore the fact that my arm and hand seemed to be deteriorating, and at an alarming speed. I was in constant pain and was now on strong pain medication. My left hand had become "claw-like"—where the muscles were wasting my fingers were being pulled in. I hated this.

It took a long time before I had my first operation. I was told the surgery would not improve the muscle atrophy as the damage had been done, but that the pain would improve. After surgery I was in agony, with the same pains and more; my left eye was also drooping. I was reassured that after a few months things would settle down.

Around six months later I still had the pains. In addition, symptoms were developing on my right side. I went to see my surgeon but she was quite dismissive. I was worried about the same problem developing on the right side so spoke with my doctor who referred me back to the surgeon. Tests detected similar problems on the right side.

I had to have the same surgery on the right side. My left side still didn't feel right though, despite my surgeon insisting it was, so I carried on researching for myself and with help from my mum we emailed a specialist in the United States. He thought I should seek a second opinion. At this point my left hand had become a lot worse and my fingers were shrinking. I couldn't keep on any of my rings. I could barely attend to my own cosmetic needs let alone do it as a career all day every day.

The second specialist said I would have to have more surgery on my left side as soon as possible. I stayed in hospital for a week. It took months to recover and I was in excruciating pain, but after a while things seemed a bit better. Unfortunately my right hand had deteriorated and I underwent a second operation. Although surgery helped the right arm, my left arm did not improve and my specialist wanted me to see a consultant in Oxford.

This specialist too seemed concerned and decided that I needed further surgery as something was definitely compressing my left side. After a fifth operation I remained in a lot of pain. Despite this I continued to try and push forward. My life had been changed and with that went my career in beauty therapy, so to try and stay positive I had to look at what I could do. I eventually enrolled in a counselling course and managed to qualify as a counselor. During my studies I was told that I needed my left side operated on again as the surgery had not worked. I was devastated by the prospect of more surgery but I did manage to finish my course first.

I have since had my sixth and seventh surgeries. The sixth was on my left side in September 2011 and the seventh on my right side in March 2012. I have now had four major surgeries on my left side and three on my right side. I have had another two ribs out, lots of scar tissue removed, tissue attached to my chest wall, and part of my lung taken away (I also had reconstructive chest surgery and the main nerve from the spine to arm cut and reattached on the left side, and the nerve straightened on the right side). I have been told that for at least two years I will need to wear splints on both hands and arms. I am hoping that the last two procedures will make a difference to my daily pain levels and disability.

Both my hands are clawed. I cannot work any more and I struggle on a daily basis with even the simplest things such as opening a can, cleaning, and even dressing and sleeping. I cannot socialise to the same extent as a typical 26 year old as I get tired from the pain. I rely on my partner, family, and friends to help me each day. The privilege of doing everyday tasks is not realised until it's taken away. As I am still in so much pain daily, I am on a lot of medication. I save up money every month and pay privately for acupuncture and sports massage.

This condition affects every part of my life. Even though I try to stay positive and active, it is hard. I still hope that I can pursue a career in counselling.

My surgeon and doctor as well as numerous other consultants have told me that this is the worst and most complicated case of thoracic outlet syndrome they have ever seen. Even though the condition has altered my life and nearly everything in it I will not be beaten by it. Thoracic outlet syndrome is a part of my life; I am not a part of its life.

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A clinician's perspective

Thoracic outlet syndrome (TOS) is often a nebulous condition of the arms that eludes diagnosis as there are no specific symptoms nor sensitive or specific investigations that confirm its existence. Many doctors are unaware of TOS or how to diagnose it, particularly when the symptoms and signs are vague. In rare cases, however, a patient has such obvious symptoms and signs that the diagnosis cannot be refuted. Lauren is one of these cases. She presented with vague arm pains but clear neurological signs of denervation of the T1 root (both the median nerve innervated abductor pollicis brevis and ulnar nerve supplied hand intrinsic muscles were atrophied). This indicated the problem was at the level of the T1 root or lower trunk brachial plexus rather than at the periphery. The differential diagnosis includes carpal and cubital tunnel syndrome or Charcot-Marie Tooth, although Charcot-Marie Tooth is bilateral, symmetrical, and involves the feet. The diagnosis of TOS is made by clinical examination, with provocation of the pain or symptoms by compression of the supraclavicular fossa being the most reliable sign coupled with the lack of localising signs around the carpal and cubital tunnel.

The cause of TOS is anatomical variations or anomalies that cause compression or irritation of the neurovascular structures in the supraclavicular fossa as they pass over the first rib between the scalenes, then under the clavicle. The most common anomaly is a cervical rib and associated musculotendinous anomalies. All these anomalies are not usually identifiable on magnetic resonance imaging or ultrasonography. And neurophysiology is often not diagnostic but will exclude carpal and cubital tunnel syndrome.

Having had little benefit from a structured TOS therapy programme, Lauren underwent brachial plexus exploration with excision of a portion of her first rib. The pain persisted. A further operation was performed after much delay, with greater success. Unfortunately this was short lived and Lauren's pain rapidly recurred.

On each occasion, the diagnosis of TOS must be checked and other potential peripheral or central causes of symptoms excluded. Having reconfirmed the diagnosis of TOS and in view of considerable loss of function, the only solution is to carry out further procedures to attempt to liberate the nerves and vessels from scar tissue and compression. Her latest procedures attempted to protect the brachial plexus nerves from scar by wrapping them in subcutaneous fat tissue transferred from the infraclavicular chest wall.

This case illustrates the difficulty in diagnosis and treatment of TOS. Although significant neurological injury makes the diagnosis easier, the severity and delay, especially when pain is established, makes treatment difficult. TOS should be suspected and treated early for optimal chances of success.

Henk Giele

Useful resources for patients and health professionals

Patient.co.uk (www.patient.co.uk)—A UK website for patients with information about medical conditions including thoracic outlet syndrome

NINDS Thoracic Outlet Syndrome Information Page (www.ninds.nih.gov/disorders/thoracic/thoracic.htm)—An American website with information about thoracic outlet syndrome, including recent research and links to other related sites

Samarasam I, Sadhu D, Agarwal S, Nayak S. Surgical management of thoracic outlet syndrome: a 10-year experience. *Aus N Z J Surg* 2004;74:450-4