Does Botox for migraine on EDS or hypermobility syndrome patients set them up for future problems?

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**What is Migraine?**

Migraine is more than a headache. It is a distinct neurological disease that changes brain biology and function.

Migraine is a long-term disabling disease that can profoundly impact someone’s ability to carry out everyday activities like attending family events or going to work. Migraine can also be difficult on family members—partners, parents, children and relatives.

# How does Botox help for Migraine?

The pathomechanism of chronic migraine has not been fully elucidated. The mode of action of onabotulinumtoxinA in the treatment of chronic migraine is suggested to be related to the inhibition of the release of calcitonin gene-related peptide and substance P in the trigeminovascular system. Randomized clinical trials demonstrated that long-term onabotulinumtoxinA fixed-site and fixed-dose (155-195 U) intra**muscular** injection therapy is effective and well tolerated for the prophylactic treatment of chronic migraine.

**What is EDS?**

Joint hypermobility syndrome (JHS) and Ehlers-Danlos syndrome, hypermobility type (EDS-HT) are two clinically overlapping heritable connective tissue disorders strongly associated with musculoskeletal pain, fatigue and headache. It may also present with neurologic manifestation including migraine.

**How many patients with EDS / hypermobility syndrome suffer from Migraine?**

Migraine with or without aura is considered the most common form of headache in JHS/EDS-HT

However, most patients with Migraine are unaware of whether they also suffer from JHS/EDS-HT. It is the most undetected diagnosis. Individuals with EDS may be prone to migraine due to an inherent disorder of connective tissue impairing the stability of the joints. This in turn increases pressure in these patients suffering from migraines on the surrounding tissues increasing pain and inflammation thus making the tissue hyperreactive causing acute symptoms but continuously resulting in a long term presentation of the problem.

Results in a *study of migraine characteristics in Joint hypermobility syndrome a.k.a Ehlers Danlos Syndrome, hypermobility type by Puledda F Et all* showed that in JHS/EDS-HT: (1) migraine has an earlier onset (12.6 vs 17 years of age; p = 0.005); (2) the rate of migraine days/month is higher (15 vs 9.3 days/month; p = 0.01); (3) accompanying symptoms are usually more frequent; (4) HIT-6 and MIDAS scores are higher (p = 0.04 and p = 0.03); (5) efficacy of rescue medication is almost identical, although, total drug consumption is significantly lower (p < 0.04). Joint hypermobility syndrome and Ehlers-Danlos syndrome, hypermobility type patients have a more severe headache syndrome with respect to the MO group, therefore demonstrating that migraine has a very high impact on quality of life in this disease.

**How do these patients present in therapy?**

Most of these patients suffering from EDS-HT syndrome are unaware of the diagnosis. They mostly present with fibromyalgia diagnosis, multiple neurological or myofascial pain complaints like tendonitis etc.

On further examination it is revealed that they present with EDS-HT and have been suffering from Migraines along with other peripheral nerve / muscular pain as part of their broad chronic pain symptoms.

**EDS presents with hypermobility, which may ultimately lead to early arthritis.**

EDS-HT patients have soft to almost no end feel in their joints. Their ligaments are too lax, thus fail to provide proprioceptive input to their joints. These patients always complain of tightness in their joints even when they are the most hypermobile patients. They never feel like they get enough stretch, so they keep stretching which causes exacerbation of symptoms.The cycle continues as they add to the problem. This over stretching causes surgeries to fail and they stretch the repairs out. It may cause neurological symptoms due to the strain on the nerves thus they get diagnosed with fibromyalgia as no other problems are detected.

**What is the treatment for patient with EDS-HT?**

* Recommendations for patients that present with migraines or neck flare ups especially after sleep was to avoid stomach sleeping or sleeping with brace to prevent overstretching of the tissues in the neck and irritating the structures thus preventing these flare ups. Braces are also recommended for the neck while driving in severe cases. Oval 8 splints for the fingers to prevent hyperextension in the fingers yet allowing them to function in pain free range providing them with a definite end feel during loading activities. Goal with splints is to allow for functional activities while preventing wearing down of cartilage that may cause early arthritis.
* Exercises for upper extremity are preferred in lying down with head supported either face down or up. Thus, all postural exercises are instructed in being performed lying down on the table isotonic prone rows/ extensions, side lying external rotation with head properly supported etc. PNFs if given had to be performed supine with T-Band instead of standing until stability is improved.
* The foam roll exercise which is part of postural correction / nerve gliding exercises are performed on the bed or with 3” roller to prevent excessive stretch on the anterior shoulder tissues.
* Patients are instructed to avoid weight bearing on hands especially pushups. Only fisted position is allowed in neural wrist.
* These patients complain of tightness in the tissues with aching. This pain tends to have a neural component, which is not relieved by stretching, partly because the joint stretches out without offering the flexibility of the tissues the patient is trying to achieve. Neural pain is managed with Myofascial Manipulation with nerve glides to glide the nerve (reduce pain / sensitivity) without overstretching the joints.
* Taping can be used between treatments to reduce pain & expedite the process to initiate neuromuscular re-ed. These patients lack end feel in the joints. Taping is done for proprioceptive input to provide that end feel and stabilization to prevent subluxation of the joints. Corrective taping also helps decrease the stress on the mechanoreceptors that cause pain & allow for neuromuscular strengthening to ensue as an exercise & with activities.

Recommendations in therapy:

Goal is to strengthen the secondary stabilizers since their primary structures (ligaments) are redundant.

* Mid-Range Strengthening or Isometrics of all joints including neck.
* The goal with rehab is to regain smooth & balanced motion, by adding dynamic muscle stabilization to compensate for poor ligament support & promote muscles that are joint protective to combine conscious & unconscious, providing stability while performing ADLs thus providing long lasting results & avoiding future problems. This is a combined effort achieved by ***splinting, taping and strengthening*** the right structures the in the correct manner.

# Botox in undetected EDS-HT patients

Since ligaments are in a lax state in EDS-HT patients, the stability for the joints is dependent on the secondary stabilizers – the musculoskeletal system. It is strengthened in mid-range to prevent stress on the ligaments. However, if the Botox intra**muscular** injection therapy is done, it would weaken the structural mechanisms these patients rely on to maintain stability. Long term effects of which may be detrimental to these patients adding to more neuromuscular symptoms.
More studies and accurate assessment may be needed before Botox is prescribed to this patient population.