**Ehlers-Danlos syndrome accessible transcript:**

**Emma**

**Visual**

**A woman in her late 20s, Emma Lett, Physiotherapist, MidCentral District Health Board (DHB), sits on a dark grey striped couch. She has blue eyes, light brown hair in a plait and wears a blue polo T-shirt with white trim. The shirt has the word ‘physiotherapist’ on it and her DHB logo, and Emma has her name badge pinned to the shirt.**

**Audio**

My role as a physiotherapist is obviously in helping people with rehabilitation. I have been working specifically with Tracey as an Ehlers-Danlos patient for four years now.

And that role, from my perspective, is involved mostly in education. And obviously exercise prescription, but also modification of exercise in order to make it appropriate for Tracey as an Ehlers-Danlos patient. I work around the progression and modification — modification especially. Because in the case of Ehlers-Danlos, I find that patients have a loss of a sense of where their limbs are in space. And so I've worked to modify some of Tracey's exercises. My role is basically guiding Tracey through her strengthening in order to make sure that she is safe, but also to try and help her regain the function that she had lost prior to me starting to work with her. Because Ehlers-Danlos affects the connective tissue, and the connective tissue is what supports your joints, you need to find a way to help support the joints that means that connective tissue gets a bit of a break. One of the things we can do from a physiotherapy perspective is actually get people stronger from a muscle sense and actually try and help stabilise some of those joints and prevent some of those injuries. We can also work to try and help strengthen some of those muscles which will have become weaker as a result of injury.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Emma explains the treatment she gave Tracey.’ The green border shrinks and the text disappears.**

**Audio**

From a specific point of view, I've worked right from the beginning on strengthening at its most basic. So we started in the core of the body. We started around the pelvis and around the abdomen to try and get the strength and the stability of the core part of Tracey's body to really start helping improve her function. From there, we've actually moved from the core out to the limbs, so working on strengthening the legs and obviously the arms. So, one of the things that struck me the most about Tracey in the beginning, when I first started working with her, was her movement. And part of physiotherapy, we tend to observe how people move and how they function. And I remember that Tracey's posture was very poor. Her ability to move was... not in a normal pattern, if that makes sense. Tracey was using any muscle she could possibly recruit in order to move like you or I would. And over the last four years, I've noticed a significant improvement in her ability to manage little tasks, but even something as simple as standing still. So standing on the spot and having a conversation with me about an exercise used to be something that was really difficult for Tracey. Whereas now we can actually talk through her exercises in standing; she's got a good posture, she's got a good position, she's not in pain when she's doing it. And I think that's probably struck me the most.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Tips from Emma for physiotherapists treating Ehlers-Danlos.’ The green border shrinks and the text disappears.**

**Audio**

Tips I would give for other physiotherapists who've never encountered Ehlers-Danlos before is to actually spend some time looking at what the condition involves, to spend some time coming to understand how it's affected each individual patient — because I think everyone's very different in their presentation of EDS — and find out what level of function that they already have.

**Visual**

**In the top-left corner of the screen, a box appears showing a hardback copy of Kevin Muldowney’s book ‘Living Life to the Fullest With Ehlers-Danlos Syndrome’. The cover of the book is a silhouetted figure running with their arms raised on an orange and yellow zebra-striped background.**

**Audio**

I found using the Kevin Muldowney Protocol — and Kevin Muldowney is a physiotherapist — or physical therapist, as they call them in the States — who used a lot of the clinical information available to develop an exercise programme specifically for EDS. Have a look at his programme.

**Visual**

**The image of the book disappears.**

**Audio**

Even if you don't use it in its completeness, the elements of it, the exercise progression it provides gives you are a really good idea of how to start people off safely, particularly if they've got a really low level of function to start with. I found that very useful. And while I do modify it to suit Tracey's specific needs, we follow the programme at its core, because it's actually been very helpful.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Emma explains the benefit of a multidisciplinary team.’ The green border shrinks and the text disappears.**

**Audio**

I think from a MDT point of view, the physiotherapy certainly... helps to improve Tracey's overall function, I think is probably the most useful contribution. It plays on or emphasises all of the treatment that... Dr Burling does in the background, that Gina, the osteopath, does in the background. All of those things start adding together. They might treat specific injuries, but I work on the overall strength and function, which once those injuries have been treated, the strength and function is really important to get better or Tracey just ends up being injured again. And so I think from that perspective, the contribution is trying to get Tracey up to the top of the pyramid, so to speak. I would say to anyone out there working with Ehlers-Danlos, it can be scary at first. It's something that until recently, particularly in New Zealand, wasn't really well understood. And I think from that respect, it's difficult to know what to do. But I found that asking for help — I approached Kevin Muldowney directly, and he was actually very helpful. I work within the multidisciplinary team to make sure that if I don't know something, that there's someone within the team that can help me cover that. Be willing to ask for help, willing to put your ideas out there, willing to listen to the patient, and willing to work as part of a team to actually help the patient.

**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