

A Primer on Ehlers-Danlos Syndrome for the Massage Therapist

Ehlers-Danlos Syndrome is, fundamentally, a genetic defect that affects the construction of the collagen protein. This has extremely far-ranging effects on the body since the connective tissues that hold our bodies together are constructed from collagen. EDS is part of a whole family of connective tissue disorders, including Marfan and other disorders. They are frequently inherited and are often found in circus/performer families, particularly those who perform contortionism. There are six different classifications of Ehlers-Danlos, each with their own set of symptoms. Within EDS, Hypermobility type is the most common form.

In Hypermobility EDS, the main symptom is the characteristic it is named after: hypermobility. The ligaments of the joints are the single-most affected tissue; they show extensibility but no elasticity, ie, they stretch but do not snap back. These leads to weak, unstable joints that are easily fully dislocated. Individuals with EDS usually have two or three particular joints that are extremely weakened and prone due to some particular injury or incident having damaged the ligaments significantly. However, all joints are affected. The second major symptom, and one that is required for diagnosis of EDS, is velvety skin that is hyper-extensible, stretching when pinched.

Poor wound healing is also seen, both superficial and deep; surgery of any kind is far more difficult in individuals with EDS. Individuals with EDS also often see issues in absorption of nutrition and therefore weight can sometimes be difficult to manage, especially with most forms of exercise made difficult by the joint problems. The immune system is often compromised if by nothing else than the chronic stresses the body suffers in EDS.

The major disabling aspect of EDS for sufferers of Hypermobility type is chronic joint and musculoskeletal pain. The frequent dislocations are, obviously, very painful and the body's response to them is problematic as well: the joints are chronically inflamed as the body responds to the damage by attempting to immobilise the joint with swelling. Further, the muscles will, in an attempt to stabilise joints that cannot stabilise themselves, lock down and that long-term severe muscular tension is extremely painful. The chronic pain and inflammation, of course, has its own effects; the long-term build-up of pain chemicals has a lot of detrimental effects. Fatigue, muscle weakness, and depression are among them.

There is no cure for Hypermobility EDS; at this time, they have not

even tracked down all of the genes involved. It is usually managed with a combination of drugs and life-style choices/changes. Massage therapy is very, very valuable in treating and managing any disorder whose major symptoms include chronic joint and muscle pain; EDS is no exception.

There are two main things that must be borne in mind when working on a client who has EDS. The first is that stretching of any kind is not only dangerous, as it risks a dislocation, but is fundamentally useless. The locked-down muscles will not stretch while the ligaments will stretch far past where they should, taking damage in the process. Stretching should never be used on a client with EDS. The second is that the skin tears easily and heals slowly. It is even more important than ever when working on a client with EDS that fingernails be kept short and well-filed.

Joints should be handled with utmost care; the shoulders, hips, knees, and ankles are among the most dislocatable, but the spine and neck should be treated with care, too, for obvious reasons.

Among the main benefits of massage therapy for a client of EDS will be the flushing of toxins: the lactic acid, pain chemicals, and other muscular toxins that accumulate due to chronic tension. Relief from muscle pain is important and part of the appeal and usefulness. However, deep tissue work cannot be tolerated. The therapist should focus on Swedish strokes with intermediate pressure interspersed with judicious, careful trigger point work (fibromyalgia is not uncommon in EDS patients, and fibro tender points should be avoided) and basic therapeutic techniques without significant pressure behind them. Unsurprisingly, lymphatic drainage is very good for EDS patients, as it can significantly reduce the swelling and retention of water in tissues as well as flushing toxins and easing the load on the immune system.

Geothermal therapy (hot stone massage) is very effective in loosening chronically tightened muscles but should be approached with caution with a client who has EDS; if the chronic inflammation is not under control, the heat will worsen it. Cold stones are generally fine, as they reduce inflammation and have an analgesic effect. If not sure, the therapist should have the client consult with his or her doctor about the value and wisdom of hot stone massage at a given point in time.

A client with EDS should be checked in with regularly on pressure and pain levels; a skewed pain scale and extremely high pain tolerance is common. It is very easy to go in with more pressure than is

appropriate to the disorder if a therapist is not careful.

Most EDS sufferers are diagnosed late and have had poor experiences with the medical world; many are told for years that it is in their head or that their symptoms are benign. Patience and a willingness to listen to what the client has to say about their body is important with any client but it is absolutely key when dealing with anyone who suffers one of the "invisible" chronic pain conditions.

EDS is a disorder that affects a client's whole life in a thousand ways, large and small. Massage therapy can help control and manage some of the symptoms, but it isn't a magic bullet. It's only one part of overall management of the disorder. A therapist will have to work with the client and the other medical and para-medical professionals who are involved in treating the client. That said, massage therapy can and does provide relief and help to those who suffer from EDS.

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