

Event Report

The Management and Wellbeing Conference

30 September -
1 October 2017
Kenilworth

"First, do no harm"

Julie Barber reports on an event organised by the HMSA (Hypermobility Syndromes Association) and EDS-UK (Ehlers-Danlos Support UK), Warwick

This was the first ever residential conference organised by the two leading UK charities supporting people affected by inherited conditions of connective tissues. The audience of 320 was a cross-section of this community: some were in wheelchairs, a proportion used crutches (see image), most were female and the majority looked in good health. Appearances can be deceptive however as most had long-term musculo-skeletal pain and, quite possibly, also suffered frequent subluxations or dislocations from loose joints or shallow joint sockets, chronic fatigue, digestive problems, problems with their nervous systems and general deconditioning as a result. This was all made worse by the time it had taken them to get a correct diagnosis of what was wrong (in many cases over 10 years) and to have a recovery action plan in place.

Over the two days many experts gave information and advice. Dr Hanadi Kazkaz, consultant rheumatologist at University College London Hospital's Hypermobility Clinic, gave an overview of the new (2017) internationally recognised classification of hEDS (hypermobility type Ehlers-Danlos Syndrome) which now has a different diagnosis from HSD (Hypermobility Spectrum Disorder). Other topics discussed included: living with a mast cell activation disorder, Cognitive Behavioural Therapy for pain and fatigue, the management of gynaecological and bladder problems, physiotherapy, occupational therapy and the importance of nutrition. The emphasis throughout was that these conditions, caused by genetic differences in the body's connective tissues (particularly collagen), affect the whole person – body and mind – and the most effective ways of managing them need to reflect this. This is new for medical thinking and diagnosis.

The Alexander Technique was on the agenda. Dr Philip Bull ended the first day with a resounding endorsement of our work and recommended it to all present. He asked for a show of hands as to who had heard of it - it was clear that most had not - but after Dr Bull's introduction they now have. He is a great advocate of our work and would love to see it available more widely in the NHS, not just through the Kent and Kingston chronic pain clinics.

On day two, I ran a brief break-out session to a capacity audience of 50. I stressed the importance of having a teacher one is comfortable with, who is open both to learning more about the condition and to having an ongoing dialogue with their student. I mentioned that we have had many articles in *Statnews* about hypermobility conditions including an article by Dr Bull, and that both he and myself give CPD workshops on hypermobility to teachers. I stressed that we work with the whole person, our work is gentle, that we are teachers rather than therapists and our aim is to help people look after themselves better. I used the tensegrity model as a way of illustrating how AT works and how locked joints and chronically tight muscles can interfere with the body's ability to distribute support as widely as possible throughout the body.

In the Q&A that followed I was asked (privately) by a young woman with HSD if I'd considered that the Alexander Technique might possibly harm people. She had undergone two years of AT teacher training, before leaving as her symptoms were getting worse. She was concerned the AT may damage by over-releasing people's muscular support system without also strengthening it. Sadly, I have heard of this from other training courses and from pupils. A very similar point was made that weekend by leading physiotherapist, Dr Jane Simmonds, who warned against massage saying that overly freeing an area



Smartcrutch was a conference sponsor, and its crutches appeared to be popular. These spread the load over the whole forearm, releasing pressure and pain from the hands and wrists, and reducing the risk of shoulder subluxation or dislocation. See <http://smartcrutch.co.uk/>

is not helpful as there is a danger it will leave a person afterwards without adequate muscular support, leading to increased pain, a sense of being disconnected and more prone to injury.

It would appear that this is one area in which the Alexander Technique inadvertently may cause harm to a pupil if a teacher does not understand the condition. It is very important that we do not over-release hypermobile pupils. It's more useful to help them find support from the ground and its response to gravity, and find balance and connection within the body. Hypermobile pupils may benefit more from a focus on reconnection rather than lengthening and widening which may leave them feeling 'taken apart' (especially for those prone to subluxation and dislocation or with autonomic nervous system dysfunction).

Amongst the participants I met some with hEDS and PoTS (Postural Orthostatic Tachycardia Syndrome, part of HSD) who wear compression garments as they

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find they help prevent faintness, relieve pain and discomfort and aid their proprioception. It was a very informative and humbling experience. People within the hypermobility spectrum are very used to being told that their pain and discomfort is all “in their head” and dismissed as hypochondriac. An HMSA survey in 2012 stated clearly that members felt far better supported by an “expert in hypermobility”. This was regardless of whether it was a doctor, physiotherapist, occupational therapist etc. It was the knowledge that the professional

they were seeing understood the hypermobility-related components but also the certain truth that the professional they were seeing didn’t doubt their symptoms and experiences. There was an overwhelming sense of validation and relief from seeing someone who they knew believed them.

It’s a great medical advance that this condition is better recognised now and the HMSA is rolling out a programme to help GPs diagnose it in their surgeries. I am not advocating that we promote ourselves as medical “experts” which we most definitely are not, but I do suggest we educate

ourselves about this condition, listen to our hypermobile pupils and offer appropriate individualised help.

This is a great opportunity for us - the Alexander Technique has so much to offer.♦

For further information look at the websites: HMSA (www.hypermobility.org) and EDS-UK (www.ehlers-danlos.org). I also recommend the website of hypermobile American teachers Ann Rodiger and Carol Boggs and their informative webinar on teaching hypermobile students: <https://www.integratinginstability.com/>.