



**Case-Base Discussion – 24th January 2023 (Ref 281)**

**Case - Ehlers Danlos Syndrome**

**Practitioners discussing the case:**

Claire Short (presenting case), discussion with members of the APM.

**Brief description of the case:**

The patients are two girls aged 14 and 17, who have hypermobility, and Ehlers-Danlos Syndrome, for which they have been referred to a specialist. They have had treatment from a physiotherapist, mainly passive joint stretching, which has caused significant pain afterwards. The 17-year-old has had enough of being "poked and prodded," which is in itself a challenge for the practitioner.

The purpose of today's discussion is to look at treatment options for the management of Hypermobile Ehlers-Danlos Syndrome (hEDS) within the realms of manual therapy.

**Key issues:**

There were issues in this case relating to the older girl's ability to cope with seemingly endless examinations by various specialists, as well as the difficulty in providing care for this patient group. It is important to recognise that there are many different types of EDS presenting with varying degrees of severity.

**Scope of practice limitations:**

While the patients will likely benefit from the treatment and advice offered by manual therapists, it is important to recognise that we can only provide management of EDS, rather than cure and we must be mindful of our scope of practice.

## **Linking this case with Osteopathic Practice Standards Themes**

### **A - Communication and patient partnership (Identifying patient's expectations)**

It is important to clearly communicate with the patients and their parents/carers that treatment might help to manage symptoms rather than cure symptoms. Clear communication is especially important with the 17-year-old who has had enough of being assessed and treated by various healthcare professionals.

### **B - Knowledge, skills and performance (Develop my scope of practice)**

Recommendations for treatment that fall within our scope of practice include: core stability and proprioceptive feedback exercises (eg wobbleboards/balance pads or SUPs); stretching techniques within end of range to avoid causing pain; low amplitude, minimal leverage manipulations applied to localised hypomobile segments; hydrotherapy or swimming; barefoot shoes; K-tape; Activator walking poles; and compression garments.

### **C - Safety and quality in practice (Ensure quality of patient care)**

During our discussion we explored possible approaches to treatment. It was pointed out that we should be careful not to 'destabilise' the hypermobile patient by over-releasing muscle hypertonia. We were also reminded that many people with EDS experience POTS and this should be factored into the treatment plan.

### **D - Professionalism (Involve others in patient management)**

It was agreed that the input of other professionals is necessary in this case – the girls have already been referred to a consultant – but that our role as healthcare practitioners should be to support the patients in carrying out as normal a life as possible by incorporating strengthening and proprioceptive exercises into their everyday life.

## **Linking this case with the Chiropractic Code**

### **Principle C - Provide a good standard of clinical care and practice**

Recommendations for treatment that fall within our scope of practice include: core stability and proprioceptive feedback exercises (eg wobbleboards/balance pads or SUPs); stretching techniques within end of range to avoid causing pain; low amplitude, minimal leverage manipulations applied to localised hypomobile segments; hydrotherapy or swimming; barefoot shoes; K-tape; Activator walking poles; and compression garments.

### **Principle F - Communicate properly and effectively with patients, colleagues and other healthcare professionals**

It is important to clearly communicate with the patients and their parents/carers that treatment might help to manage symptoms rather than cure symptoms. Clear communication is especially important with the 17-year-old who has had enough of being assessed and treated by various healthcare professionals.

### **Principle G - Maintain, develop and work within your professional knowledge and skills**

It was agreed that the input of other professionals is necessary in this case – the girls have already been referred to a consultant – but that our role as healthcare practitioners should be to support the patients in carrying out as normal a life as possible by incorporating strengthening and proprioceptive exercises into their everyday life.