Thoracic Outlet Syndrome: Expanded Community Findings

What 282 Additional Reddit Posts Reveal Beyond the Original Research

A Companion to the TOS Community Research Report, Diagnostic Checklist, and Surgical Outcomes Report

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About This Document

The original TOS resource documents were compiled from the top 100 posts on r/ThoracicOutletSupport. This companion document captures new findings from an expanded scrape of all 382 available posts in the subreddit. Rather than rewriting the original reports, this document highlights what the additional 282 posts reveal that the originals did not cover — new symptom patterns, practical treatment details, additional surgeons, safety considerations, and community-reported experiences that add meaningful context.

Posts 101–382 generally have lower engagement than the top 100 but contain valuable first-person accounts, niche topics, and practical details that fill real gaps.

Cognitive and Cerebrovascular Symptoms

This is the single biggest gap in the original reports. Multiple users in the expanded dataset describe neurological and cognitive symptoms that go well beyond arm and shoulder pain.

Reported symptoms include memory problems, word-finding difficulty, severe confusion and brain fog, head and eye pressure, jaw pressure, and vision changes.

These symptoms may be connected to subclavian steal syndrome, a condition in which TOS-related compression of the subclavian artery redirects blood flow away from the brain. One user describes it this way: “It definitely causes issues. I’ve had memory problems, word finding issues, strange sensations, head and eye and jaw pressure, vision issues, severe confusion. I think it could be due to subclavian steal syndrome.”

Another user notes: “It can also cause something called cerebrovascular hyperperfusion although that is not medically accepted yet. There’s a study by K. Larsen called ‘Does Thoracic Outlet Syndrome Cause Cerebrovascular Hyperperfusion.’”

A third user, who had already undergone one rib removal, reports: “Every morning I wake up with horrendous headaches…memory problems an issue too.”

What this means: If you experience cognitive symptoms alongside your TOS, they may not be a separate problem. Mention them to your TOS specialist. Screening may include Doppler ultrasound with arm provocation or dedicated cerebrovascular imaging. This is not standard TOS workup, but the community data suggests it should be considered when cognitive symptoms are present.

POTS, Dysautonomia, and Autonomic Symptoms

TOS and POTS (Postural Orthostatic Tachycardia Syndrome) appear together across multiple posts in the expanded dataset, suggesting a meaningful comorbidity pattern.

The anatomical basis: The stellate ganglion, part of the sympathetic nervous system, sits within the thoracic outlet and can be compressed alongside the brachial plexus. One user explains: “The stellate ganglion however is in the thoracic and can get compressed — panic attacks? Unexplained anxiety?” The vagus nerve also runs near the thoracic outlet structures, and some users report vagus-related symptoms including nausea, heart rate irregularities, and gut dysfunction.

Reported overlap symptoms include blood pooling in extremities, dizziness, exercise intolerance, unexplained anxiety and panic attacks, and fatigue that goes beyond what the arm pain alone would cause.

Multiple users note that TOS, EDS (Ehlers-Danlos Syndrome), and POTS frequently appear together as a triad. If you have TOS and experience autonomic symptoms, it may be worth asking about dysautonomia screening.

TMJ, Facial Pain, and Jaw Symptoms

The expanded dataset reveals a connection between TOS and facial or jaw symptoms that does not appear in the original 100 posts.

Reported experiences include facial pain and numbness on the TOS-affected side, tongue numbness (“Yes. My tongue went slightly numb on one side”), jaw paralysis-like sensations (“the lower half of my jaw on that side immediately became paralyzed feeling”), and ear symptoms initially mistaken for TMJ (“I thought I had an ear and TMJ jaw problem that turned out to actually be TOS”).

These symptoms likely relate to scalene tightness affecting nearby nerves and structures in the neck. If you experience jaw, ear, or facial symptoms, they may be connected to your TOS rather than being a separate issue.

Botox: Practical Guidance the Original Reports Were Missing

The original reports discuss Botox as a treatment option but lack the practical details that the expanded dataset provides.

Dosing

The standard dose for anterior scalene injection is 100 units. For a first-time combined injection (scalene and pec minor together), doses as low as 41 units total have been used. On the high end, one user received 300 units across multiple sites. Insurance often does not cover Botox specifically for TOS, but it may be covered under cervical dystonia codes.

Rebound Warning

Multiple users describe significant symptom rebound when Botox wears off. One user warns: “Keep current on the Botox. The rebound if it wears off is terrible.” This suggests that if you start Botox, plan for consistent scheduling rather than sporadic use.

Timeline

Expect a potential pain flare for 1–3 weeks after injection as the Botox may irritate nearby nerves. Relief typically begins around week 3. Some users report relief lasting months; others only days to a week.

Diminishing Returns

Multiple users report that Botox stopped working effectively after 5–6 rounds. One user describes: “I’ve had 3 so far and they don’t seem to be working as well as I hoped.” Another had 6 rounds before the effect faded. This appears to be a known pattern — the muscle may atrophy with repeated injections, changing the dynamic.

Trapezius Botox

One user reports that trapezius Botox (rather than scalene) was “a godsend.” This is a different injection target not discussed in the original reports and worth raising with your provider if scalene Botox alone is insufficient.

Sequential Injections to Isolate Compression

One of the most actionable findings for anyone with compression at multiple sites: inject one site at a time rather than all sites simultaneously. One user describes: “I had mine injected 1 at a time, started with pec minor, then anterior scalene, then middle scalene. Each injection removed some symptoms, but the middle scalene was definitely the culprit for me as all symptoms resolved.”

Another user’s accidental experience confirms this: “When I was expecting to get the trigger point injections for both, my pain specialist by mistake only did them for the scalenes, and although it helped a little, I was still symptomatic. And then when they injected both the scalenes and pec minor that was when the significant relief came.”

This approach gives you diagnostic clarity about which compression site drives which symptoms, and directly informs surgical planning.

Cervical Instability: A Critical Safety Consideration

This topic does not appear in the original reports and represents an important safety gap.

If cervical instability is present (common in hypermobile and EDS patients), the scalene muscles may be compensating to stabilize the cervical spine. Paralyzing them with Botox — or removing them surgically — can make things significantly worse.

One user warns: “I had a really bad reaction to Botox in my scalenes because those muscles (along with my traps and such) were trying to stabilize my cervical spine. Before they paralyze other muscles…think about any possible cervical instability.”

Another user with craniocervical instability found that neck cracking and manipulation were “making things worse by shifting things in the wrong direction, which could also lead to compression.”

Recommendation: Before undergoing scalene Botox or scalenectomy, ask about cervical stability screening. Flexion/extension cervical X-rays and a Beighton score assessment for hypermobility are reasonable starting points. This is especially important if you have known or suspected EDS, hypermobility, or a history of cervical trauma.

Counterstrain Physical Therapy: Stronger Evidence

The original reports mention counterstrain PT briefly. The expanded dataset makes a significantly stronger case for it.

One user reports: “Counterstrain has improved mine 70–80%. I’ve probably had about 8–10 sessions at this point now and I feel like I’m back to living my life pretty normally now.” Another credits counterstrain with restoring their ability to sleep: “My physical therapist used counterstrain to unlock my back…started sleeping again…technique restored my sleep.”

Counterstrain is a gentle, indirect manual therapy technique — distinct from standard PT exercises or aggressive stretching. Multiple post-surgical patients also find it helpful for residual symptoms. If standard PT has not worked, counterstrain may be worth specifically seeking out.

Exercises: What to Avoid and What Works

The expanded dataset provides clearer guidance on specific exercises.

Exercises That Aggravate TOS

Planks: Multiple users report significant worsening. Running: The arm swing and impact can aggravate compression; if running worsens symptoms it may be posture-related or from arm motion. Push-ups and pull-ups: Specifically warned against for vascular TOS patients. Incline walking: Promotes hunching, which closes down the thoracic outlet. Yoga: Some users worsened; one user's doctor specifically prescribed Pilates instead of yoga.

Exercises That Help

Pilates (modified): Repeatedly cited as better tolerated than yoga for TOS. Glute resistance band work: Encouraged by physiotherapists. Lower body strengthening: "Low ab work. Glute work. Hamstrings. Give the upper body a reason to relax." This reinforces the bottom-up kinetic chain approach from the original report. Shoulders-up during exercise: "I've learned the key is keeping shoulders up to prevent clavicle crushing nerves. With this approach I can do everything in the gym."

One user summarizes the principle well: "Pilates had to be slightly modified but was great. Glute resistance band work was also good. Latter two are very much encouraged by physio."

Sleep: Expanded Guidance

The expanded dataset adds substantially to sleep recommendations beyond what the original reports cover.

U-shaped pregnancy pillow: Multiple users recommend hugging a large U-shaped pillow to keep arms separated and supported through the night. Pillowise measured pillow: An ergonomic pillow sized to your body, called "a game changer" for neck support. Sleeping upright: One user with arterial TOS had to sleep sitting straight up for 6 months. Back sleeping with arm elevation: Pillows at sides to elevate arms while on your back. Tennis ball trick: One user's family member sewed tennis balls onto the front and sides of a sleep shirt to prevent rolling off the back — "sleeping on my back for the entire night, I feel significantly better." Mattress firmness: "My symptoms increased in a pretty severe way when I started sleeping on a mattress that was way too soft." Avoid overly soft mattresses. Holding small pillows: One user sleeps clenching small pillows to keep hands from going numb.

Pain Medications: Additional Community Data

Cymbalta (duloxetine): "Cymbalta changed my life." Multiple data points support this for TOS nerve pain.

Gabapentin dosing: Some doctors start patients on doses too low to be effective. One user takes 900mg during the day and 1800mg before bed. If gabapentin has not helped, dosing may be the issue rather than the medication itself.

Flare management combination: “Lidocaine patches and Lyrica on top of NSAIDs and Tylenol took the edge off for me.” A practical multi-modal approach for bad days.

Phoenix Theralase laser: One user reports consistent help from this modality for TOS symptoms.

Somatics: SheBREATH Somatics on YouTube was mentioned as helpful for coping with severe pain during the diagnostic waiting period.

Additional Conditions to Rule Out

The expanded dataset identifies several conditions that can co-exist with or mimic TOS that the original diagnostic checklist does not include.

Eagles Syndrome (vascular or cervical): Shows up as a comorbidity in multiple posts. Can cause overlapping neck, jaw, and vascular symptoms. Diagnosed via CT scan of styloid processes.

Craniocervical Instability: Can mimic TOS symptoms and complicate treatment. One user discovered this was contributing to their neck symptoms alongside TOS. Evaluated with upright MRI of the craniocervical junction.

Pronator Teres Syndrome: Forearm nerve compression that overlaps with TOS symptoms. One user had both conditions: “thoracic outlet syndrome combined with pronator teres syndrome… diagnosed by a Physiotherapist and therapy took me about one year to recover.”

Cervical Instability: Broader cervical spine instability, especially in hypermobile patients. Covered in detail in the cervical instability section above. Evaluated with flexion/extension cervical X-rays and Beighton score.

Robotic-Assisted Surgery: Expanded Data

The original surgical outcomes report mentions robotic surgery from a single post. The expanded dataset provides much richer detail.

One user who had both ATOS and NTOS reports: “Yes, I got it, and it was great. My ATOS symptoms are totally gone; my nerve sensation and pain are still there.” This suggests robotic FRR may be more effective for vascular symptoms than neurogenic ones.

A key concern raised by multiple users is incomplete rib removal. One user notes: “I have heard that it is very difficult to remove the entire first rib through robotic surgery.” Facebook TOS groups tend to caution against robotic for this reason, while Reddit users are generally more positive. One user characterizes the Facebook groups as “echo chambers with fearmongering.”

NYU Langone is mentioned as a facility performing robotic FRR. Recovery may be faster with the robotic approach — one user was back at the gym within weeks.

Bottom line: Robotic FRR is a developing technique with potential benefits (smaller incisions, faster recovery) but real concerns about whether the full rib can be removed. Ask your surgeon specifically about this if considering the robotic approach.

Scapular Winging After Surgery

A post-surgical complication that the original report does not address: multiple users develop scapular winging after rib resection and scalenectomy.

One user over a year post-op describes: “I still have symptoms after mine. Hypermobile. Shoulder girdle still moves too much. Pressure around the clavicle. It’s been over a year now. I’m thinking my trap is atrophied. Still fatigues significantly.”

Another notes visual asymmetry: “I have the same thing where the side of surgery, the trap looks like it attaches higher up on the neck.”

This appears to result from altered biomechanics after removing structural components (rib, scalene muscles), combined with disuse during recovery. Post-surgical PT specifically targeting scapular stabilization is critical for preventing and managing this issue.

EDS, Hypermobility, and Surgical Risk

The original report mentions Ehlers-Danlos Syndrome briefly. The expanded dataset significantly deepens the picture.

A 36-year-old female with both vTOS and hEDS describes three blood clots over 15+ years before finally pursuing surgery. After VATS first rib resection, she reports improvement in neck, clavicle, and trap tightness.

The critical concern for hypermobile patients: removing the scalenes, which help stabilize the cervical spine, may cause cervical instability in patients whose ligaments are already lax. One user raises this directly: “Very hypermobile with hypermobile shoulders and suspected EDS. Main concern is cervical instability. Main risk of removing scalene muscles is the neck could destabilize.”

Another hypermobile patient over a year post-surgery: “Shoulder girdle still moves too much. Pressure around the clavicle.”

If you have known or suspected hypermobility or EDS, pre-operative cervical stability assessment is strongly recommended before scalenectomy.

Bilateral TOS: Surgical Sequencing

The expanded dataset includes discussion about which side to operate first when TOS is bilateral.

Worse side first approach: “I have marked weakness on my left side, which is where it started. And although I have strong flareups on my right side, I am choosing my left side first due to said weakness.”

Non-dominant side first approach (risk mitigation): “I’m right handed but my left side was slightly worse so I started on my left side. My reasoning was it’s slightly worse but also if surgery makes things a lot worse permanently it’s not my dominant side.”

Surgeon experience matters more for bilateral cases: “If your surgeon has rarely seen this, he probably doesn’t have the level of expertise you need for bilateral TOS.”

One user who had surgery on both sides over a decade emphasizes permanent lifestyle changes: “Very long healing process. Key thing I wish I had known sooner are all the movements, activities to AVOID.”

Additional Surgeons Named in the Expanded Dataset

Dr. Gelabert: Described by one user as “arguably the #1 surgeon.” Note: the same user reports a bicep nerve damage complication at 4 months post-op, described as expected to resolve with time.

Dr. Pearl: Named in the context of diagnostic CTA imaging.

Dr. Senthil Jayarajan, Allina Health, Minneapolis: Recommended by the TOS Outreach Network as the surgeon for the Minneapolis area.

Temple Hospital, Philadelphia: A female surgeon there is described as willing to operate based on clinical presentation even when test results are inconclusive.

MUSC, Charleston, SC: Performs open supraclavicular approach. Surgeon described as doing multiple TOS cases per week and preferring this approach for safety reasons — closer access to anatomy if complications arise during surgery.

Practical Notes

Pre-Surgery

Ask about chest tube management. One user warns: “Don’t let them take the chest tube out early post surgery or at least discuss it before hand. They took mine out early because I’m a young otherwise healthy guy.” This led to complications.

Surgery Costs

With insurance in the US, out-of-pocket cost depends on your deductible and yearly maximum. One user reports approximately $4,500 yearly out-of-pocket. In Canada, surgery is covered under universal healthcare.

Returning to Athletics

Recovery varies enormously. One competitive athlete returned to full activity in 3 months with some PT. A former powerlifter and nurse reports: “After surgery I haven’t been able to work or lift. The surgery is rough but it’s a long convoluted recovery.” Wide variance is the norm — set expectations accordingly.

Post-Surgical PT Is Not Optional

One user who was told PT was not necessary later developed scar tissue and needed a stent: “I would get a second opinion on PT…mine also said it wasn’t necessary but about 3 months later I started experiencing weakness.”

Work and Career

Trackball mouse is specifically recommended for desk work. Short-burst physical jobs may be better tolerated than sustained computer work — suggested careers include swimming instructor, park ranger, and knowledge-worker roles that are primarily meeting-based. Voice dictation and minimizing keyboard time are common adaptations. Multiple users are on short-term disability or SSDI.

Rare But Notable

Focal dystonia from TOS: One user developed focal dystonia in the forearm caused by TOS, treated successfully with 100 units of Botox across six forearm injection sites.

Langers Arch Muscles: One post raises this anomalous muscle variant as a potential compression source in the armpit area. Rare but worth knowing about if armpit symptoms persist without explanation.

Subclavian steal syndrome after surgery: One user who already had a rib removed still experiences morning headaches and memory problems, wondering if residual vascular compression is the cause.

Summary

The original three documents hold up well. Most of the 282 additional posts reinforce rather than contradict their findings. The genuinely new information falls into five categories:

1. Cognitive and cerebrovascular symptoms — completely absent from the originals, meaningfully discussed in the expanded data
2. POTS and dysautonomia — absent from the originals, appears as a recurring comorbidity pattern
3. Cervical instability — absent from the originals, important safety consideration before Botox or surgery

4. Practical Botox details — dosing, rebound, sequential injection strategy, diminishing returns
5. Robotic surgery — barely covered in the originals, significantly more data now available

This document is intended to be read after the original Community Research Report, Surgical Outcomes Report, and Diagnostic Checklist. Together, they represent the most complete picture available from the r/ThoracicOutletSupport community as of March 2026.

This document was compiled from 282 Reddit posts (Posts #101–382) from r/ThoracicOutletSupport. This is community-reported data, not medical advice. Always consult with a qualified healthcare provider before making treatment decisions.