**Ehlers-Danlos syndrome accessible transcript:**

**Gina**

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Gina Morris is an osteopath and treats Tracey Jourdain’s Ehlers-Danlos syndrome. Here she explains her role in Tracey’s treatment.’ The green border shrinks and the text disappears. A woman in her 50s, Gina Morris, sits on a dark grey striped couch. She has wavy light brown hair in a bob and wears a green and black long-sleeved top and a sliver belcher chain necklace.**

**Audio**

Ehlers-Danlos is fairly new to me. Tracey was diagnosed in 2012, and I've been working

with her ever since. So until she was actually diagnosed, we didn't actually know what

we were dealing with. Just that we knew there was something not quite fitting here. And she was at times severely debilitated and sometimes not so badly debilitated. So having her diagnosed was really important. EDS in New Zealand is relatively new. And there doesn't seem to be a hell of a lot known about it, other than what Fraser has been teaching us, so it's been a huge learning curve for all of us. And Tracey has been dogmatic in finding out about Ehlers-Danlos and the treatments that are available for it overseas, and the Kevin Muldowney programme, which is her physiotherapy programme, which is doing wonders for her as well. So, it affects all the connective tissue in the body. So what I treat is, I keep the joints in place most of the time. But before she had the strengthening exercises and the prolotherapy with Fraser, she was actually falling to bits again just as quickly. It's caused by accidents, life doing what life does. She would fall or trip over or go for a bike ride or dance and something would fall out of place if she made the wrong movement. So what I was doing with her weekly was putting her back together, basically, so that she could live a bit more. Yeah, basically I put her together, put things back in place. Because when a joint is out of place, it's putting pressure on a nerve supply and a blood supply. In order to heal, things need a nerve supply and a blood supply to work properly. Well, my role is really, in treating Tracey, one of keeping her functioning optimally.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Gina talks about her learning journey with Ehlers-Danlos.’ The green border shrinks and the text disappears.**

**Audio**

I knew absolutely nothing about EDS. So when she diagnosed it, I thought, 'What on earth is EDS?' And it's been a whole learning curve for me altogether. But it's also been a learning curve to be part of a multidisciplinary team. And learning about EDS, you know, you've got to really go to Google and look it up. There's not a lot, in my... my reference books and things about EDS at all. Even in the medical ones that I have, there isn't a lot about Ehlers-Danlos syndrome, so it's just been a whole learning thing. I knew nothing, and now I know more. And I think we'll just keep on learning.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Gina’s tips for other osteopaths.’ The green border shrinks and the text disappears.**

**Audio**

So for other people treating Ehlers-Danlos in our profession, it's a matter of finding out about what that particular person has, what problem areas they have and what you can do to fix it, basically. You're never gonna cure it, but you need to keep these people functioning optimally. So, osteopathy, a lot of people think it's about bone crunching. But really, with people with Ehlers-Danlos, you need to do it very gently, if you must bone-crunch at all. I tend to use a lot of muscle energy and muscle release techniques instead, which are much kinder to the body. The changes I've seen, mostly, in what's happening with Tracey have mostly occurred since Fraser and Emma started. Because I was trying to manage her on my own, it was very difficult. Because of the nature of the disease, things didn't stay in place once you put them in place. You’d only have to do one slight thing, and everything would fall out of place again, and I'd be back to square one every week.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Tracey received prolotherapy injections of a sole sclerosing agent into her ligaments and tendons to strengthen and rebuild her damaged soft tissue. The process works by laying down extra soft tissue in areas that have been injured.’ The green border shrinks and the text disappears.**

**Audio**

Since the prolotherapy and the physiotherapy have come on board, she has improved out of sight. It's been absolutely amazing to see her grow and recover. I can just keep her together to a certain degree. But with the strengthening and the therapy into her muscles and joints, it certainly has improved her outcome.

**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**

**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