



# Venous TOS Comprehensive Overview

## SYMPTOMS

Venous TOS is when the axillary-subclavian vein is compressed within the costoclavicular space between the first rib and the collarbone. There are two types of VTOS. The first type is the thrombotic form which involves a blood clot (called an effort thrombosis) and is known as Paget-Schroetter Syndrome. The second type is a non-thrombotic form which involves symptomatic intermittent positional compression of the vein but no blood clot and is known as McCleery Syndrome.

### THROMBOTIC VTOS (PAGET-SCHROETTER SYNDROME)

A blood clot is a gel-like collection of blood that forms in your veins or arteries when blood changes from liquid to partially solid. The axillary-subclavian vein is considered a deep vein, so when a blood clot forms within it, it is considered a deep vein thrombosis or DVT. Because the veins return blood back to the lungs and the heart, a DVT can break loose and travel to the lungs resulting in a pulmonary embolism which can be life threatening. Although the risk of this occurring with an upper extremity DVT is not as high as with a DVT of the lower extremity, it can still be around 10-20%. In the case of VTOS, chronic damage occurs to the vein from repeatedly being compressed by the rib and surrounding structures which leads to scar tissue and thickening of the wall of the vein causing the inside of the vein to become narrowed. The clot forms as a result of stagnant and turbulent blood flow through the narrowed part of the vein. This process can take quite awhile with symptoms not immediately appearing because the body forms new veins called collateral veins to help keep the blood flowing by taking a different route. This is similar to when a serious traffic accident closes part of a highway and the cars end up getting rerouted to side streets to take a different path to get to their destination. A blood clot in a vein obstructs the vein preventing blood from flowing through it. When the axillary-subclavian vein becomes obstructed, blood in the arm cannot flow back to the heart and thus it becomes trapped in the arm which is what causes the arm to be swollen and tight. Once a blood clot forms, symptoms usually follow soon thereafter.

### Symptom Features:

- Patient population split evenly between male and female
- Most frequently presents in patients ages 15-35, but can & does occur outside of this range
- Patients are typically young, healthy, and active
- Usually presents on 1 side of the body at a time
- Symptoms typically present with sudden onset and are very dramatic, but not always
- Can often present immediately following an activity requiring heavy arm usage especially repetitive and overhead

### Most Common Symptom Presentation:

- Sudden onset of swelling of the entire arm and hand typically starting at the level of the shoulder. Swelling is usually quite significant with the diameter of the arm being twice the diameter of the unaffected arm.
- Blue, purple or red discoloration of the arm and hand
- The arm and hand will often feel warmer or hot compared to the unaffected arm

- Fatigue, tightness, heaviness, aching or pain in the arm and hand particularly when trying to use it
- Very visible, large collateral veins can often be seen across the chest and the front of the shoulder
- Shortness of breath and chest pain can occur if the clot has traveled to the lungs resulting in a pulmonary embolism.
- Rarely, patients with VTOS will also have NTOS. Go to [www.tosoutreach.com](http://www.tosoutreach.com) to learn more about the symptoms of NTOS.

### Less Common Symptom Presentation:

- Minimal or no swelling
- Intermittent swelling that continues for weeks or months which is activity dependent
- No visible collateral veins on the chest and front of the shoulder
- No arm and hand discoloration
- Heaviness, fatigue, aching or pain only intermittently which is typically activity dependent
- Usually diagnosed as a result of a flare up of intermittent symptoms or when testing to rule out other conditions or other types of TOS

### NON-THROMBOTIC VTOS (McCLEERY SYNDROME)

With non-thrombotic VTOS, symptoms of vein compression are intermittent, positional, and not due to formation of a blood clot. This type of VTOS is less common than the thrombotic form. Most surgeons will offer to operate with this form of VTOS, but others recommend only conservative treatment until such time that a clot occurs. Vein compression with the arm elevated without symptoms of venous congestion is **not** considered to be VTOS.

### Symptom Features:

- Patient population split evenly between male and female
- Most frequently presents in patients ages 15-35, but can & does occur outside of this range
- Patients are typically young, healthy, and active
- Usually presents on 1 side of the body at a time, but can be on both sides
- Symptoms are only present during activities of heavy arm usage especially repetitive or overhead and then resolve when the arm is at rest

### Symptoms:

- Arm and hand swelling (typically not as significant as with thrombotic VTOS)
- Blue, purple or red discoloration of the arm and hand
- Fatigue, tightness, heaviness, aching or pain in the arm and hand
- Warmth or hot feeling of the arm and hand
- Bulging veins in the arm and hand

## DIAGNOSIS

### DIAGNOSIS CHARACTERISTICS

The diagnostic process for both forms of VTOS is very similar with the main difference being whether or not the testing reveals a blood clot. When a blood clot is found on imaging, and it is verified that the compression of the axillary-subclavian vein is at the costoclavicular

space, the diagnosis will be thrombotic VTOS (Paget-Schroetter Syndrome). If a blood clot is not present but imaging shows positional compression of the axillary-subclavian vein at the costoclavicular space resulting in symptoms of venous congestion, then the diagnosis will be non-thrombotic VTOS (McCleery Syndrome). It is very important to confirm the location of the compression and the clot as only 60% of upper extremity (arm) blood clots are TOS related.

### **Who Diagnoses & Treats VTOS?**

Any doctor who is familiar with VTOS can give a preliminary diagnosis. These most commonly are emergency room physicians. Once a diagnosis of VTOS is suspected, referral should be made to a TOS specialist to make a definitive diagnosis and treat accordingly. TOS specialists are usually vascular surgeons and occasionally cardiothoracic surgeons. However, most vascular surgeons and cardiothoracic surgeons DO NOT specialize in TOS. In fact, most of them have very little experience with TOS. Therefore, it needs to be a vascular surgeon or cardiothoracic surgeon who specifically specializes in TOS.

### **VASCULAR TESTING**

**Venous Duplex or Doppler Ultrasound** this is the least invasive, least expensive, and most readily available test out there to check for blood clots and blood flow abnormalities. Duplex ultrasound involves using high frequency sound waves to look at the speed of blood flow, and structure of the veins. It involves an instrument called a transducer being placed on the skin in the area of the vein being imaged, and it is moved around on top of the skin to get different views in different areas. It can also be performed with the arm in different positions. However, by itself, compression of the vein with the arm elevated in the absence of symptoms of venous congestion is not diagnostic of either form of VTOS. With thrombotic VTOS, because it is often associated with a sudden onset of very dramatic symptoms, patients often present to their local ER where an ultrasound can be done to check for clots. However, due to the location of the blood clot with VTOS, which can be directly behind the collarbone, it can be difficult to detect and can depend on the level of skill and experience of the ultrasound technician. This is particularly true in the very early stages of the clot when it has not extended further along in the vein. For these reasons, ultrasound can have a fairly high false negative rate with respect to thrombotic VTOS. Some studies have quantified this as high as 30%. Therefore, if the ultrasound does not detect a clot but the clinical suspicion for a clot is still very high due to the patient's presentation and symptoms, more advanced and definitive imaging should be done as described below. Consequently, a negative ultrasound cannot be used to rule out thrombotic VTOS in the setting of high clinical suspicion. However, an ultrasound which is positive for an axillary-subclavian clot is extremely reliable.

**CT Angiogram/MR Angiogram of the Chest (CTA or MRA)** this is a CT scan or MRI of the chest which can show the vessels, particularly the axillary-subclavian vein and axillary-subclavian artery. This is also sometimes referred to as a CT Venogram or MR Venogram. These tests involve injecting contrast material into a vein and taking x-ray images to determine how the blood moves through the vein, the exact location of the vein compression, and to see what physical condition the vein is in as far as damage or blockage. Either test can be performed both with the arm up and with the arm down. Again, by itself, compression of the vein with the arm elevated in the absence of symptoms of venous congestion is not diagnostic of either form of VTOS. For a diagnosis of either form of VTOS, the compression of the vein needs to be shown to occur at the costoclavicular space where the first rib and collarbone intersect. The 3 most likely scenarios in which to use this test are:

1. If a patient has a positive ultrasound showing a clot, these tests can be used to get a closer look at the vein to see exactly where the clot is and the condition of the vein and any collateral veins which have formed. However, in that situation, it is usually recommended to go ahead and perform a direct catheter venogram (described below) as it is the gold standard for vein imaging and allows for thrombolysis to be performed at the same time to break up the clot.
2. If a patient has a negative ultrasound which did not show a clot, but they have history and symptoms which are highly suspicious for a clot, these tests can be done to get a better look at the vein to see if there is a clot, what the physical condition of the vein is, and what the collateral vein situation looks like. Again, if the suspicion of a clot is high enough, it is usually recommended to perform a direct catheter venogram (described below) as it is the gold standard for vein imaging and allows for thrombolysis to be performed at the same time to break up the clot. There are also rare situations where a clot will not be seen on CTA or MRA and so if clinical suspicion remains high, a direct catheter venogram should then be performed.
3. If a patient has a negative ultrasound and has intermittent venous congestion symptoms mostly with the arm elevated, these are good tests for diagnosing non-thrombotic VTOS. In this instance, it is extremely important to get images with the arm up to determine that the vein is being compressed within the costoclavicular space with the arm in the elevated position. These tests can show where the compression is occurring and how severe the compression is. These tests can also show whether the vein is sustaining damage, which can assist with making treatment decisions pertaining to surgery and perhaps help determine if there is a high risk for clot formation. Because in these circumstances the suspicion of a clot is low, CTA or MRA is a good choice since it is minimally invasive and more readily available than a direct catheter venogram.

**Catheter-Directed Venogram** This is considered the gold standard for imaging and diagnosing thrombotic VTOS. Not only can it identify clots and assess the condition of the vein and collateral veins, but it can also be used as a first line of treatment via thrombolysis to break up the clot and can be used as an anatomical road map for surgical treatment in the future. This procedure is usually performed by a vascular surgeon or an interventional radiologist. Often, the patient is given mild sedation. It involves inserting a needle or sheath into a vein on the affected arm. A catheter will be inserted into the vein, contrast dye will be injected into the vein, and x-ray images will be taken to assess blood flow and condition of the vein. Depending on the findings on the images, during the same procedure, this same catheter can be used to reach and try to break through the clot and/or to administer medication to the area of the clot to help dissolve it.

## PHYSICAL EXAM

Physical exam is important in a patient with suspected VTOS as it can provide clues as to whether a clot is likely, whether other types of TOS are involved, and it can help determine the best next step in the diagnostic process. Below is a list of what is typically assessed during a targeted VTOS physical exam:

- Magnitude of arm swelling often with comparison to the opposite arm including arm circumference measurements
- Location of the swelling within the arm i.e. fingers, hand, lower or upper arm
- Exam of upper arm veins for signs of clot that has extended from the axillary-subclavian vein

- Presence of very visible collateral veins across the chest, front of the shoulder, and/or upper arm
- Discoloration of the arm and hand
- Whether symptoms are mainly triggered when the arm is raised or when it is at rest
- Temperature of the arm and hand
- Signs of pulmonary embolism (blood clot that traveled to the lungs)
- Identification of any signs of ATOS or NTOS

## BLOOD CLOTTING DISORDER TESTING

Some people have specific genetic markers that make their blood more likely to clot which can make them more likely to form blood clots. This is a type of blood clotting disorder. Technically, VTOS is a mechanical issue wherein the clot forms due to physical compression of the vein. Which is a different mechanism for clotting than having a blood clotting disorder. However, it has been shown that a fair number of VTOS patients do have a blood clotting disorder. Therefore, a referral to a hematologist and having lab work done to test for blood clotting disorders is a good idea as having one of these disorders can impact future treatment plans for VTOS.

## PUBLISHED DIAGNOSTIC CRITERIA

In 2016, the top TOS specialists in the United States collaborated to come up with standardized diagnostic criteria for all 3 types of TOS. It was published in an article in the Journal of the Society for Vascular Surgery. Below are the published standardized criteria for the diagnosis of VTOS.

### VENOUS TOS

**Definitions and diagnostic criteria.** VTOS is defined as an abnormality of the subclavian vein caused by extrinsic compression at the costoclavicular junction (VTOS) or, rarely, the pectoralis minor space (VPMS). Such compression can be intermittent involving a normal vein (McCleery syndrome), be intermittent leading to a damaged vein, or result in thrombosis of the vein at presentation.<sup>12</sup> In general, all three of the following criteria must be present in patients with this diagnosis; but even if the patient is asymptomatic, ultrasonic or venographic documentation of axillosubclavian thrombus in the absence of other factors is enough for the diagnosis to be made.

#### 1. HISTORY

- Arm swelling, usually with discoloration and heaviness
  - This can occur with the arms overhead only, suggesting nonthrombotic VTOS, or present as a fixed symptom, suggesting subclavian vein thrombosis.
- Absence of inciting cause (indwelling catheter, malignant neoplasm)

#### 2. EXAMINATION

- Visible arm swelling at rest, although if the arm swelling is reported only with exertion or arms overhead, the arm may be normal at rest.
- Arm discoloration
- Shoulder, upper arm, or chest wall venous collaterals

#### 3. IMAGING

- Documentation of venous compression at the costoclavicular junction by ultrasound, venography, or cross-sectional imaging:
  - If the vein is occluded from mid upper arm to the innominate in the setting of appropriate symptoms (and no secondary cause is present), VTOS may be assumed to be present.
  - If the vein is patent but abnormal, the location of the abnormality (costoclavicular junction or pectoralis minor space) should be documented.
  - If the vein appears normal at rest, results of ultrasound or venography with the arm abducted >90 degrees should be reported.
  - In all cases, every attempt should be made to obtain venography through the brachial or basilic veins rather than the cephalic vein as disease sometimes extends lateral to the cephalic arch.

Illig KA, Donahue D, Duncan A, Freischlag J, Gelabert H, Johansen K, Jordan S, Sanders R, Thompson R. Reporting standards of the Society for Vascular Surgery for thoracic outlet syndrome. J Vasc Surg. 2016 Sep;64(3):e23-35.

# TREATMENT

## General

All TOS experts agree that, for the thrombotic form of VTOS when a blood clot has occurred, surgical treatment is a necessity. The majority of conservative (non-surgical) treatment is done in addition to surgery either to prevent further clotting while waiting for surgery or to make surgery more easily accomplished and more successful. Occasionally, there can be certain situations in which a patient might have a medical condition or circumstance which renders surgery not an option, but in general, it is recommended. For thrombotic VTOS, without surgery, the risk of clotting again is very high ranging from 30-70%. This also includes a 10-20% risk of the clot traveling to the lungs resulting in pulmonary embolism which can be fatal. Conservative treatment in a patient not electing to undergo surgery typically consists of:

- Lifelong or chronic use of blood thinners (clotting can still occur despite the blood thinners)
- Significant restrictions in arm activity and usage (especially overhead)
- Compression sleeve worn on the arm to help promote blood flow

Also, without surgery, symptoms of venous congestion are likely to continue and can lead to post-thrombotic syndrome which includes chronic symptoms of pain, swelling, and arm fatigue. As for non-thrombotic VTOS, surgery is usually not as urgent. Therefore, the recommendation for surgery can be treated more like it is for NTOS whereby it depends on how the patient's life is being impacted by the condition. Surgical treatment for non-thrombotic VTOS is the same as that for thrombotic VTOS.

## CONSERVATIVE TREATMENT (NON-SURGICAL OR PRE-SURGICAL)

### Anticoagulation (Blood Thinners)

Almost all TOS experts agree that once a patient has been diagnosed with a VTOS blood clot, blood thinner medication should begin immediately. This is typically in the form of an injection or an oral medication. The main goals of blood thinners with respect to VTOS are:

- Prevent the clot from extending and progressing further into the venous system
- Prevent further clots from forming
- Prevent clots from traveling to the lung and resulting in pulmonary embolism

Blood thinners are only meant to be an interim treatment until the patient can have surgery. Because VTOS blood clots are caused by extrinsic (external) compression of the vein by the first rib and other structures, clots can still occur despite being on blood thinners.

### Thrombolysis (Breaking Up/Dissolving the Clot)

Thrombolysis involves inserting a needle or sheath into a vein on the affected arm. A catheter is then inserted into the vein and is slowly guided through the vein until it reaches the location of the clot. Thrombolysis can be done in a few different ways. One way is to use medication only. This involves continuous infusion of medication to dissolve the clot via the catheter that was inserted into the vein next to the clot. This is usually done over 24-48 hours and requires hospitalization to be monitored in the ICU. The other way to

accomplish thrombolysis is by a combination of medication to dissolve the clot and a mechanical device on the tip of the catheter to physically break up the clot. This can usually be achieved in a matter of hours and typically does not require overnight hospitalization.

Experts have found that thrombolysis is typically only successful if performed within the first 14 days of the formation of the blood clot. It can often be performed during catheter directed venogram done during the initial diagnostic process. Almost all TOS experts agree that, if the patient presents during the initial 2-week window, thrombolysis should always be performed unless the patient has a medical condition or circumstance for which it would not be safe. Successful thrombolysis allows for:

- return of blood flow which can provide symptom relief
- even further confirmation of diagnosis because with the clot gone, the true contour of the vein is able to be seen on imaging showing the extent of stenosis (narrowing)
- potential for a more successful long-term surgical outcome due to less scarring and damage to the vein by the time surgery is performed

Many experts believe that successful thrombolysis is the key to an excellent long-term successful outcome for thrombotic VTOS patients when combined with surgery. However, a few experts believe that the outcomes of patients who are treated with both thrombolysis and surgery are similar to those who are treated only with surgery.

### Balloon Angioplasty

After thrombolysis, there is the option of doing balloon angioplasty which involves using a catheter with a balloon attached to it inserted into the vein which is slowly guided through the vein until it reaches the location where the vein is narrowed. The balloon is then inflated to expand the vein to its normal diameter. However, since the compression of the vein is caused by external compression of the vein by the first rib and other structures, most TOS experts believe that, until surgery is performed, the improvement in the diameter of the vein is just temporary, and therefore, pre-operative angioplasty is not likely to be of much value.

### Stents

Placing stents inside vessels to help them remain open is commonplace for narrowed vessels in other parts of the body and under different circumstances. However, all TOS experts agree that stents should **never** be placed into the axillary-subclavian vein prior to surgery. Because the vein narrowing in the case of VTOS is caused by external compression of the vein by the first rib and other structures, failure or fracture of the stent is almost guaranteed. If this occurs, it can lead to further clotting and pain, and can also make future surgical treatment much more difficult.

## SURGICAL TREATMENT

Surgery is the mainstay of treatment for VTOS. In the case where a blood clot has occurred, it is the only definitive long-term treatment. If the mechanical compression that is compressing the vein is not removed, the patient risks developing further clots (even on blood thinners) and permanently damaging the vein. There is also risk of a clot going to the lungs as a pulmonary embolism which can be fatal. Some cite the risk for this as high as 10-20%. As with any type of TOS, the surgery is extremely complicated and takes place in a very complex area of the body where several vital structures are all packed tightly together in a very small space. In the case of VTOS in particular, it can be even more technically challenging and risky especially if vein reconstruction is attempted. With a surgeon who is **not** experienced in TOS surgery, damage to vital vessels and to nerves that serve the arm

and hand can occur and can be devastating. Therefore, of the surgeons available to a patient, it is recommended to choose the surgeon who has the highest level of TOS experience possible. There are very few dedicated TOS centers in the United States and even fewer throughout the rest of the world. Because of this, many patients must travel to other states or other countries for experienced care. However, choosing a highly experienced TOS surgeon gives the patient the highest chance for a successful outcome and the lowest chance for serious complications. Under these circumstances, TOS surgery can be very safe and successful. For help finding a TOS surgeon, go to [www.tosoutreach.com/find-a-surgeon](http://www.tosoutreach.com/find-a-surgeon). In addition, VTOS surgery is usually **not** an emergency surgery. Therefore, after diagnosis of the clot, there should be time for a patient to be referred to an experienced TOS surgeon, if possible. Some TOS experts actually prefer to wait 4-6 weeks after thrombolysis to do surgery as this provides time for the inflammatory process around the clot location to resolve which they believe can reduce risk during surgery. Most experts believe that it is safe to perform VTOS surgery right away or after a brief waiting period, and that timing doesn't really impact the outcome. However, the longer the wait time before surgery, the higher the risk is for further damage to the vein and for clotting again.

### What does surgery for VTOS entail?

In general terms, VTOS surgery is often referred to as thoracic outlet decompression surgery as it involves removing anatomical structures and scar tissue in order to decompress the vein. VTOS surgery usually involves of hospital stay of 2-6 nights depending on what was done during surgery. The main goals of VTOS surgery are (1) to decompress the vein to prevent any further damage or blood clots and (2) to restore and maintain normal blood flow through the vein. There are actually several components to VTOS surgery. Depending on the patient's findings and the surgeon's protocol and experience level, VTOS surgery includes some or all of the following:

- Removal of the first rib known as First Rib Resection (complete or partial)
- Removal of the anterior scalene muscle known as Anterior Scalenectomy (complete or partial)
- Removal of the middle scalene muscle known as Middle Scalenectomy (complete or partial)
- Removal of scar tissue from around the nerves known as Brachial Plexus Neurolysis (complete or partial)
- Removal of scar tissue from around the vein known as Venolysis (complete or partial)
- Removal of the subclavius muscle/tendon (complete or partial)
- Removal of costoclavicular ligament or any other compressing structures
- Intraoperative venogram
- Balloon angioplasty
- Vein reconstruction

Most TOS experts believe that, at a minimum, removing the first rib, most or all of the anterior scalene, and most or all of the subclavius muscle in addition to performing venolysis is the best way to achieve a complete and thorough decompression and to prevent recurrence of VTOS. However, there are differences of opinion among the experts when it comes to handling VTOS when the vein remains narrowed after decompression has been performed. Namely whether to surgically reconstruct the vein or to use post-operative angioplasty. There are also several different surgical approaches to take, and each of them allows for different variations in treatment. Also, because TOS is not a well-known condition and surgery for it is not regularly performed by most surgeons, there exists a wide variety of surgical component combinations that can be performed for VTOS. For this reason, let's break each component down a little further:



**Removal of the first rib known as First Rib Resection (complete or partial)** As far as history goes, removing the first rib is probably the oldest and most common component of TOS decompression surgery. All TOS experts believe that all or part of the first rib should be removed for VTOS patients. Technically, the part of the first rib closest to the sternum (anterior portion of the rib) is what compresses the axillary-subclavian vein. Therefore, some surgeons believe that the anterior portion of the rib is all that needs to be removed to decompress the vein. This is true, however, it has been shown that removing only the anterior portion of the rib and leaving a significant amount of the posterior portion of the rib can lead to post op development of secondary NTOS due to the remaining rib and any scar tissue that might attach to it compressing the brachial plexus nerves. In addition, certain surgical approaches can limit access to the posterior portion of the rib and thus only partial rib removal is possible. Most TOS experts believe that the entire first rib should be removed in VTOS patients.

**Removal of the anterior scalene muscle known as Anterior Scalenectomy (complete or partial)** Because the anterior scalene is attached to the first rib, in order to remove the first rib, it must, at a minimum, be detached from the first rib. Whether it also gets removed either partially or completely is up to the surgeon. Detaching the anterior scalene from the rib but **not** removing it is called anterior scalenotomy. Almost all TOS experts agree that either some or all of the anterior scalene muscle should be removed for purposes of complete decompression of the vein. In addition, some surgical approaches limit access to be able to remove the entire anterior scalene muscle. One potential issue with a partial anterior scalenectomy or anterior scalenotomy is that there is a chance for the remaining part of the scalene to reattach to other structures and cause compression of the brachial plexus nerves resulting in development of secondary NTOS. This has been a consistent finding during reoperations on patients who had either prior partial anterior scalenectomy or anterior scalenotomy.

**Removal of the middle scalene muscle known as Middle Scalenectomy (complete or partial)** Because the middle scalene is attached to the first rib, in order to remove the first rib, it must, at a minimum, be detached from the first rib. Whether it also gets removed either partially or completely is up to the surgeon. Detaching the middle scalene from the rib but **not** removing it is called a middle scalenotomy. Since the middle scalene doesn't typically play a part in axillary-subclavian vein compression, some TOS experts believe that it is unnecessary to remove the middle scalene at all and that simply detaching it from the first rib in order to remove the first rib is all that is needed. In addition, some surgical approaches limit access to be able to remove the entire middle scalene muscle. Other TOS experts believe that the middle scalene muscle should be removed particularly due to the fact that there is a chance for the remaining part of the scalene to reattach to other structures and cause compression of the brachial plexus nerves resulting in development of secondary NTOS. This has been a consistent finding during reoperations on patients who had either prior partial middle scalenectomy or middle scalenotomy.

**Removal of scar tissue from around the nerves known as Brachial Plexus Neurolysis (complete or partial)** Even though a patient might be primarily undergoing surgery for vein compression, it is not uncommon for these patients to also have some level of scar tissue around the brachial plexus nerves from generalized compression within the area in addition to the overall inflammatory process triggered by a blood clot. Most TOS experts will go ahead and perform neurolysis if they notice scar tissue around the nerves during surgery. Some surgical approaches for VTOS allow access for a complete neurolysis of all five brachial plexus nerve roots, some only allow access for neurolysis of the lower three nerve roots, and some do not allow for any access to the nerves to perform neurolysis. Some experts believe that leaving any scar tissue around the nerves would not constitute a full decompression and could therefore continue to cause symptoms.

**Removal of scar tissue from around the vein known as Venolysis (complete or partial)** Almost all TOS experts agree that venolysis of the vein should be done for complete decompression. However, some experts believe that certain surgical approaches allow for a more complete external venolysis than others, and removal of all scar tissue from around the vein is critical to achieving complete decompression and restoring the vein to its normal diameter.

**Removal of the subclavius muscle/tendon (complete or partial)** All TOS Experts believe that either all or some of the subclavius muscle/tendon should be removed. Some surgical approaches limit access to be able to remove the entire subclavius muscle/tendon. Some experts believe that partial removal of the subclavius muscle/tendon does not achieve complete decompression and can result in continued or recurrent vein compression.

**Removal of costoclavicular ligament or any other compressing structures** The costoclavicular ligament is typically removed along with the subclavius muscle/tendon. It is an important part of decompression of the vein.

**NOTE: Most TOS experts agree that, even after all compressing structures and scar tissue have been removed, around 50% of patients will still have a narrowed vein due to scarring or chronic clot inside the vein. The 2 most common ways to deal with this issue are balloon angioplasty and surgical reconstruction of the vein. Angioplasty can be done either during surgery or after surgery. Below are descriptions of the components of VTOS surgery related to this issue.**

**Intraoperative Venogram** Some, but not all TOS experts, perform a venogram during surgery. Some use it at the beginning of surgery to assess the condition of the vein and degree of stenosis. Some will use it following the decompression part of surgery to determine whether the vein is open and flowing or whether it is still narrowed and therefore needs angioplasty or reconstruction. Venogram can also be done at the end of surgery to determine whether any angioplasty or reconstruction performed was successful and has opened up the vein. For the experts who prefer balloon angioplasty over reconstruction, the most common protocol is to wait until a week or two after surgery to perform a venogram to see whether blood flow is still maintained and determine whether balloon angioplasty is needed.

**Balloon Angioplasty** As mentioned earlier on this page, some experts are of the opinion that balloon angioplasty before surgery is an extremely temporary solution and of little value since the external compression of the vein has not been removed. However, balloon angioplasty following surgical decompression of the vein can be quite helpful for restoring and maintaining good blood flow. This can be performed either during or after surgery. No matter when it's done, it involves performing a venogram and inserting a catheter with a balloon attached to it into the vein which is slowly guided through the vein until it reaches the location where the vein is narrowed. The balloon is then inflated to expand the vein to its normal diameter. Most TOS experts use this technique after decompression surgery to treat a vein that is still narrowed. However, some experts believe that around 20% of patients will have a vein that is too narrowed and scarred internally to be able to pass the catheter through it to insert the balloon. Therefore, balloon angioplasty is not an option for those patients, so the other interventional option to open the vein is surgical reconstruction of the vein. In addition, if balloon angioplasty is physically possible, has been tried multiple times and is not keeping the vein open, another option experts will try is putting a stent in the vein to keep it open. As mentioned earlier on this page, stents should only be an option after decompression surgery. Some experts are also of the opinion that observation over time to see if the collateral veins develop enough to provide substantial blood flow is a good alternative option.

**Vein Reconstruction** if the vein is too damaged internally, it will not stay open on its own even after decompression surgery. In many cases, balloon angioplasty will help this problem. However, it can take more than 1 attempt, it's not guaranteed to be a permanent solution, and is not an option for those patients whose veins are too scarred. Only certain surgical approaches allow for vein reconstruction, and of those that do, some offer more direct access than others. Vein reconstruction can be quite technically challenging for the surgeon. Therefore, there aren't many surgeons who offer this option, but when performed by a highly experienced surgeon, it is a very definitive treatment with excellent long-term outcomes. For most TOS specialists, there are essentially two modern day options for vein reconstruction: (1) patch angioplasty and (2) bypass grafting. Once the intraoperative venogram has been done and it has been determined that the patient needs reconstruction, the surgeon cuts open the vein to see the internal damage. If the vein is mildly to moderately damaged, only patch angioplasty is needed. Patch angioplasty involves a patch being made from a donor vein and then it is used to replace part of the vein wall which is damaged. If the vein is very scarred and severely damaged inside, then bypass grafting is needed. Bypass grafting involves removing the damaged section of the vein and replacing it with a donor vein. After reconstruction, another intraoperative venogram is done to confirm that normal blood flow has been restored. Some experts prefer to do the decompression and reconstruction all in the same surgery to get everything done all at once, so the patient leaves surgery with normal blood flow restored. However, if a patient has surgery and requires balloon angioplasty or other attempts to open the vein are not successful, vein reconstruction can be done later in a separate procedure. Not all patients are candidates for vein reconstruction, in particular, those who have long chronic clotting of the vein which extends beyond the pec minor muscle. Experts have found that a bypass graft of that length is unlikely to remain open.

As with any surgery, the decision to have surgery and which components should be included in said surgery should be made based on advice given by the patient's surgeon as to what is best for their specific clinical situation.

### **VTOS Surgery Recovery**

In general, the post-hospital recovery for VTOS surgery is usually fairly straightforward. Of course, this can depend on what exactly was done during surgery and what complications occurred. Below is a list of expectations following VTOS surgery keeping in mind that every recovery is different and not everyone will experience the things listed.

- Can include continuing to experience pre-op symptoms such as arm swelling, pain and fatigue
- new symptoms can be felt in the neck, chest, upper back, shoulder, arm, or hand
- because nerves usually have to be manipulated during surgery and some patients also require brachial plexus neurolysis, some experience nerve symptoms from surgery such as numbness, tingling, pain, burning, skin hypersensitivity, itching, stinging, electrical zaps, cold sensations, hot sensations, skin color and temperature changes, muscle twitching, neck and upper back muscle tightness
- nerve symptoms are usually very temporary only lasting a few weeks
- Some loss of arm strength and range of motion. Although, some can have full range of motion immediately after surgery, most have some degree of diminished strength and range of motion
- Low energy and general fatigue with activity. For some, this can last for a few months.
- Remaining on blood thinners for at least 3 months post op
- Most do PT to regain arm strength and range of motion
- Most are fully healed after 3-6 months

## Restrictions

- Most return to work anywhere from 4-12 weeks post op depending on how physically demanding the job is
- Most have weight restrictions of no more than 5-10 lbs for at least 6-12 weeks. This usually includes lifting, pushing, pulling, etc.
- Most have activity restrictions including no overhead or above shoulder activity and nothing repetitive for at least 6-12 weeks
- Most are able to return to driving by 4 weeks post op
- Restrictions are at the discretion of the surgeon as to when they are imposed and when they are lifted.

## Return of Symptoms (Recurrent VTOS)

Sometimes a patient will experience initial relief and then have symptoms return. The two most likely causes for a recurrence of VTOS symptoms are:

**Complete decompression not achieved during surgery** this would occur as described earlier on this page when some anatomy, usually rib, scalene muscle, or subclavius muscle/tendon was either not removed at all or only partially removed.

**No, reoccluded or failed Vein Reconstruction/No or failed Balloon Angioplasty** this would occur when a patient whose vein is not completely open following decompression surgery did not have balloon angioplasty or vein reconstruction performed, had unsuccessful balloon angioplasty or vein reconstruction, or the reconstructed vein reoccludes.

## Secondary NTOS

Sometimes a patient who has VTOS which was successfully treated with surgery will begin to experience symptoms of NTOS sometime after surgery. As described earlier on this page, this can occur when too much of the posterior portion of the rib is left in or when there is incomplete anterior and/or middle scalenectomy.

**For more information on all types of TOS including symptoms, diagnosis, treatment, and more, please visit [www.TOSOutreach.com](http://www.TOSOutreach.com).**