Thoracic Outlet Syndrome

Surgical Outcomes Report

Community-Reported Surgical Data from r/ThoracicOutletSupport, Cross-Referenced with Published Clinical Literature

Procedures, Surgeons, Outcomes, Failures, and Post-Op Recovery

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Executive Summary

This report synthesizes surgical outcome data from two sources: **100 community posts** on r/ThoracicOutletSupport and **published clinical literature**. The goal is to give you a clear-eyed view of what surgery involves for TOS, how often it works, how often it fails, what specific procedures entail, and what people do when surgery doesn't fully resolve their symptoms.

The overall picture: surgery is **highly effective for vascular TOS** (90–95% success rates), **moderately effective for neurogenic TOS** (60–82% depending on timeframe and criteria), and carries real risks and a meaningful failure/recurrence rate (15–20%). Surgeon specialization is the single biggest variable in outcomes. The community data strongly aligns with published literature on these points.

Surgical Procedures Described in the Community Data

Across the 100 posts, the following surgical procedures are discussed. Here is what each involves and how frequently it appears in the dataset.

First Rib Resection (FRR)

The most commonly discussed procedure by a wide margin. FRR removes the first rib to permanently widen the costoclavicular space and eliminate the bony compression point. Three surgical approaches appear in the data:

- **Transaxillary approach** (Posts #31, #67, #77): Incision through the armpit. Most traditional approach. The rib is accessed from below.
- **Supraclavicular approach** (Post #3): Incision above the collarbone. Allows simultaneous access to scalenes and brachial plexus. Often preferred for nTOS cases.
- **Robotic approach** (Post #13): A newer, less invasive technique. One user reports robotic first rib removal with scalenectomy.

Intraoperative findings from community reports: Surgeons frequently discover pathology worse than expected. One surgeon found scalenes so thick they extended past the first rib into the second (Post #34). Another had to make three attempts to cut through hypertrophied muscle (Post #18). Nerves embedded into scalenes with C8/T1 roots tethered to the first rib (Post #3). A broken/deformed rib only discovered during surgery (Post #67). Extensive scar tissue and inflammation (Post #67).

Scalenectomy

Removal or partial removal of the anterior scalene muscle, and sometimes the middle scalene as well. Almost always performed alongside FRR, though occasionally done alone.

- **Anterior scalenectomy alone** (Posts #18, #58): Some surgeons prefer this for nTOS when vascular compression isn't the primary issue. One surgeon explicitly states that nTOS cases don't always require rib removal.
- **Complete resection of both anterior and middle scalenes** (Post #34): More aggressive approach used for severe compression. The patient notes Dr. Thompson performed complete resection of both muscles.
- **Scalenectomy without FRR**: Published literature shows a 90.9% success rate for rib-sparing scalenectomy using QuickDASH improvement scores, with lower complication rates than combined procedures.

Pec Minor Release / Resection

Release or complete removal of the pec minor tendon to decompress the subcoracoid space.

- **Combined with FRR + scalenectomy** (Posts #31, #39, #42): Full decompression surgery. Dr. Apple in Austin performed this combination; the patient drove a manual car back to work the following Monday.
- **Isolated pec minor resection** (Post #42): Dr. Donahue at MGH performed a standalone right pec minor resection after bilateral FRR. Published literature shows 90% good-to-excellent outcomes for isolated pectoralis minor syndrome at 1–3 year follow-up.
- **Caution** (Post #20): One user reports worsened shoulder instability after pec minor release, noting it's a major stabilizing muscle. Published data confirms isolated PMT has a 15% recurrence rate vs. 5% when combined with supraclavicular decompression.

Brachial Plexus Neurolysis

Surgical freeing of the brachial plexus nerves from surrounding scar tissue and adhesions. Typically performed as part of a full decompression (Post #31). Particularly relevant when nerves have become embedded in surrounding tissue (Post #3).

Surgical Success Rates: Literature vs. Community

The following table cross-references published clinical data with what the community reports.

TOS Type	Published Success Rate	Community Sentiment	Key Caveat
vTOS	90–95% excellent/good outcomes. 98% long-term venous patency.	Strongly positive. Multiple users describe vTOS surgery as life-saving. Post #84 comment: vTOS responds well and you'll likely get your life back.	Best outcomes when treated quickly after clot diagnosis. Delay worsens prognosis.
nTOS	60–82% good/excellent short-term. Declines to ~70% at 5+ years. 27–30% excellent, 36–41% good, 15–26% fair, 11–12% poor.	Mixed. Many positive stories but significant number of partial recoveries. Post #88: nTOS success rate much lower than aTOS and vTOS. Post #40: classic symptoms predict better outcomes.	Forum skews negative as successful patients leave (Post #95). Cervical rib presence may predict better surgical response.
aTOS	High success when structural pathology (aneurysm, clot) is addressed surgically.	Less discussed but generally positive when diagnosed. Post #63: if surgery is necessary, go for it.	Often underdiagnosed. Post #44: more people have aTOS than are aware.

Long-Term Outcome Trajectory

Published data reveals a concerning pattern of outcome deterioration over time:

- **3 months post-op:** 88–90% reporting improvement
- **1–2 years:** 73–76% maintaining good outcomes
- **3–4 years:** 69–71% maintaining good outcomes
- **5+ years:** ~65–70% reporting sustained improvement; 54% complete relief
- **10–15 years (revision cases):** Success drops to ~41%

Source: Journal of Vascular Surgery; PMC5871990; Royal College of Surgeons review of 17 years experience.

Surgical Failures and Complications

Failure Rates

Published literature documents a 15–20% recurrence rate after first rib resection or scalenectomy. The community data corroborates this:

- **Post #95:** “My first FRRS went fantastic at first, the mess came later purely due to my cervical rib.” Initial success followed by regression.
- **Post #42:** Rib cartilage left in place causes immense pain. “Just make sure everything gets taken out if you do surgery.”
- **Post #36:** “After rib resection I have [shoulder pain] 24/7 and it’s horrible. Didn’t have any of that pain prior to surgery.” New symptoms post-surgery.
- **Post #72:** “This surgery crippled me and I am unable to move around without constant pain.” One of the most negative surgical outcomes in the dataset.
- **Post #26:** “I had TOS surgery in October and I am still battling this.” Ongoing symptoms months after surgery.
- **Post #55:** Revision surgery after 18 months following initial FRR + scalenectomy. Patient reports improved outcomes after revision.

Post-Surgical Complications

Published complication rates from large database reviews:

Complication	Published Rate	Community Reports
Pneumothorax	2.5–33%	Post #30: collapsed lung with chest tube, hospital for 6 days. Post #39: “collapsing a lung to break a rib.” Multiple users reference this.
Nerve injury (brachial plexus)	0.3–5%	Post #72: biomechanical effects of rib removal + scalenectomy are “completely overlooked.” Phrenic nerve palsy reported in literature.
Vascular injury	1–2%	Post #74: patient concerned about complications post-surgery from vTOS; RN in comments worried about the case.
Severe post-op pain	Common (weeks)	Post #13: first 3 days brutal, breathing shallow. Post #30: pain level 10. Post #49: vomiting all day. Multiple users describe pain as worse than expected.
Post-op nausea/vomiting	Common	Post #49: “puked all day and night.” Post #58: vomiting after surgery. Post #80: history of post-anesthesia vomiting. Users

		recommend anti-nausea medication preemptively.
Residual rib cartilage pain	Variable	Post #42: rib cartilage left in causes immense pain. Advice: ensure complete removal.
New shoulder pain post-op	Not well quantified	Post #36: 24/7 shoulder pain that didn't exist before surgery. Post #37: TOS shoulder sits lower post-rib removal.
Overall 30-day complication rate	9.8%	Increases to 18.8% at 1 year per national database review.
Mortality	0.6%	Not reported in community data, but acknowledged in published literature.

Sources: PMC6759959; PMC5295481; Annals of Vascular Surgery contemporary practices review; ScienceDirect Finland national registry 2025.

Why Surgeries Fail: Patterns from the Data

- **Incomplete decompression:** Residual rib cartilage (Post #42), scar tissue reformation, or failure to address all compression sites (e.g., FRR without pec minor release when pec minor is involved).
- **Wrong diagnosis:** Post #20 describes a patient who was told they don't have TOS after failed diagnostic injections. Shoulder instability, cervical disc disease, or other conditions can mimic TOS.
- **Scar tissue/adhesion formation:** Multiple users report initial improvement followed by gradual regression as scar tissue reforms around the brachial plexus.
- **Cervical rib complications:** Post #95 describes initial success undermined by a cervical rib that wasn't addressed. Only some TOS cases involve cervical ribs.
- **Biomechanical destabilization:** Post #72 raises concerns about the structural consequences of removing a rib. Published research confirms ribs are critical to thoracic biomechanics.
- **Surgeon inexperience:** Post #74 describes a frightening post-surgical experience. Community strongly emphasizes only using TOS-specialist surgeons (Post #42, #10).

Named Surgeons and Their Community Reputation

The following surgeons are named in the dataset. This section combines community sentiment with publicly available information about their credentials.

Surgeon	Institution	Community Data & Published Credentials
Dr. Robert Thompson	Washington University, St. Louis	Most-referenced surgeon in dataset. Co-editor of the definitive TOS textbook (Springer, 2nd Ed). Post #34: performed complete resection of both scalenes. Post #88: described as “the big cheese.” Published outcome data: QuickDASH improvement of 41.2%. Nationally recognized referral center.
Dr. Dean Donahue	MGH (Massachusetts General)	Post #42: “Phenomenal surgeon and person who is incredibly thorough.” Performed 3 surgeries on one patient (bilateral FRR + pec minor resection). Co-editor of TOS textbook. Specific expertise in combined procedures.
Dr. Julie Freischlag	Multiple institutions	Post #42: “Saved my life! Got me back to about 99%.” Pioneer in TOS surgery. Co-contributor to SVS reporting standards.
Dr. Apple	Austin, TX	Post #39: Performed FRR + scalenectomy + pec release. Patient drove manual car back to work the following Monday. Cited positively.
Dr. Kay Johansen	Seattle, WA	Post #42: “Saved my life twice.” Performed 2 TOS surgeries for recurring condition. Patient emphasizes TOS is congenital and lifelong.
Dr. Lum	Johns Hopkins	Post #12: Referenced as a specialist who can provide definitive diagnosis. Part of Hopkins’ vascular surgery team.
Dr. Humphries	UC Davis	Post #42: Treated congenital/classic nTOS with hand muscle atrophy. Patient satisfied with surgical outcome as it stopped further atrophy.
Dr. Agrusa	New York Presbyterian	Post #86: Performed vTOS surgery. Patient returning for second surgery (bilateral). Described as “great.”
Dr. Merry	Providence	Post #42: NEGATIVE report. Patient feels decompression was adequate but residual rib cartilage causes immense ongoing pain.
Dr. Pearl	(International)	Post #78: Positive fresh post-op report. Patient inquiring about cost suggests non-US surgeon. Cited positively.
Dr. Sheng	Indianapolis	Post #12: Recommended on TOS groups. Patient seeing him after neck surgery-related TOS.

Critical community finding: Post #10 warns that some TOS Facebook groups censor negative surgical experiences and may have surgeon-affiliated staff as admins. Post #42 explicitly solicits both good and bad experiences. The Reddit community appears to allow more balanced reporting than some Facebook groups.

Detailed Clinical Pictures from the Community

The following posts provide the most complete surgical narratives in the dataset, including diagnosis, procedure, surgeon, and outcome.

Case 1: Full Decompression Success (Post #31)

- **Diagnosis:** nTOS
- **Procedure:** Transaxillary first rib resection + anterior scalenectomy + brachial plexus neurolysis
- **Timeline:** 5 months post-op at time of AMA post
- **Outcome:** “Back and better than ever.” Self-described full success.
- **Notable:** Patient specifically mentions neck pain and occipital pain as pre-op symptoms that resolved.

Case 2: Bilateral vTOS with nTOS Overlap (Post #42 — Dr. Donahue)

- **Diagnosis:** vTOS + significant nTOS, bilateral
- **Procedures:** 3 total surgeries — left FRR, right FRR, right pec minor resection
- **Surgeon:** Dr. Donahue at MGH
- **Outcome:** Positive. Described surgeon as “phenomenal” and “incrediby thorough in his evaluation.”

Case 3: vTOS with Complete Scalene Resection (Post #34)

- **Diagnosis:** Venous TOS
- **Procedure:** Complete first rib resection + complete resection of right anterior scalene + complete resection of right middle scalene
- **Surgeon:** Dr. Thompson, Washington University
- **Notable findings:** Scalenes were abnormally thick, extending past the first rib into the second. Surgeon had not seen this before. Patient placed on low-fat diet post-op.
- **Demographics:** 26-year-old female. Previously healthy.

Case 4: Combined Procedure, Rapid Recovery (Post #39)

- **Procedure:** First rib resection + scalenectomy + pec minor release
- **Surgeon:** Dr. Apple, Austin TX
- **Recovery:** Surgery on Friday; drove a manual car back to work the following Monday.
- **Caveat:** This is exceptionally fast recovery. Other users in the same thread report weeks to months of significant pain.

Case 5: Severe TOS with Lung Fusion (Post #3)

- **Diagnosis:** Severe nTOS
- **Findings:** Nerves embedded into scalenes. C8 and T1 nerve roots tethered to first rib. TOS so severe it fused to the patient's lungs. Supraclavicular approach used. Surgeon had to clear extensive scar tissue.
- **History:** Years of dismissal. Told it was anxiety and conversion disorder before diagnosis.

Case 6: Revision Surgery (Post #55)

- **Initial procedure:** First rib resection + scalenectomy
- **Timeline:** 18 months post-initial surgery
- **Revision:** Required second surgery. Reports feeling great after revision and improving each day.

Case 7: Surgical Failure with Ongoing Disability (Post #72)

- **Procedure:** First rib resection
- **Outcome:** "This surgery crippled me and I am unable to move around without constant pain." Highly negative.
- **Commentary:** User explicitly advises against surgery unless severe vascular issue is present. Raises concern about biomechanical destabilization.

Case 8: Recurring TOS, Two Surgeries (Post #42 — Dr. Kay Johansen)

- **Diagnosis:** Congenital TOS, recurring
- **Procedures:** Two TOS surgeries in Seattle
- **Outcome:** "Saved my life twice." Patient emphasizes strict activity restrictions ("Know the NO's. Stick to them always or regret.")

Post-Surgical Recovery Timeline

Synthesized from both community reports and published rehabilitation data:

Timeframe	What to Expect
Days 1–3	Brutal for most. Shallow breathing, chest/shoulder popping, severe pain (often 8–10/10). Nausea and vomiting common from anesthesia. Narcotics alone often insufficient — muscle relaxers and nerve pain meds recommended. Risk of pneumothorax requiring chest tube and extended hospital stay.
Days 4–14	Pain begins to subside. Soreness dominates. Arm exercises help. Some users feel better after stopping narcotics. Sleeping remains difficult — propped position with pillow support. Coughing and sneezing extremely painful.
Weeks 2–4	Two-week follow-up typically shows good healing. Surgical tape removal. Some fluid accumulation normal. Many users begin light activity. Most can shower and dress independently.
Weeks 4–12	Nerve remyelination expected in 4–12 weeks. This is when neurogenic symptoms begin to resolve. Physical therapy typically begins. Published data: median 2 months of PT for vTOS, 4 months for nTOS.
Months 3–6	Most patients report significant functional improvement. Return to running/athletics: average 4.6 months (published). Post #32: running at 4 months post-FRR. Post #48: positive outcome at 6 months. Some residual nerve pain persists.
Months 6–12	Continued gradual improvement. Post #88: 11 months out, “quite successful” with occasional positional nerve pain. Medication reduction possible (Post #88: halved pregabalin dose).
1–5+ years	Post #46: 5 years post-rib removal, positive outcome. Post #70: 10 years later, symptoms improved by 3rd week post-op. Long-term success depends on adherence to activity restrictions and ongoing PT. Published: ~65–70% maintain good outcomes at 5+ years.

What Helped People Who Had Surgery and Still Had Issues

This is one of the most important sections for understanding the full surgical picture. Multiple community members report partial improvement or new symptoms post-surgery. Here is what they found helpful:

Revision Surgery

- **Post #55:** Revision surgery 18 months after initial FRR + scalenectomy. Reports significant improvement after second procedure.
- **Post #42:** Dr. Kay Johansen performed two surgeries for recurring TOS. Described as life-saving both times.
- **Published data:** Revision surgery has 84% success at 3 months but declines to 41% at 10–15 years. Temporary plexus injury occurs in 0.7% of revisions; phrenic palsy in 3.7%.

Post-Surgical Physical Therapy

- **TOS-specialized PT** is critical after surgery, not just generic rehab. Post #73: finding a TOS-expert PT is the most important variable. Post #94: “PT exasperated and made worse issues after surgery” when not specialized.
- **Postural retraining**: Post #57 describes working on shoulder elevation and posture correction post-surgery. Ongoing work required.
- **Published:** Standard protocol is 2 months PT minimum. nTOS patients require median 4 months before symptom-free. 85% return to athletics at average 4.6 months.

Medications for Residual Symptoms

- **Pregabalin**: Post #88 describes halving the dose 11 months post-surgery. Still needed but less. Post #100: pregabalin as ongoing management for partial recovery.
- **Nerve pain medications**: Multiple users maintain gabapentin or amitriptyline long-term after surgery for residual nerve irritation.
- **Muscle relaxers**: Ongoing use for post-surgical muscle spasm, especially when scar tissue creates new tension patterns.

Continued Exercise-Based Interventions

- **Serratus anterior and scapular work**: Even post-surgery, the underlying muscular imbalances that contributed to TOS often persist. Post #57 describes continuing scalene and scapular rehab post-operatively.
- **Nerve glides**: Ongoing nerve mobilization to prevent adhesion reformation around the brachial plexus.

- **Strict activity restrictions**: Post #42 (Dr. Johansen's patient) emphatically states: "Know the NO's. Stick to them always or regret." This implies permanent lifestyle modifications.

Addressing Co-Existing Conditions

- **Dorsal scapular nerve entrapment** (Post #98): Common alongside TOS. Published research from China shows surgeons need to address DSN entrapment to clear all pain. Duloxetine specifically helped one 12+ year sufferer.
- **Cervical disc disease** (Post #20, #35): Multiple users have overlapping cervical compression. Getting thoracic spine and cervical MRIs is repeatedly emphasized.
- **Shoulder instability/labral tears** (Post #20): Can mimic TOS or co-exist. Must be identified before surgery to avoid worsening with pec minor release.
- **Ehlers-Danlos Syndrome** (Post #71, #72): Connective tissue disorders complicate TOS surgery outcomes. Surgeons may note that PT alone won't be sufficient for these patients.

Pain Management and Coping

- **Counterstrain PT** (Post #53, #97): Gentle manual technique that multiple post-surgical patients find helpful for residual symptoms.
- **Dry needling** (Post #53, #66): Trigger point work for post-surgical muscle tension.
- **Ergonomic adaptations** (Post #61, #91): Split keyboards, vertical mice, dictation software, arm rests. Multiple post-surgical patients report permanent workstation modifications.
- **Mental health support** (Post #82): The chronic pain and incomplete recovery cycle generates anxiety and depression. Therapy specifically recommended.

Predictors of Surgical Success

Both published data and community experience point to several factors that predict whether surgery will help:

Positive Predictors

- **Positive scalene block:** Published data shows 63% complete improvement and 35% partial improvement when patients respond to a diagnostic scalene block before surgery. The block serves as a "surrogate for surgical expectations."
- **Classic nTOS symptoms:** Post #40: "People who have the best response to surgery are those that have the classic symptoms" including numbness, tingling, weakness, and pain in hands/fingers.
- **Vascular pathology:** Blood clots, positional vascular compression confirmed on imaging, or visible discoloration all predict strong surgical response.
- **Cervical rib presence:** Post #88: One user suspects nTOS surgery is much more beneficial for people who have a cervical rib.
- **Shorter symptom duration:** Multiple community members and published data suggest earlier intervention correlates with better outcomes.

Negative Predictors

- **Negative scalene block:** Post #20 describes no reaction to diagnostic injections, later told they don't have TOS. A non-response predicts poor surgical outcome.
- **Major depression:** Published data identifies depression as a predictor of poor surgical outcomes.
- **High pre-operative disability scores:** DASH score > 50.5 or BPI > 73.5 predicts worse outcomes.
- **Atypical symptom presentation:** Post #40: non-classic presentations have lower surgical success rates.
- **Co-existing structural pathology:** Unaddressed cervical disc disease, labral tears, or Ehlers-Danlos syndrome complicate outcomes.

Key Takeaways

1. Surgeon selection is everything. The community is near-unanimous: go to a surgeon who *specializes* in TOS. Not a general vascular surgeon, not an orthopedist who does TOS sometimes. The named surgeons in this report (Thompson, Donahue, Freischlag, Johansen) are all high-volume TOS specialists with published outcomes.

2. vTOS surgery is highly effective; nTOS surgery is a gamble worth understanding. 90–95% success for vTOS vs. 60–82% for nTOS, declining over time. This distinction is critical for setting expectations.

3. A positive scalene block is the strongest pre-surgical predictor. If a scalene block provides relief, surgery is much more likely to help. If it doesn't, question the diagnosis before proceeding.

4. Incomplete decompression is the leading cause of failure. Residual rib cartilage, unaddressed pec minor involvement, and scar tissue reformation are the most cited failure mechanisms.

5. Surgery is not the end of the road. Post-surgical PT, medication management, activity restrictions, and ergonomic adaptations are required long-term. "Know the NO's" applies indefinitely.

6. Forums skew negative. Multiple users point out that successful surgical patients leave the forum and move on with their lives. The community is not a representative sample of outcomes.

7. Co-existing conditions must be identified. Cervical disc disease, shoulder instability, DSN entrapment, and Ehlers-Danlos can all confound TOS surgery outcomes. Comprehensive imaging and evaluation before surgery is essential.

References and Resources

Published Literature

Long-term outcome over a decade after first rib resection (PMC)
Long-Term Functional Outcome of Surgical Treatment (PMC)
Morbidity of First Rib Resection (PMC)
Evaluation of Complications of TOS Surgery (PMC)
Rib-sparing scalenectomy early results (J Vasc Surg)
TOS Pattern of Clinical Success After Surgical Management (J Vasc Surg)
SVS Reporting Standards for TOS (J Vasc Surg)
Pectoralis Minor Tenotomy Utilization and Effectiveness (SAGE)
Scalene Block Predicts Surgical Outcomes (SAGE)

Contemporary Practices and Complications (Annals of Vasc Surg)
Paget-Schroetter Outcomes (CDT)
17 Years Surgical Management Experience (Royal College of Surgeons)
TOS Textbook, 2nd Edition (Springer)

Community Resources

TOS Outreach — Surgeon Finder
MSK Neurology (Kjetil Larsen)
r/ThoracicOutletSupport

This report combines community-reported data with published clinical literature. Community experiences represent individual cases and may not be generalizable. Published statistics come from peer-reviewed studies with their own methodological limitations. Always consult with a qualified TOS specialist before making treatment decisions.