**Ehlers-Danlos syndrome accessible transcript:**

**panel part 1**

**Visual**

**White text on a dark blue screen with a green border around it reads**

**‘Part One – Introducing and setting up a multidisciplinary team (MDT).’ The green border shrinks and the text disappears. Four people sit at a glass-top table. Second from the left is a woman in her early 40s, Tracey Jourdain, Consumer and Lead Coordinator, Ehlers-Danlos advocacy organisation. She has long, wavy light brown hair and wears an indigo V-neck top.**

**Audio**

Hi. I'm Tracey. I have a rare condition called Ehlers-Danlos syndrome. And when I got injured, that meant that I needed a multidisciplinary team to help with my injury rehabilitation. The team's very important — working together to do that. And I have Emma from the DHB, who's been doing the tailored physiotherapy exercises.

**Visual**

**On the far right is a woman in her late 20s, Emma Lett, Physiotherapist, MidCentral DHB. 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 a company logo, and Emma has her name badge pinned to the shirt.**

**Audio**

(Tracey): I have Gina, who does the manual therapy needed for the programme I'm on.

**Visual**

**Second from the right is a woman in her 50s, Gina Morris, Osteopath. 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**

(Tracey): And Dr Burling does the injections into my ligaments to help heal the injured tissue.

**Visual**

**On the far left is a man in his 50s, Dr Fraser Burling, Rheumatologist. He has balding dark grey hair and wears a white shirt and tie, a black, grey and maroon argyle patterned V-neck jumper and a navy jacket. Pinned to the lapel of Fraser’s jacket is a looped campaign ribbon with black and white zebra stripes on it.**

**Audio**

(Gina): So, to have Fraser come on board and do what he does and Emma to come on board and do what she does, we've just seen a marked improvement in Tracey's mobility and function, and it's been really exciting.

(Emma): I came on board with Tracey about four years ago now and started working with her with the physio. And I find it really helpful as part of a team to know that if I'm struggling with something that Tracey's working on, I've got backup, in terms of, you know, Gina and Dr Burling.

(Fraser): And my job as a role as physician and rheumatologist has been to firstly come on board with Tracey's initial diagnosis. Tracey was one of my first patients with Ehlers-Danlos syndrome. It really has been a coordination of care. It's not just about the soft tissue treatments, which strengthen damaged ligaments, but it's also been about getting people like Gina and Emma on board to direct care further, to help understand what's happening to the body, how we can coordinate that treatment to better facilitate a good outcome. And the result is that Tracey has come a very long way from where she was six or seven years ago.

(Tracey): Yeah, I could not have got where I am without each member of my team, and alone I would have got nowhere.

**Visual**

**White text on a dark blue screen with a green border around it reads**

**‘Other people involved as part of a wider team.’ The green border shrinks and the text disappears.**

**Audio**

(Fraser): The key also is remembering that there are other people in the MDT who aren't here, such as orthopaedic surgeons, gastroenterology people, other physicians who have been involved as well.

(Emma): I think the other part of the MDT that we've kind of missed already is also Tracey's family. Her son and her husband have really helped guide Tracey through some of the exercises when I'm not available to be eyes-on. We underestimate how much help we get from, you know, the people around you as well.

(Tracey): Yeah.

(Gina): I also initially taught Nigel some techniques so that he could treat Tracey when I wasn't available or if something happened in the night that he had to deal with.

(Fraser): Likewise, yes.

(Emma): Yeah.

(Tracey): And Emma reached out to Kevin Muldowney, cos my husband was struggling to relocate partly dislocated ribs.

**Visual**

**In the bottom-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**

(Tracey): So she reached out to Kevin Muldowney who gave some instructions that worked. So most of the time, about 80% of the time, Nigel can get a rib back in if it's out.

(Emma): So I reached out to Kevin Muldowney, who is a physiotherapist in the States who works exclusively with the population, and he was actually able to help me a lot as well. And so he's, kind of, a very satellite part of our team as well, but he's still there in the background. He never fails to respond if I need anything.

(Tracey): And he's also helped each member of my team. He's always been in contact with you, in contact with Gina through me, in contact directly with Emma as well, so he's been involved in communicating with all members.

(Emma): And I've actually found Kevin Muldowney's programme, while it was designed for Ehlers-Danlos, I find it's been actually very helpful for some of my older population,

because the exercises start at a lower level and they work their way up. And, you know, I've actually integrated them into my practice quite a bit.

(Tracey): And I think, for me, I was managing my physical therapy, which is important, using pretty much any standard programme until I got injured. And once I got injured, that's when the wheels fell off and I needed the tailored programme.

(Gina): I think Tracey has really been the key person in getting us all together. She's certainly been no shrinking violet in all this, because she's the one who has got us all together and been willing to have a go at what we all did.

(Fraser): And the interesting thing about a multidisciplinary team is the number-one coordinator is actually the patient — how much they're willing to have, how much they want to do. And most people actually really want to get better, and it's really important to understand that the multidisciplinary team is putting the patient first. Definitely a multidirectional street. It's not a one-way street.

(Tracey): And I think, for me, I've had, obviously, quite a few surgeries because of my condition, so I have had a lot of medical involvement that has been successful, but this is the first time I've needed a team to work together this way. These injuries were so major; I wasn't able to do my rehabilitation. I wasn't able to progress, and I'd lost all of the function, pretty much. I couldn't drive; I couldn't dress myself; I couldn't shower myself. I was being helped to the toilet. And that was a necessity for me. I don't wanna stay like this; I wanna be better. And to have the privilege of finding each member of my team, that's actually helped me get all those functions back. It's been a really amazing journey.

(Fraser): And not forgetting Nigel has been a huge part of your team as well. That's Tracey's husband.

(Tracey): He has.

(Fraser): And it's good that around the country, we have lots of other people like Emma and Gina who have come on board and are helping other patients in the same situation. And it is really, really important to have this sort of a team set up right around the country. Those who have the best teams with them actually do best with their outcomes as well.

(Tracey): Yeah. And trying to behave — I get told that I'm not allowed to do things and try and comply as much as possible, but sometimes, yeah, you can just forget. I think for most of my life, I self-managed a lot of my disability, but the injuries that I suffered in 2014 certainly were the catalyst. I couldn't do it alone anymore; I couldn't just do it with one person. And my motivating factor for really driving to try and find a team was I wanted to get my function back. It has been hard, and it has been painful, and it has been long. It's not been easy, but every time you gain function back, to me, it's worth it. I got misdiagnosed with multiple sclerosis; I got misdiagnosed with fibromyalgia.

(Gina): Dystonia.

(Tracey): Dystonia. I got misdiagnosed so much that by the time I got the diagnosis that actually fitted me and I actually did fit the box, a lot of people had given up.

(Fraser): Tracey and one other patient were a huge impact on my knowledge. And rather than say, 'Go away and live with it,' I said, 'OK, let me go and find out about it.' And my radar went up, and the ability to treat not just the musculoskeletal aspects but also the gastrointestinal aspects, the cardiovascular aspects, the genito-urinary aspects. All those other issues started to come into the foreground.

(Emma): One of the most important aspects of it has always been, and probably will always be, Tracey's attitude and her approach to both her condition and how she manages it, because, I'll be honest, you know, like, the amount of pain and the amount of difficulty Tracey's faced in the last four years I've worked with her, her attitude and motivation are still really important to acknowledge, because we can't make someone do something. We can support them; we can help them; we can make things better or easier, but we can't make someone do something. And this is very much a self-reliant programme, even with the team support.

(Fraser): What Emma mentioned about giving up is really important. There are people who come to me who are on the verge of suicide, and with help from the multidisciplinary team that they get around them, we have turned their lives around and brought them back from that brink. And it's not all my work. It's the work of each individual and the teams together that gets there, and it really is important to note it's a team effort.

**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**

**Fraser, Emma, Tracey and Gina stand on a patch of grass in a cobbled courtyard, framed by a pink cherry blossom tree. They all smile widely. 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.

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