**Ehlers-Danlos Accessible Transcript:**

**Tracey**

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Tracey Jourdain shares her experiences of living with Ehlers-Danlos syndrome (EDS) and key moments in her rehabilitation and recovery after an injury.’ The green border shrinks and the text disappears. A woman in her early 40s, Tracey Jourdain, Consumer and Lead Coordinator, Ehlers-Danlos Advocacy Organisation, sits in a floral-patterned armchair. She has long, wavy light brown hair and wears an indigo V-neck top.**

**Audio**

My name's Tracey Jourdain, and I have Ehlers-Danlos syndrome. Ehlers-Danlos syndrome is a genetic complex disorder which affects collagen in the body. And collagen is the glue that holds us together. So, it helps to support structures such as blood vessels, organs, ligaments, skin. It means that as the connective tissue is weak, if I fall over, for example, a normal person might be just be able to heal in six weeks. I'm more likely to dislocate or partly dislocate, and once that starts to happen, my body can't heal itself without help. Ehlers-Danlos syndrome has significantly impacted my life in a very negative way. It affects my ability to function because of the amount of injuries and untreated injuries that I've endured over the years. I was in my late 30s when I was diagnosed, but I was born with a birth defect that should have pointed the way toward the condition. So it took decades to be diagnosed. You're much more prone to injury with Ehlers-Danlos syndrome, because your connective tissue is weak. The glue that holds your body together is not working properly. And it means that when you're injured, the injury is far more significant. And it takes longer to heal, and you have very limited treatment options. And unlike most in the normal population, you won't heal unassisted.

I would try the physiotherapy programmes that were painful for me or damaging me,

and I'd get more damaged. But I knew from experience that if I let the muscles waste any further, I was gonna end up in trouble. With muscle wastage, it means that the joints have less support. You've already got weak ligaments, weak structures holding, and if you let the muscles deteriorate, you get in real trouble, and that's where you end up bedridden. With the injury, I've gone from not being able to dress myself, not being able to shower myself, not being able to drive, to being able to do all of those functions. I was fortunate enough to be seeing a doctor who was 90 years old. And as soon as he examined me, said that be believed I had some sort of issue with my connective tissue, and to go to a geneticist and find out what the issue was. The only time I've been emotionally harmed is when symptoms such as injury symptoms haven't been believed. And that can be very painful for me. Psychologically, I am healthy and I cope really well. But that, I believe, is because I have support of my husband, my family — I've got supports in place. I can work. And I think working was a major thing for me. After my injury, it was very difficult to sit there and do my job. So then I was referred up to Dr Burling for sclerosing injections.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Tracey received injections of tetradecyl sulphate, a sclerosant, diluted with prilocaine anaesthetic. Sclerosants, used in varicose veins, make the body lay down more scar tissue. In soft tissue, they are administered at a weaker concentration. This builds up the tissue to ultimately stop dislocations. ’ The green border shrinks and the text disappears.**

**Audio**

And those sclerosing injections go into the injured bit of the ligament and just builds up a bit of extra tissue with each injection. And that gave me the ability to actually start exercising, and then we started doing the manual therapy, physiotherapy, sclerosing injections together, and my progress has just been exponential. The quality of my life is significantly improved. My pain levels have gone down. But more than that, I do all my own personal cares. I am able to work part time. I'm able to drive myself places. I'm able to get out and socialise. And I think my life has improved... you can't actually put a quantity on it, but it's been massive for me. It's taken me four years to get to where I am. I'm probably a good six months away from finishing my rehabilitation programme. I think the number one, from medical literature and studies that have been done and my own experience is don't palm us off in the psychological category. If people need psychological support in addition, that's fine, but look for what the actual cause is, and it won't be psychological issues causing the pain and the dysfunction. It'll always be physiological. I think Ehlers-Danlos syndrome, statistically, we'd have around 1800 with the condition in New Zealand. But it's now starting to be recognised that it's most likely a lot more common than that. I think for medical teams, one of the things I'd say is don't give up on us. We take time. We take effort. But the positive results that we achieve are just amazing with your help. And for people suffering Ehlers-Danlos syndrome, this is a disability, and it can be manageable. And if you're prepared to put the effort in and you can get a team around you that won't give up on you and that will give you best care and practices, your life can actually be significantly improved.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘This series of videos describe the experience and treatment of one consumer with Ehlers-Danlos Syndrome (EDS). Three members of the multidisciplinary team (MDT) involved in the care and treatment of this person are interviewed. We acknowledge that a MDT can be much larger than this and the video does refer to the wider MDT as an important aspect of diagnosis, treatment and care of people with EDS.’**

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Owing to the diverse and complex presentation of EDS, Rare Disorders NZ (formerly NZORD) has produced guidance (funded by the Ministry of Health) that will help health care professionals and providers to assess, diagnose and plan care for people with EDS. Such guidance will hopefully promote discussion amongst health providers treating EDS, resulting in improved care and outcomes for consumers.’**

**Visual**

**White text on a dark blue screen with a green border around it reads ‘ACC sourced expert opinion about the evidence-base of prolotherapy being provided by Dr Burling. This expert opinion stated, ‘Clearly there is support for this in the literature’.**

[**https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Prolotherapy-review-letter-Dr-Rabago.pdf**](https://www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Prolotherapy-review-letter-Dr-Rabago.pdf)**. At an ACC review hearing, the reviewer considered this treatment had been excluded from the ACC prolotherapy assessment and that it was ‘a generally accepted means of treatment within New Zealand.’ As such, ACC paid the cost of prolotherapy for the consumer during the entire rehabilitation programme. The prolotherapy treatment described by Tracey has had positive results for her.’**

**Visual**

**White text on a dark blue screen with a green border around it reads ‘There is mention throughout the videos of the prevalence of EDS and indication that this is varied; prevalence will depend upon the definition being used and this will determine the inclusion criteria. The green border shrinks and the text disappears.**

**Visual**

**A white screen with blue and green text reading ‘Health Quality & Safety Commission New Zealand. Kupu Taurangi Hauora o Aotearoa.’ The blue and green company logo comprises of three thin square blocks with white circles of differing sizes within them. Beneath the text and logo, in black text reads ‘New Zealand Government’.**

Accessible transcript by Able.

www.able.co.nz