**Ehlers-Danlos syndrome accessible transcript:**

**panel part 2**

**Visual**

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

**‘Part Two – Tips for working in a multidisciplinary team.’ The green border shrinks and the text disappears. Four people sit at a glass-top table. 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**

(Emma): So, my tip for people working in this situation or any similar situation — never be afraid to ask for help. You don't know everything, and there are people out there that can help make it better for what you're doing and for your patient. So never be afraid to ask.

**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**

(Fraser): My key and tip for people is, again, looking for help not just amongst colleagues, and I have some really good colleagues around the country amongst cardiology, gastroenterology, some genetics, obstetrics and gynaecology, urology; many of the orthopaedic surgeons have been involved as well. The key is not just them but also the other health professionals such as our physiotherapy, occupational therapy, the manipulative therapists, other allied health professionals including nurses. So you can get some really good help from multiple sources. And I will say places like Facebook have actually supplied help for various parts of the country. If someone's, say, in Christchurch and they need a good physiotherapist in Christchurch, I'd say go check on Facebook. Ask there. They'll let you know who's good in that area, who knows about EDS, who knows about the Muldowney Protocol, who knows how to help in that area. Likewise for the manipulative therapists, for the occupational therapists. And also for the other medical specialists as well. EDS is multi-organ involvement, and multisystems often need to be addressed all at the same time.

**Visual**

**White text on a dark blue screen with a green border around it reads ‘Team communication – how they work together.’ The green border shrinks and the text disappears.**

**Audio**

(Emma): Part of my role is obviously various assessments in various different levels,

and I tend to write letters at various different letters to explain Tracey's progress —

where she's at, where she's up to, what she's struggling with. And those letters are always forwarded on to both Tracey and to everyone else involved in her care. Any of the more immediate or urgent communication tends to come through Tracey because, you know, posting, especially within a DHB, I find it takes a little while to get to me sometimes. But the communication through that way has been very good. Cos I've got a lot of the definite things in writing, and then some of the more informal things, or the things I need to know right then and there come to me, you know, verbally. And so I've got good information coming from both respects.

(Fraser): My communications with not just Tracey but with other patients can happen at multiple levels. So first and foremost, it's with the patient directly. The patients come and see me. They might send me an email; they might send me a letter; they might send me a text message; letters that are written to the GP; letters that are written to other specialists, both for referral and for updates. Frequently, we have six or eight people listed on one letter as to who it's sent out to. And then if there's something urgent, there's always the phone call that can be made as well. And from time to time, we do have phone calls, either me to another specialist or another allied health professional, or from them to me. And it can make a very important, fast way of getting that information across as to when a patient needs acute care.

**Visual**

**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**

(Tracey): Mm. And I think for me, Gina might find a particular rib is going out every week, because the programme requires weekly manual therapy, and Gina can tell me where that rib is. And I can then give that information to Dr Burling, who will then go in and check and go, 'Yeah, that is an issue,' rather than me turning up, going, 'It hurts everywhere,' isn't that useful. So to have Gina isolate a point, or Emma might say, 'You're having problem with a particular exercise,' I can then come to Dr Burling and say, 'Emma's saying I'm struggling with this movement.' And then Dr Burling will look at what ligamentous tissue is actually— could potentially be injured, stopping that movement. So I think that's been quite key to communicate through me — as well as by official letter.

**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**

(Gina): Tracey knows her body probably better than anybody I know knows their body.

(Fraser): Too true.

(Emma): Mm-hm, yep.

(Gina): So she's really taught us all a lot, and actually, I think she's been at the forefront of getting EDS,... you know, out there and known and knowing what's needed to treat it.

Everything's about education.

(Tracey): Yeah.

(Gina): It's got to be education. Because it's just something that's come out of the woodwork that nobody knew about, I guess. It's certainly something fairly new in New Zealand.

(Tracey): And I think multidisciplinary teams are quite new for EDS in New Zealand. It's not new internationally. But because we are so often palmed off, because people don't think that there's anything you can do. So it's not from nefarious intent, it's just because clinicians and specialists haven't known what to do with us. And now that the information's coming out, it really has been since 2017 that it's come out that, 'Actually, this is manageable. 'This isn't a disease; it's a disability. We can actually manage you,' that people are actually starting to change their attitudes. And that's why I've encouraged people, you know, 'Look and try and find a multidisciplinary team.' Cos there's nothing more discouraging for a clinical team to believe that there's nothing

they can do, and they're watching this patient in pain thinking, 'We can't help.'

(Fraser): Mm.

(Tracey): And that must be frustrating. So the 2017 publications has really turned EDS upside down, really, worldwide and is actually showing people you can help, and I think that's where the team gets encouraged.

**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 document on a dark blue background. It’s titled ‘Hypermobility and Ehlers-Danlos Syndromes (EDS) New Zealand Guideline 2019. Includes Generalised Joint Hypermobility (GJH) and Hypermobility Spectrum Disorders (HSD). . 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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