Joint hypermobility syndrome: An introduction for Alexander Technique teachers

By **Dr Philip Bull FRCP, Consultant Rheumatologist**

About the author

Dr Bull trained at St Thomas' Hospital in London and has worked as a Consultant at East Kent Hospitals University Foundation Trust based at the William Harvey Hospital since 1990. He retired from the NHS in 2014 and continues to run a private clinic at The Chaucer Hospital in Canterbury. He has a special interest in joint hypermobility syndrome and plays bass guitar in his spare time.

As a consultant rheumatologist you receive training in all forms of arthritis, including rheumatoid, psoriatic and osteoarthritis, and gout and immunological conditions such as lupus. Although doctors aspire to be holistic you will not find the Alexander technique on the medical curriculum!

When I was training it became clear to me that as a musculoskeletal specialist, "use" and "function" were critical factors in the management of many of my patients. I became interested in the technique in the 1980s and have received lessons from a variety of different Alexander teachers, this has helped me both physically and with general wellbeing. Members of my family have undertaken lessons with significant benefit particularly in the area of music and sport.

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As a result, AT has become an essential part of my tool kit which I recommend to my patients in order to help with self management. Fortunately it has become available locally via the NHS community pain team (see the article on page 14 of this issue).

On arrival in East Kent as a consultant in 1990 I was fortunate enough to meet a specialist physiotherapist who had a particular interest in joint hypermobility: she was herself hypermobile. Her approach to treating patients opened a door for me on a condition which is recognised as difficult to treat. The results achieved were remarkable and led me to develop a specialist interest. It is very rewarding being able to help this group of patients.

I hope in this article to give you some guidance as to how I approach the condition. I would be interested to hear about your experiences with this poorly managed group of patients who have an invisible illness.

Joint hypermobility: What is it?

For the majority of individuals hypermobility can be a great natural asset giving a person flexible joints that have a greater than average level of movement leading to an advantage for many athletes and performers (you can witness it every week on *Strictly Come Dancing*!).

It is important to understand that the vast majority of patients with hypermobility have no symptoms and live normal lives. However, for a minority it can result in a variety of symptoms including joint pain, soft tissue injury and joint instability.

For some, joint manifestations are just the tip of an iceberg of underlying associated symptoms caused by excessively stretchy collagen and other connective tissues.

These symptoms may include autonomic dysfunction, proprioceptive impairment, intestinal dysfunction, anxiety and chronic pain.

In your practice, you will have certainly worked with many pupils who have joint hypermobility, the prevalence being 10-20% in the population depending on your ethnic background (it is more common in people of Asian and African descent). Some Alexander teachers report a higher incidence in their practice. You will have also seen pupils whose pain includes fibromyalgia which is associated with joint hypermobility syndrome.

This disorder forms a spectrum from the mild to the severe, known as the *Ehlers-Danlos* syndrome (EDS), and is part of a group of connective tissue diseases which also includes conditions such as *Marfan's* syndrome, *osteogenesis imperfecta*, *Stickler* syndrome and other rare diseases which will not be covered in this article.

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The Beighton Criteria offer one of the simplest ways to identify people with hypermobility

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To avoid confusion, joint hypermobility syndrome (JHS) is the same as EDS-hypermobility type and HMS.

How do you identify the patient with joint hypermobility?

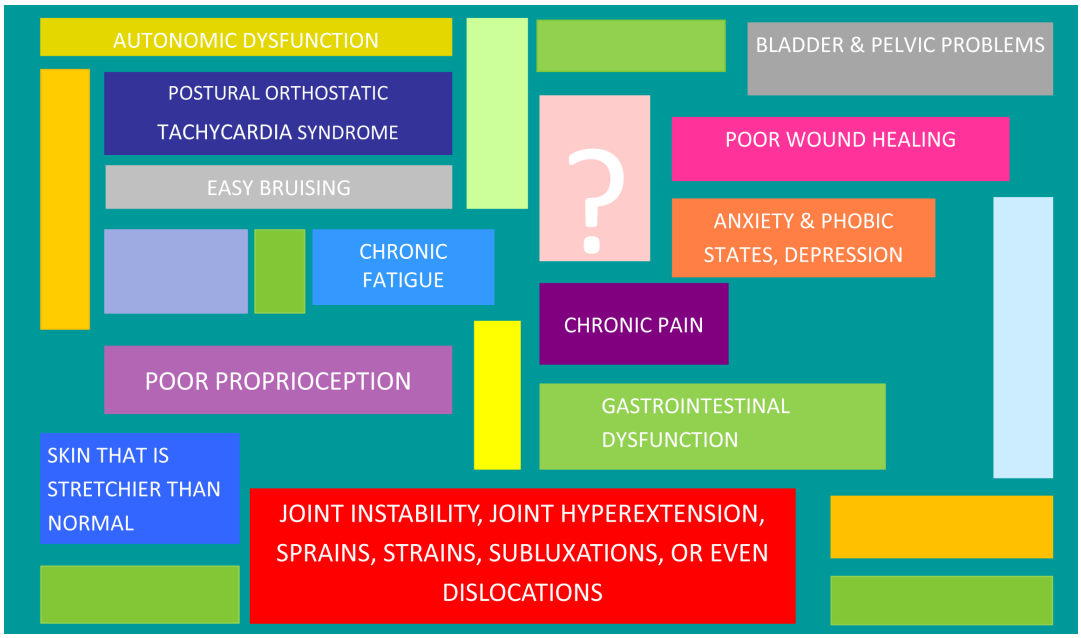
For practical purposes the Beighton criteria are an easy way to identify individuals, the physical findings outlined in the diagram on the previous page. It is important to realise that it only includes a certain number of joints and the hypermobility itself could be regional: For example, just affecting the knees and spine. The 1998 Brighton criteria are more helpful, but don't forget these are just criteria, there isn't a black and white test for the condition; symptoms and signs vary from one individual to another.

Other important things to look for

As a health professional it is important to ask the right questions when you suspect joint hypermobility:

1. Do you have clicky joints, joint pain, instability, dislocation and soft tissue sprains or scoliosis?
2. Is your skin stretchy, does it have a soft feel?
3. Do you bruise easily?
4. Is there evidence of poor proprioception or are you clumsy?
5. Do you suffer from fatigue?
6. Do you suffer from anxiety or depression? (this is strongly associated with the condition)
7. Look for symptoms of autonomic nervous system dysfunction such as temperature control or sweating.
8. Do you experience palpitations or dizziness on standing up from sitting, suggestive of the postural orthostatic tachycardia syndrome? (POTS)
9. Do you have gastrointestinal symptoms, such as irritable bowel syndrome or gastric reflux?
10. Do you have abnormal scar formation?
11. Do you suffer with bladder irritability or pelvic problems?
12. Do you have chronic pain or symptoms suggestive of fibromyalgia?
13. What were you like when you were a child or a teenager? Could you do the splits or the crab?
14. A history of scoliosis may be relevant.

A fuller explanation of this can be found on the Hypermobility Syndromes Association (HMSA) website.



Why do so many patients struggle to find an explanation and the correct diagnosis and appropriate treatment?

Surveys have shown that many patients take up to 10 years before they arrive at the correct diagnosis. Many people go undiagnosed or remain unaware that many of their symptoms could be linked to hypermobility. This is because there is a poor understanding of the condition amongst health professionals, particularly doctors, compounded by the fact that the condition can hide itself well as you get older, as the joints stiffen up.

Patients complain that their condition does not generate much sympathy because it is so poorly understood and invisible. They frequently go round in circles trying to find a solution for their problems with many unfruitful or wasted consultations.

This difficulty is compounded by the highly specialised nature of medical training where for example consultants are no longer trained as generalists, they are specialists or "organologists". Even rheumatologists have moved away from being general musculoskeletal specialists to what I call "rheumatoidology" which deals almost exclusively with inflammatory joint diseases, such as rheumatoid arthritis, for which there are now effective medical treatments.

The situation is further complicated by different views amongst rheumatologists regarding the significance of the condition. Many of my colleagues feel that hypermobility is simply a label which can be misused, allowing patients to jump on the benefits bandwagon. Others are more empathic, but simply do not have the resources or expertise to help.

Then there are *disbelieviologists* who leave the patient feeling confused and disregarded or even humiliated!

So the unfortunate reality for patients with hypermobility is that you cannot expect the average GP or hospital consultant necessarily to be well informed regarding this condition. Physiotherapists with real expertise in this condition are few and far between.

Ill-informed health professionals are a hazard for the patient and hence you might have already gathered that I am one of a small group of enthusiasts on a mission to increase awareness of JHS through education. I hope to develop effective services from existing resources, through a process of locally delivered masterclasses in conjunction with the HMSA.

As Alexander teachers you will recognise the difficulties in making obvious approaches mainstream!

In the absence of a solid evidence base I would like to outline what I have found useful for hypermobile patients and my humble observations on the role of Alexander in the treatment of the condition.

My approach and the "do's"

1. Give time and information:

Patients with established hypermobility syndrome may have a long story of wasted consultations and need to be listened to carefully. They may have a long story. This does not mean they are hypochondriacs. It is important to be clear about the diagnosis and to diplomatically unpick some of the damage that may have been

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caused by what went before. Patient information from the HMSA has the information standard assurance.

2. Specialist physiotherapy

An essential starting point for treatment with the emphasis on "specialist", by which I mean somebody with a track record of understanding and getting results with this group of patients. The physios who I work with have a very gentle approach starting by:

a. clearing joint restrictions (stiff joints) by a process of gentle mobilisation techniques.

b. Gently mobilising the *myofascial* tissues.

c. Checking neural tissue mobility and releasing where appropriate.

d. When everything is moving properly, move on to an exercise programme to stabilise and strengthen .

e. Offer advice on joint care , ergonomics and posture.

In outlining the above approach I am aware that we might on occasions be at odds with some of Alexander's principles. I try to help the patient understand what we are trying to achieve and ask them to think of themselves as a car and for the physiotherapist to be a mechanic and for the Alexander teacher to be the driving instructor.

For patients who are hypersensitised, i.e. who can't be touched, I would start with Alexander before physio.

3. Introduce Alexander lessons when the patient's pain is at a level compatible with chair work.

4. Expert podiatry assessment is important.

Hypermobile patients frequently have flat feet which cannot necessarily be corrected by exercises or Alexander. Orthotics may be required. This will also help to improve knee and hip function and spinal balance.

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5. Consider and address anxiety, depression and mental wellbeing.

Whilst Alexander can help with this, another important tool in the box is mindfulness as outlined in the government's all-party Mindfulness Initiative (essential reading!). Did you know that 100 MPs have undertaken the eight-week mindfulness course?

I suggest that patients visit the Frantic World website or read *Finding Peace in a Frantic World* by Professor Mark Williams. Alexander is of course a form of mindfulness, very much about being in the present, fully conscious.

6. Follow-up

Reinforcement and encouragement is essential , particularly in teenagers who are growing. I follow up until such time as "the penny has dropped" and the patient has the skills to self manage. Consultant follow-up is discouraged in secondary care in the NHS.

The above summarises "the toolbox" I use to help individuals self manage. None of the individual therapies are necessarily a panacea, but I find an appropriately sequenced multidisciplinary approach works well for most patients. the key is to create a network around you.

It is important to catch patients early to minimise the risk of moving into chronic pain. Decompensation (relatively sudden onset widespread symptomatology) usually occurs when a number of underlying vulnerabilities, physical and psychological are triggered by things like trauma, such as whiplash, or possibly a viral infection. I conceptualise this for the patient by the domino effect analogy.

The future and the "don'ts"

There is much more work to be done finding the best approach with this group of patients.

Medication needs to be kept simple and narcotics and opioids avoided. Antidepressants can help with pain, but with current evidence mindfulness is likely to play an increasing role in pain management, anxiety and depression and is NICE recommended.

I believe Alexander technique has a major role to play in partnership with a multidisciplinary team approach that enhances the effectiveness of treatment.

With the growing evidence base lets hope that Alexander gets the NICE endorsement it deserves, in a variety of situations.

I have created a network of trusted and capable individuals which has led to my experience of hypermobility being rewarding. This is not rocket science and can be replicated nationally through education.

"I ask the patient... to think of themselves as a car and for the physiotherapist to be the mechanic and for the Alexander teacher to be the driving instructor."

I believe this approach gives individual skills for life to stop them ending up in the chronic pain clinic.

What we need now is to develop evidence based guidance for Alexander teaching tailored for patients with hypermobility. You can help with this!

I would be interested to hear from you about your experience in treating hypermobile patients and would invite you to contact me with your thoughts regarding what works well... Let us share experiences and I will write further in a future issue. I can be contacted via STAT. Thank you for reading my article.♦

Useful reading

• HMSA website http://hypermobility.org/

• "The Alexander Technique" by Dr Philip Bull, *HMSA Journal* Spring 2015. Available at http://www.alexandertechnique.co.uk/

• *Hypermobility, Fibromyalgia and Chronic Pain* by Hakim, Keer and Graham.

• Frantic World (mindfulness) at www.franticworld.com.

• The Mindfulness Initiative http://www.themindfulness initiative.org.uk/.

Roxani's Story

Roxani is currently training as an Alexander teacher in London with Karen Wentworth, having moved from Greece where she worked in Athens as an aerialist, acrobat and singer, notably she was involved with the Athens Olympics and the opening ceremony of the special olympics in 2011 .

She knew at the age of 7 that she was hypermobile. However she also had a number of other symptoms including easy bruising, *gastrooesophageal reflux*, irritable bowel, syndrome, fatigue, anxiety and insensitivity to local anaesthetics.

It was only when she heard Julie Barber's talk on hypermobility (see page 26) that she discovered that there was a link that tied all of these together..Joint hypermobility syndrome!..what a revelation to understand that these were connected! Her story is typical of many individuals who struggle with getting the diagnosis right! Roxani also gained benefit from tai chi.