



Information for Family & Friends of Patients with Neurogenic TOS

TOS, in particular Neurogenic TOS, is a very unique and complex condition which can be difficult for friends and family to understand. This can make it difficult for the patient to ask for and maintain the support of friends and family. It often leads to great conflict within the family and the home involving a lot of miscommunication, frustration, and resentment. It can also make it difficult for the patient to explain to their employers and co-workers. This often results in the loss of friends, significant others, and family members and can result in the patient feeling or becoming isolated with little to no support. The information below is designed to help families and friends of TOS patients understand a little more about the condition and what it is like to live with the condition. In addition, it can be quite helpful for the patient and any close family members to seek out a mental health professional, specifically one who has experience with chronic pain or illness, to help guide them through this journey.

The Invisible Illness

An invisible illness is one in which the patient experiences symptoms, but there are no external signs or anything about their appearance that would make others aware that the patient has an illness or medical condition. In other words, the person "looks fine" as most would say. There are no bruises, cuts, scrapes, casts, slings or other obvious signs that would telecast that the person has a medical condition. Most chronic pain conditions are invisible. Neurogenic TOS is for the most part an invisible illness. However, invisible does not mean that the condition is not real or extremely debilitating.

The Long Road to Diagnosis

Neurogenic TOS is difficult to diagnose mainly because it does not really show up on any tests and because most doctors do not know what it is or how to diagnose it. This leads to patients usually seeing an average of 7 different doctors, waiting several years, and sometimes having several unnecessary procedures before getting a proper diagnosis. It is an extremely scary and frustrating process to have symptoms, know that something is wrong with you, and yet no doctor can tell you what it is or how to treat it. Often patients will begin to think that the symptoms must just be in their head, and, even worse, some have doctors who actually suggest this theory as a possible answer. This can cause emotions to run high and even lead to friends and family starting to doubt the legitimacy of the patient's symptoms. When patients are finally able to get that diagnosis, many of them literally burst into tears with relief that they have found an answer and that someone finally believes them and can offer help.

The Broken Record

Many people with NTOS will say that they receive comments from family and friends that they only want to talk about their illness or that all they ever talk about is their medical condition. This is more likely to occur at the beginning of the condition when symptoms are first beginning, and a diagnosis is being sought. This is not shocking considering horrible symptoms are overtaking their life and they are spending large amounts of time looking for relief and a diagnosis. It can basically consume their life. It is new, and it is extremely difficult to handle. They are often scared and do not understand what is going on, and they usually don't know anyone who has experienced or gone through the same thing. Of course, they are going to want to talk about something that is seemingly destroying their life. They need friends and family to be there with support, understanding, and patience. Often, they are not looking for solutions to their problems, but rather just to vent about the insanity that is happening to their body and the difficulties they are having with seeing doctors and getting a diagnosis. It might be helpful to start off conversations with asking them how they are doing or how things are going which

can allow them to get whatever they need to off their chest which usually allows for the rest of the conversation to revolve around other topics.

The Great Pretender

We have all heard stories at some point or another about someone who pretended to have cancer or some other devastating illness only to make money from a GoFundMe or other fundraising medium. So, obviously there are a few bad eggs out there who will make up an illness for ulterior motives. During the diagnostic process, co-workers, friends and even sometimes family of neurogenic TOS patients will make the accusation that the person is making up the illness just to get attention or to get out of working etc. It can be easier to make these accusations with an invisible illness such as this. The person looks fine, the doctors can't find anything wrong, so they must be making it up. This is a devastating accusation for the patient who is already in a ton of pain and going through an emotionally and physically exhausting process. A little bit of common sense can go a long way here. If you ask any NTOS patient about their symptoms, almost all of them can describe them in excruciatingly great detail. Most people who are faking an illness will be pretty vague about the supposed symptoms they are experiencing. Most NTOS patients have had numerous tests and radiology exams and can also detail them and the results they received in great detail. Those who are faking an illness will, again, be pretty vague about any testing they have done and the results of those tests. Think about what activities the patient has had to give up or limit doing. Are these activities things that they love or have a huge passion for? If so, then usually something pretty serious must be going on for them to quit those activities. Think of whether this person has a history of making things up or being deceitful. If they do not, why would they start now? Some will think that the patient is making up the illness if they are seen interacting with others by laughing or joking around, enjoying dinner out with their family, or at the grocery store with a full cart of groceries. The theory behind this is that if the person was in that much pain, why are they laughing or how are they able to go to the grocery store? The truth is that life does not stop just because someone is in terrible pain. Chronic pain does not mean that someone sits in a room by themselves crying all day every day. People who are having chronic pain try as best they can to lead a normal life. Most of them do not have a choice and have families that they are trying to live for every day. Also, people with chronic pain as a matter of necessity and adaptation, end up being able to perform many daily functions that you wouldn't think someone with that level of pain would be able to do. This does not mean that they are fabricating an illness. This just means that they are surviving. Also, most people living with a high level of chronic pain do not walk around every day talking about how much pain they are in. It becomes a normal part of their daily life. It is always there, so there is no need to keep announcing it. It is no different than how those whose normal daily life does **not** include pain are not walking around every day announcing how they are not in pain.

Pain and Its Effects

Neurogenic TOS affects the brachial plexus nerves. These nerves serve the chest, shoulder, upper back, arm, and hand. It can cause pain in the neck, chest, head, upper back, shoulder, arm, and hand. It is mostly nerve pain and muscle pain in these areas. Nerve pain is basically the worst type of pain a person can experience. It is agonizing, relentless, and very difficult to treat as far as pain control. Anyone who has ever had nerve pain never wants to experience it again. Have you ever had one of those excruciating toothaches? The kind where you are just clutching your face in agony, and you can't get to the dentist's office fast enough just to make it stop? It seems like you can't do anything -- can't work, can't focus because the pain is so severe. This is because the nerve to the tooth is being affected. That's nerve pain. Now, fortunately, in the toothache scenario, the dentist can take pretty immediate action to solve the tooth problem and get the patient out of pain relatively quickly. This is not the case for the brachial plexus nerves being compressed with NTOS. And these nerves can cause a myriad of different agonizing symptoms and sensations such as burning, stinging, electrical zaps, nerve tension pulling, sharp pain, stabbing pain, shooting pain, numbness, tingling, skin hypersensitivity, weakness, heaviness, fatigue, cold sensations, hot sensations, swelling, skin color changes, and skin temperature

changes. It can even impact the ability to move and use the arm, hand, or fingers. And, unfortunately, every task that someone does with any part of their body involves the nerves, so moving and using the affected part of the body increases the pain and symptoms. These symptoms can really impact all aspects of a person. They can lead to overall fatigue and low energy, brain fog, inability to focus, being overly emotional, anger, frustration, or short temper. Someone who is usually easygoing and mild mannered might have a short fuse when dealing with a spouse, co-worker, or even their child and can just snap at people. Pain wears a person down. It eats away at them all throughout the day so even having normal conversations such as what to eat for dinner or what is needed at the grocery store can be taxing and overwhelming. Imagine having that excruciating, throbbing toothache and trying to cook a meal, do laundry, help kids with homework, focus on your job tasks, sit through meetings, drive across town, or take care of pets. Tasks that are seemingly fairly routine are extremely taxing when someone is in severe pain. Even more mild pain that is nagging and constantly picking away at a person can lead to behavioral and attitude changes. A person who is in pain is doing the best that they can, so try to be understanding, supportive, and don't take it personally. Think of how the person behaved prior to being in chronic pain and know that their actions are only as a result of the pain. It is difficult to know exactly what another person is going through when you haven't experienced it yourself. If you notice the person acting out and not like themselves, perhaps ask them what is hurting them or how you can help. Sometimes communication can help both parties understand what is going on a little better and make it easier to work through.

A Change of Plans

One thing about neurogenic TOS is that it can really vary from day to day or even throughout the day. The person might not know what to expect for the day until they wake up and are living it out. This can mean a lot of changing or cancelling plans. They might make plans with a friend or significant other to go out to dinner, see a movie or go dancing, but when the time comes to go out, the pain might just be too much. They might cancel altogether or ask to change plans to watch a movie at home instead. Chronic pain is very exhausting, and it wears a person out. Their body might just be completely spent when it comes time for the scheduled plans. Also, because the pain is so hard to control, it typically involves a lot of modalities that are not conducive to use when not at home such as ice packs, heating pads, TENS units, laying down, topical creams, patches, etc. Pain medications or muscle relaxers can also make the person tired and unable to do normal activities. You might find that every time you invite the person to participate in plans, they decline the offer. This might seem like the person is blowing you off or doesn't care. However, they are just not physically able to participate even though they would love to. If you know the person is experiencing chronic pain, perhaps sometimes take the initiative to make plans to go see them at their house instead of just inviting them to plans out which you know they likely won't be able to attend. Many people with this condition end up losing friends because they can't go out and be the fun carefree person that they used to be. Many people will find that the person's illness is inconvenient for them and just ruins the plans that they want to do. Try to think about how the person used to be and what must be going on for them to cancel plans and not go anywhere. It is not that they don't *want* to go. It's that they *can't* go. If they have always been a really good friend or partner, they still are but it just looks a little bit different. Try to give them the benefit of the doubt and see them in settings where you can still be together.

Triggering Activities

Even though NTOS patients have some level of pain all the time, there are certain activities that can make the symptoms worse. Unfortunately, many of the activities that can trigger or flare symptoms are some of the most basic such as brushing teeth, brushing hair, washing hair, styling hair, showering, washing dishes, loading or unloading the dishwasher, laundry, folding clothes, driving, vacuuming, mopping, typing, and even sleeping. Therefore, all the tasks that the person is used to doing on their own everyday either can't be done at all or require assistance. This can be very surprising to most family members and significant others. How can someone who looks perfectly fine not be able to brush their teeth or fold a towel? Doing any task that requires the arm to be raised at all causes the nerves

to be further compressed. This leads to extreme fatigue of the arm and additional pain. These are also all activities that involve a lot of fine or repetitive motor skills which require a lot of intense nerve work by nerves that are already taxed due to damage and compression. This can put a lot of stress on family members who need to help with or assume responsibility for these tasks. Being unable to perform these tasks is also extremely frustrating for the patient. Someone who was once completely independent is now relying on assistance to take care of themselves and their family. These tasks might seem easy and like no big deal, but to someone with NTOS, they can be extremely difficult.

The Ghost of Chores and Housework Past

Most people like to feel valuable and needed. Part of the way someone feels valuable is the role they have in their household and the things they can do or provide for their loved ones. In someone with NTOS who can no longer perform their basic household chores anymore, the inability to perform these duties can make them feel worthless or of little value. It also makes them feel like a burden to others. Most people take for granted the ability to mop, vacuum or go to the grocery store and, frankly, most people would probably say that they wished they didn't have to do these tasks. However, wishing that you didn't have to do these tasks is different than wishing that you were physically unable to do these tasks. Being unable to do laundry or wash the dishes can really make someone feel devalued. This can lead to a lot of emotions surrounding these tasks and can leave the person desperately trying to find something they can do to contribute to the household. Those who live by themselves can really feel like a burden or worthless requiring friends or family to come over to help with basic household chores. They can feel as though they lost their independence. Please be aware that these subjects can sometimes be touchy for the person and help to make them feel that it is okay to need help. If the person continues to do these activities on a regular basis, this can ultimately worsen their condition and cause further nerve damage. Therefore, it is best to find a way for them to not have to do these activities, and they should be encouraged not to and to find an alternative solution.

Occupation: Unemployed

Many people spend years and a lot of hard work to find a job that they love. A lot of people have their identity and self-worth tied to their job. Obviously, a job is how a person supports themselves and their family and it's what allows them to participate in recreational activities such as travel and hobbies. Let's face it, being employed is a huge part of almost every person's life. Many people with neurogenic TOS must either change occupations or stop working altogether. This can be devastating. When diagnosed, most people are in the prime of their work life. Suddenly, they are left with having to start over again to find a new career path or being unable to perform any job. It can be overwhelming to think about what kind of job they can do and whether any future employer will accept their physical restrictions. Not only is this demoralizing, but it also leaves the person unable to support themselves and/or their family or unable to monetarily contribute to their household. This can cause a lot of stress within a household and can lead to being unable to pay bills. A lot of guilt can be felt for being unable to contribute and for putting the laboring oar onto a spouse or family members. Then there's the difficult choice of whether to pursue disability benefits. This is tough to do for someone who is young, and it is extremely difficult to obtain and usually requires multiple attempts to obtain benefits. It also comes with all the stereotypical criticisms that the person must just be lazy or not want to work. However, most people with NTOS would give anything to be able to work and to be able to contribute to the household and feel good about themselves. In a typical household, if a person does not work, then they usually would take care of the house and chores, but for someone with NTOS, they might not be able to do either. This further contributes to depression and the feeling of worthlessness as a person, parent, or significant other.

There are many occupations where either the type of work itself or the inherent risk of injury contributes or causes NTOS such as hairstylist, dental assistant or hygienist, sonographer, artist, mechanic, factory worker, nurse, or jobs requiring a lot of typing. In these scenarios, the person is often forced into the arena of workers compensation which often involves being quite limited on which

medical specialists can be seen, which treatment will be approved, and being told when they are “ready” to go back to work. This can add an additional level of stress as many employees are not in control of which doctors to see or which treatment to obtain.

Death of an Identity

Due to NTOS, many people will have significant changes in their life such as loss of job, friends, hobbies or favorite activities, independence, and sometimes family or significant others. This takes a toll on mental health and, in combination with the pain, can change their personality and behavior. Due to these losses and changes, they literally don't feel like the same person they once were. The life they had known is no longer there. So many will say, “I just want to go back to being the same person I was before.” It's a constant battle to get back to doing everything they did before NTOS. With treatment, some are able to get back to those things or at least something close, but for many, it may never happen. Trying to get back to their prior self and prior activities and consistently failing can lead to a lot of disappointment. There is a lot of internal pressure felt to get back to “normal.” Some will even feel pressure from friends and family members. At some point, there is acceptance of the fact that things can't be exactly as they were before. Then, there is mourning the death of the life they once had. It can help to encourage the outlook that they don't *have* to go back to exactly who they were before, and that they can find new activities and hobbies to love. Reassure them that they are still the same person inside and that their worth is not measured by what things they can physically do. This is an extremely difficult and emotional process that can linger for quite some time.

Surgery and Beyond

The surgery for any type of TOS 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. 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, please encourage the patient to choose the surgeon available to them that has the highest level of TOS experience possible.

The decision to have surgery can be quite daunting for most people with NTOS. However, having usually tried a million other things without relief, surgery with an experienced TOS surgeon can be their best bet. Surgery for most medical conditions usually involves a steady linear progression of getting better each day after surgery typically for an average of 6-12 weeks. This is NOT the case for NTOS. Nerves, especially near the brachial plexus, have a very complicated and somewhat turbulent regeneration process. Complete nerve healing for sites at the brachial plexus can take up to 2 years or longer. The recovery trajectory is typically not linear. Instead, it bounces around more like a roller coaster. It is very difficult to predict what each patient's recovery will be like, and it is different for each patient.

Very commonly, post-op NTOS patients will mention that friends and family members will question them or comment as to why they are not completely healed shortly after surgery. This is not surprising given that most people are not familiar with the surgery or recovery process. Following NTOS decompression surgery, the nerves will be decompressed, but this does not mean that they are healed. The typical NTOS patient has nerves that have been compressed for several years, and despite being decompressed, they still need to heal from the damage sustained from the compression. The nerves also get worked on and manipulated during surgery particularly when scar tissue is removed from them, so they must heal from this as well. For this reason, many patients will experience pre-op pain and symptoms that are temporarily worse than before surgery which is normal. Most will also likely experience new symptoms after surgery which they did not have before surgery. Symptoms can change daily in type, location, and/or intensity. New symptoms can pop up weeks or even several months into recovery as the nerves enter different phases of regeneration. It can take several months for them to notice significant improvement and, for some patients, up to a year or longer. It's not uncommon for them to still experience some level of symptoms including flares of symptoms during

the entirety of the healing phase. They usually experience a cycle of “good” days and “bad” days where they feel like they are really making progress and then the next day feel like they are completely back at square one. Eventually, they will have more good days than bad days.

Surgery Recovery: A Team Effort

Following surgery, the nerves are extremely fragile. They require rest to properly heal. Almost all post-op patients will have activity and weight restrictions after surgery. This is usually, at a minimum, for the first 4-6 weeks, but can last longer at the discretion of the surgeon depending on how the nerves are healing. The first 4-12 weeks can be a critical healing time for the nerves. This means that it is crucial for the patient to keep activity to a bare minimum to allow for proper nerve healing. This will typically require a lot of preparation and a good amount of assistance from others. Activities involving house cleaning and household chores should either be put on hold or taken care of by someone else. This includes things like cooking, mopping, sweeping, vacuuming, laundry, errands, grocery shopping, washing dishes, loading and unloading the dishwasher, taking out the trash, dog walking, and caring for pets or children. Putting too much stress on the nerves and overworking them can lead to delayed healing and risk of scar tissue formation around the nerves leading to compression and resulting in return of symptoms. Many NTOS patients are young and very active and tend to have go-getter personalities which lead them to go back to normal activities too soon. Please encourage them to take it slow and put their surgery recovery above all else. This is what is needed to ensure a successful long-term surgical outcome.

For more information on all aspects of TOS including symptoms, diagnosis, treatment, and more, please visit www.TOSOutreach.com.

