Upledger Institute Case Study

CranioSacral Therapy – Fibrodysplasia Ossificans Progressiva (FOP)

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Background:

Fibrodysplasia Ossificans Progressiva (FOP) is a rare genetic and congenital disease that affects primarily muscles, tendons, ligaments and other connective tissues by turning them into bone. Also commonly referred to as heterotopic ossification. Bridges of bone form across joints that cause a permanent loss of mobility. I have found that a combination of CranioSacral Therapy (CST), Lymph Drainage Therapy (LDT), and a modified Visceral Manipulation (VM) have been very helpful. Due to the loss of mobility, these techniques maintain what I call "a larger margin for error" within the body. It is estimated that there are 2,500 people worldwide, that's 1 in 2 million people, and only 800 known cases. I have had the opportunity to work on 2 individuals with this disease. *

Flare-ups are events where new bone is forming. This occurs from an invasion of lymphocytes and macrophages to an area. Primarily muscle tissue and its surrounding tendons, ligaments, fascia, and aponeuroses begin to die. It does not seem to affect viscera and organs directly but bone formation around the organs can cause problems. As the tissues are destroyed, stem cells begin to divide and multiply and further surround the tissues. Eventually, on average 6-8 weeks, the connective tissue turns to cartilage, and then bone. In some cases the flare-ups can stop at forming cartilage but typically new bone is formed. Once fully formed, it is just as strong and durable as any other bone in the body. Flare-ups are very painful. Patients should avoid intramuscular injections and inoculations. As these can create more flare-ups. *

Traditional physical therapy is contraindicated for them. The light assisted and passive stretches can cause additional flare-ups. Hydro-therapy and safely staying as independently mobile as possible is highly suggested for them. Individuals with this condition are also prone to kidney stones and often live with pain. *

The client is a 52-year-old female that I have worked with consistently for 12 years. She is lucky and does not live with daily pain. She suffers from intense headache pain related to changes in the barometric pressure, occasional vertigo, and spatial issues. In order to feel safe and stable, she needs visual and kinesthetic cues to orient herself in space.

At this stage in life she is fused into one position. The only movement that she has is in the one ankle, partial knees, wrists, and fingers. The right knee has about 20% ROM and the left knee has about 10%. The wrists and fingers have full ROM. She can not walk but can shuffle side to side to get from her wheelchair to the bed and vise versa. Her ribcage does not expand with breath and she is very fortunate that her disease has progressed in a way that there is not any bone pressing on her organs. Even though her jaw is fully fused, she is able to speak and eat on her own. It fused with a space between the teeth for her to pass food through and she still has full motion of facial muscles.

Treatment:

At her request, she has regularly scheduled appointments. She feels this is best for her overall quality of life and keeping her more independent. Moving her on and off of the massage table is similar to moving a large box. Using her hips as a fulcrum to lift, tilt, pivot and turn her body. Her hips and upper legs are fused into flexion. 3 pillows are stacked under her lower legs and feet for support. Several homemade pillows are placed around her body for support and spatial awareness.

Her right hip and leg are forward and the left is high. The pelvis is fully fused. The spine has a left side bend from the sacrum to C1. The coccyx is fused with a right side bend and rotation to the right. This pattern carries on into the intracranial membranes. There is more restriction on the left and within those cranial sutures. The right cranial sutures have more mobility. She experiences what she calls "right sided" or "left sided" headaches. The overall feeling for her is that "the brain is too large for the skull". The ribcage does not move with breath. Palpating the CSR can be challenging and has unique differences.

I always start at her feet and work around the body. Often checking back in at her feet (her foundation) throughout the session. She responds best to full-body Regional Positional Tissue Release (RPTR). This gives her "the increased margin for error". Her body responds well to the subtle touch of CST. She often feels changes throughout her body from one specific point. This is the reason I check back at the feet periodically for rebalancing. It helps her integrate the work better.

During the 12 years that we have worked together she has had 3 full flare-ups and 4-5 beginnings of a flare-up. All 3 were within the first few years of us working together. 1 full flare-up to the right extensor digitorum muscle. This one fortunately did not change the mobility in her wrist and fingers. Simply left a nodule of bone that I can independently mobilize. 2 full flare-ups to the right hamstring origin and hip have occurred. This created excess edema in the right leg. During flare-ups treatments included Lymph Drainage Therapy and increase to 3x per week for 2-3 weeks. The partial or beginnings of a flare-up were to the same location. With a combination of CST and LDT, inflammation was minimal by comparison and no new bone has formed in that area.

What we've discovered about her body is that the right leg begins to pull into more abduction as it is preparing to pass a kidney stone. At the first sign of this pattern, I focus on soft tissue alignment with RPTR from the feet to the kidneys and diaphragm. This seems to be very helpful in passing kidney stones with minimal to no pain.

Conclusion:

CST is helpful for maintaining a higher quality of life on a day to day basis, assisting the client through FOP flare-ups and other challenges that come with FOP. This is a unique body to work with and the specialized touch of CST is especially beneficial to them.

* FOP description was provided directly from the FOP Guidebook for families and the client herself.