

# The Role of Narrative Medicine in The Management of Joint Hypermobility Syndrome/Ehlers–Danlos Syndrome, Hypermobility Type

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Joint hypermobility syndrome/Ehlers–Danlos syndrome hypermobility type (JHS/EDS-HT) is a hereditary connective tissue disorder affecting every bodily system. It is largely underdiagnosed by many practitioners, with the result of a considerable delay in diagnosis and, consequently, in the onset of adequate management schedule and treatment. Patients may also experience to be misbelieved, erroneously considered affected by a psychiatric or psychosomatic disorders, and rejected by the medical profession, which can lead to feelings of anger and resentment. Patient journeys are often long and complicated, but if doctors allowed the patient time to tell the full story, and were more prepared to think holistically, there may be a far more positive outcome. Here, the patients' perspective is presented with a narrative medicine approach, illustrating the tri-dimensional experience of a JHS/EDS-HT patient, who is also a Bowen Practitioner and a medical writer/educator. Narrative medicine would be invaluable in working with JHS/EDS-HT so that the patient can tell the story, and offer the practitioner a whole picture of her/his suffering and, often, the key for understanding the cause(s). Once this has been achieved, it might be possible to build upon a more positive and therapeutic dialogue which would result in better treatment and more effective management. It is also important for doctors to communicate with JHS/EDS-HT experts who will ultimately improve the patient journey and treatment outcomes of such a complex connective tissue disorder. © 2015 Wiley Periodicals, Inc.

**KEY WORDS:** Bowen Technique; Ehlers–Danlos syndrome; joint hypermobility syndrome; narrative medicine

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## INTRODUCTION

“The Hypermobility Syndromes Association (HMSA) is a support group run by and for people who have hypermobility syndrome [...]. With such a complex disorder it is often difficult for patients to tell their doctors the impact that hypermobility syndrome has on their lives” [Gurley-Green, 2001].

The nosologic dilemmas of joint hypermobility syndrome/Ehlers–Danlos syndrome, hypermobility type (JHS/EDS-HT), which were partly addressed along this monograph, mirror the many problems which patients encounter in

being believed and properly managed. From a clinical perspective, the lack of a molecular confirmatory test [Mayer et al., 2013], the extreme inter- and intra-familial variability [Castori et al., 2014] and the general lack of a consensus in assessing joint mobility and skin involvement [Remvig et al., 2014] in JHS/EDS-HT represent the major problems for disease recognition and assessment. On a patients' perspective, this results in a general disbelief by untrained practitioners, in requesting an increasing number of consultations by a wide variety of specialists and, eventually, in patient's development of a lack of confidence in medical professionals. The consequence

is the “explosion” of a great number of self-help initiatives and unofficial documents in lay websites and publications which are substituting the traditional scientific knowledge that, at present, is limited to exploring marginal aspects of JHS/EDS-HT. I, as affected by JHS/EDS-HT, a dedicated Bowen Practitioner and a medical writer, have experienced the entire journey of a patient with JHS/EDS-HT.

This article will explore the complexities of diagnosis, the use of narrative medicine as a tool to facilitate patient-medical professional relationships, as well as the possibilities for ongoing and future management.

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## LIVING WITH JHS/EDS-HT

Very often, the diagnosis of JHS/EDS-HT is significantly delayed—possibly up to 10 years [Hakim, 2012], with many patients being dismissed, told that their symptoms are psychosomatic, or generally disbelieved [Bulbena et al., 2004; Ercolani et al., 2008; Baeza-Velasco et al., 2011; Eccles et al., 2012]. Partly this can be accounted by the condition being genetically linked to anxiety, with patients with joint laxity having a prevalence of panic attacks—sixteen times higher than for those in control groups [Martin-Santos et al., 1998]. A study by Eccles et al. [2012] shows that the amygdala, which processes pain, anxiety and “psychosomatic” conditions, is larger in a hypermobility cohort meaning that we can actually see real changes in the brain, shown through research into MRI scans of hypermobile individuals versus controls. This may also account for the reasons for anxiety and pain-processing, because changes have already taken place in the brain [Eccles et al., 2012]. It is therefore difficult to see what comes first—the actual physical symptoms from the genetics and make-up of brain physiology, or the pain and myriad of other physical problems. Another factor that, in my opinion, also leads to an increase in fear, is the known lack of proprioception, or an awareness of oneself in space, that is a feature of patients with JHS/EDS-HT [Ferrell and Ferrell, 2010]. The lack of joint and joint awareness can be very unsettling and frightening for those whose joints dislocate. This entirely psychological blame factor can have very damaging implications in this patient group, as well as significant delay in obtaining the correct diagnosis and treatment itself [Grahame, 2009; Hakim, 2012].

### Invisible Illness

Frequently, JHS/EDS-HT patients present looking “deceptively well” [Grahame, 2003, 2009] and from that point alone, JHS/EDS-HT might be considered an invisible illness, with

many patients cut-down in their prime. Some patients will have encountered comments such as, “you look fine”..... Many patients will indeed have seen large numbers of medical experts, with many failing to piece together the complexity of a condition such as JHS/EDS-HT. There is an anecdote amongst JHS/EDS-HT patients about zebras [Tinkle, 2010]. One patient from the HMSA facebook forum explains that, “*the (American) medical slang for someone with a rare or obscure medical condition is a zebra. Medical students are sometimes taught ‘When you hear hoofbeats, think horses not zebras’. In other words, always look for the obvious problem rather than the unusual. We are the unusual, so we are medical zebras(!).*” Recognizing JHS/EDS-HT is rather difficult for the untrained practitioner because most standard diagnostic procedures and physical examinations resulted normal or negative. The correct diagnosis can be achieved only after a focused and meticulous evaluation, which, once mastered, makes easier the detection of future patients (*You can’t miss it when you know it, once you have seen it you cannot miss it again!*—UK Rheumatologist).

### The Story and Route to Diagnosis

My story begins in 2008, at 34 years of age [Knight and Bird, 2010], when I suffered a grade 2 tear of my medical gastrocnemius during a ballet class. This was by no means my first injury, and since I was so “fed up” initially with musculoskeletal injuries, I applied that very week to do an M.Sc., in Dance Science in a quest to understand the reason behind my injuries. I started to have rehabilitative physiotherapy for the calf injury, and then saw a dance specialist physiotherapist who begun to suggest that the reasons underlying my calf-tear were far more complex, and that I had global widespread muscle weakness and inefficient and incorrect movement patterns.

### Digestion

As time went on, I realized that there was more going on than just muscu-

loskeletal problems, and although I was fortunate enough not to dislocate my joints (subluxate, perhaps yes), as do many JHS/EDS-HT patients. However, I had many other multisystem problems. For example, I experienced a combination of constipation and diarrhea and symptoms that were more suggestive of functional bowel disorder because of the mechanisms and behavior of the tissue laxity of the gut tissue [Fikree et al., 2014]. My symptoms started young with abdominal pain, and by my early twenties I regularly experienced gastro-esophageal reflux, which seemed to resolve, but a whole host of other problems relating to gut motility eventually followed on. Symptoms mainly included problems in bowel evacuation with a need to do up to ten bowel movements per day. Quite simply, the muscles involved in excretion were not working very efficiently, which was shown in an MRI proctogram, although some bowel retraining helped. I did not have a retrocele or anal prolapse that some JHS/EDS-HT patients have owing to tissue laxity [Fikree et al., 2014], but I developed anal fissures and an anal fistula which both required surgery. A combination of gut stimulant drugs, such as Senna laxatives, and drugs for gut spasm—e.g., *Buscopan*, helped. Most interestingly, omitting wheat and gluten from my diet had a very positive effect. A low FODMAP diet (i.e., low Fermentable, Oligo-saccharides, Di-saccharides, Mono-saccharides, and Poly-saccharides), also appears to be helpful in some patients [Williams, 2014].

### Headaches and Problems With Temporomandibular Joint

I regularly had headaches and then started to experience problems with my temporomandibular joint in my early twenties with resultant jaw pain and a both clicky and “sticky” jaw. An orthodontic appliance along with physiotherapy and osteopathy helped with some of the symptoms. Even going to the dentist can be a traumatic experience for those with JHS/EDS-HT, aside from the difficulty of maintaining a wide jaw movement, it is now known that local

anesthesia, namely lidocaine, does not work as effectively or hold as long in JHS/EDS-HT patients [Hakim et al., 2005]. I remember having wisdom teeth out and swearing that I could feel it, despite the dentist stating that given the many injections it was not possible. Some JHS/EDS-HT patients even experience problems with swallowing and fatigue on talking—again due to tissue laxity [Hunter, 2011]. I particularly hate eating some types of lettuce, as I fear I might choke!

### **Asthma**

I had mild asthma, which begun in my teens, but this is now only a problem if I have colds or chest infections. Asthma can be shown to be linked to tissue laxity in JHS/EDS-HT patients [Soycen and Esen, 2010].

### **Urinary and Bladder**

I had problems with a weak bladder ever since childhood, and would at times need to micturate at night up to six times. A cystoscopy in my late thirties showed a bladder of normal capacity, but urodynamic testing showed that I was never utilizing my full bladder capacity. Pelvic floor exercises through Pilates and physiotherapy have, over time, improved my bladder capacity. It appears that some patients with JHS/EDS-HT will have weak bladders, while some, in fact, retain, owing to the stretchiness of the tissues [Norton et al., 1995; Tinkle B, 2008].

### **Endometriosis**

It maybe considered contentious to mention the fact I have endometriosis, as this is not formally linked to JHS/EDS-HT. However, I was diagnosed in my mid-twenties following years of extreme dysmenorrhea, where I would be incapacitated for days by the worsening pain and fatigue. Increased tissue laxity owing to higher levels of progesterone just prior to menstruation worsened my JHS/EDS-HT symptoms [Bird, 2007]. Although there is insufficient research to link endometriosis to

EDS-HT, one paper shows an increased prevalence [McIntosh et al., 1995]. In my case endometriosis made many of JHS/EDS-HT symptoms worse—including bladder and digestive symptoms. It also caused severe inconvenience to my working life, and I eventually worked part-time by the time I was in my late twenties because of the disruption caused by my myriad of symptoms. I had several laparoscopies, and the most effective treatment used gonadotropin-releasing hormone analogue to artificially stop my periods with hormone replacement therapy given to replenish bone density. This has allowed for a vastly improved quality of life.

### **Development Coordination Disorder, Dancing and Attention Deficit Disorder**

I showed signs of development coordination disorder from a very young age. I was very late walking which is often typical with JHS/EDS-HT patients [Knight and Bird, 2010; Knight, 2011]. I could never run. I had great trouble with handwriting, and things like painting and sewing [Kirby et al., 2005; Kirby and Davis, 2007]. Some JHS/EDS-HT patients experience problems with attention deficit disorder, and difficulty concentrating owing to continuous fidgeting [Koldas et al., 2011]. I was often pulled up about not concentrating during ballet classes or going wrong during dance sequences. Many patients with JHS/EDS-HT are also report dyslexia, but as yet, there is no official link to JHS/EDS-HT. But again, it just shows the myriad of symptoms at the helm of this multi-system condition—even learning appears to be affected.

### **Dance and Sports**

I was terrible at sports, but fortunately had an aptitude for classical ballet, where my hypermobility was actually a natural asset [McCormack et al., 2004; Knight, 2011; Knight et al., 2012]. There is a high prevalence of hypermobility in the

performing arts per se [Ruemper and Watkins, 2012]. *“Team sports were a nightmare. Nobody wanted me in their team, a stigma which remains with me still. There is no doubt that friendships and popularity are heavily based upon one’s ability in the sports field. Those who lack this ability are often shunned in other activities, because it appears they are useless. Not surprisingly, I started to skip PE by the time I was in my early teens. I would schedule my piano lessons to be during these times, if possible. Although I wasn’t too bad at netball on account of my height and being a good goal shooter, I was hopeless at hockey and spent more time running (or what I do as ‘running’) away from the ball. I loathed athletics and was no good at swimming on account of being afraid of the water. Although I had taken ballet classes as a young child, between the ages of six and nine, I recall how much longer it took me to learn to do a polka step compared to the other children, and yet I had much better facility for classical ballet than most of the children. For example, I had a good range of turnout, the aesthetics of swayback knees and a pleasing instep”* [Knight, 2011, p65-66]. I am happily still dancing, when I can, and still find my hypermobility an asset in class.

### **Anxiety and Depression**

I suffered from bouts of anxiety and, later on, depression. I was an anxious child, and research shows that those with JHS/EDS-HT are 16 times more likely to experience panic disorder compared to control group patients [Martin-Santos et al., 1998]. Anxiety was compounded with problems of dizziness, and at times short episodes of tachycardia, in the end I received a diagnosis of postural orthostatic tachycardia syndrome (POTS). I experienced episodes of depression from my early thirties, which I would say stemmed from a not being believed about my myriad of symptoms and from extremely poor physical health. I could not achieve what I wanted to, or have the career I had originally planned, although it has now taken a very interesting twist through my work as a writer and as a Bowen practitioner.

## Social Life

I have also lost out on many social occasions owing to being regularly unwell, which has at times resulted in increasing isolation and depression. Charities such as HMSA are instrumental for people with JHS/EDS-HT in providing help in the forms of helplines, support groups and also online forums and social media (e.g., Facebook).

## Pain and Fatigue

Above all, I suffered from persistent pain which seemed to “bounce” around my body and varied in intensity and this was coupled with severe fatigue. My pain started initially with growing pains followed by regular calf micro-tears and overuse injuries during ballet in my teens. Overuse is a very common phenomenon in those with JHS/EDS-HT [Keer, 2003; McCormack et al., 2004]. Just before my 18th birthday I started to experience some localized lumbar spine pain which I initially thought was due to excessive dance training prior to a ballet exam. This pain became more insidious overtime, but physiotherapy seemed to have little impact, and neither neurosurgeons nor orthopaedic surgeons could explain my pain; an MRI scan showed a disc prolapse and degeneration at L4/L5, where I also had a significant hinge in my spine. Although Bowen Technique did help with this, it was not until I received considerable remedial physiotherapy that my back pain considerably improved. As time went on, my pain became more widespread, or what I described to doctors as “globalised widespread pain” with accompanying “spiky” pain, which was (and remains) quite unbearable at times. A range of different medications frequently employed such as Gabapentin and Amitriptyline did not make a difference, although Diazepam has been excellent for relief of muscle spasm.

## Sleep

My sleep was always poor, something that begun in childhood, and not helped

by frequent night-time micturition; even if I got 12 hr of sleep it didn't (and still doesn't) often feel sufficient. This is a well-known fact in the JHS/EDS-HT patient cohort [Castori, 2012].

## Skin Healing

I always suffered of skin fragility accompanied by poor, delayed healing and regular bruising [Russek, 1999; Hakim and Sahota, 2006]. This caused me a series of minor, but still annoying post-surgical and post-traumatic complications, such as widened scars. Adequate practitioners' education in suture execution and wound healing could minimize these problems.

## Postural orthostatic tachycardia syndrome

POTS is caused by disturbances to the autonomic nervous system. Patients with POTS might complain of symptoms such as tachycardia, palpitations, fatigue, light-headedness, exercise intolerance, nausea, headache, mental clouding or brain-fog, and syncope (fainting) [Mathias et al., 2012]. I endured two days of testing for POTS in a laboratory type setting, which involved being attached to heart monitors and tests including holding ice blocks, performing math tests, squeezing objects, and being tilted on a table and staying at a 30° angle for as long as I could take before feeling faint, and then having a blood test immediately on standing. An exercise test involved horizontal cycling, which I found quite strange! I was then attached to a portable blood pressure monitor for 24 hr and asked to do various strange things including lying down, sitting after eating and then walking at random times. The machine also ran at night. The following day I had to eat a liquid meal horizontally and was left with blood pressure testing for a further 45 min. After this test I felt quite unwell resulting in the need for an ECG test because my pulse rate (I felt) had changed, although this was not in fact the case. Testers, should, I believe ask

participants how they subjectively feel after each test, because it was more unexpected times when my actual POTS symptoms were picked up in testing—and certainly during the activities I had to follow between the testing days. I received a confirmed diagnosis in 2012. I manage this conservatively by ensuring I drink plenty of fluids and keep salt levels reasonable. I still have trouble and significant dizziness on crouching down in shops and in libraries, which has led to very close fainting episodes which are most unpleasant. Even despite medical evidence of testing, some doctors do not fully understand the implications POTS can have, and how unsettling and unnerving it can feel for the patient.

## Obtaining My Official Diagnosis

My physiotherapist was the first to suggest JHS/EDS-HT, which was shortly then confirmed by Professor Howard Bird [Knight, 2011]. The relief of diagnosis was immense, as I realized my problems were real and not at all in my head—despite what some medical professionals were beginning to imply: an orthopaedic consultant who looked at my back (which had been painful since my late teens) said that it was completely normal, a neurosurgeon and many physiotherapists were dismissive because my back looked “normal.” My global hypermobility was constantly missed. Visits to the emergency room with either injuries, back pain, and episodes of POTS, closely related to JHS/EDS-HT were frequently dismissed as panic attacks. I never bought up the array of other symptoms until much later on, but all of these had been going on for some time. For me, I suspect that a spiral fracture of my right leg aged seven was the start of my problems, with the rest of the bodily systems going down like a pack of dominos.

## Disbelief by the Medical Profession

In short, the doctors often disbelieved me and all that was going on. It took some insight of a physiotherapist and

later of course, a rheumatologist, to piece everything together. I was initially relieved by a confirmed diagnosis of JHS/EDS-HT, but upon reflection I felt angry towards the other medical professionals I saw over the years, including copious visits to general practitioners, who did not start to piece together a very global and multisystem problem. I also felt tremendous sadness in the loss of my life, career and how I expected my life to turn out. In summary, if other doctors had begun to look more holistically at what was going on, there need not have been such a long delay (probably some 30 years) in my diagnosis. This has made me feel resentful and rather bitter towards the medical profession at large.

## NARRATIVE MEDICINE IN JHS/EDS-HT

My story is unfortunately far from uncommon. Patients have often told their story many times only to be met with disbelief or other such negative barriers. One of the most important things that any medical professional encountering an JHS/EDS-HT patient can do is to listen, and to let them tell the story; and this forms the basis of narrative medicine [Nowaczyk, 2012].

Charon first used the term “narrative medicine” in 2000. She writes that to employ narrative medicine means “*to refer to clinical practice fortified by narrative competence—the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness. Simply, it is medicine practised by someone who knows what to do with stories.*” [Charon, 2007]. In science and medicine, there has been a recent interest and attention paid to qualitative research including the narrative element, participant-observer studies, ethnographical interviews and focus groups, for example [Charon, 2012]. Divinsky [2007] suggests that “*in scientific terms—if we make sense of the world by recognizing patterns and thinking in categories—being able to narrate a coherent story is a healing experience*” [Divinsky, 2007].

Indeed, there is something fundamentally human about telling and sharing stories, in order to gain insight and meaning into another person’s world. It is what we do every day. Narrative medicine suggests that the medical professional tries to honor and understand the stories of those they are caring for [Nowaczyk, 2012]. This can also benefit the medical professional in that they have the ability to also share the story so that they can come to an agreed meaning with the patient [Charon, 2001, 2007; Nowaczyk, 2012]. This, in turn, leads to a deepening understanding and empathy by the medical professional of the patient’s plight, and improves patient-physician relationships [Charon, 2001]. Another advantage of narrative medicine for medical professionals is that it can help prevent burnout and retain empathy that may become somewhat diminished during their career [Divinsky, 2007].

It has already been suggested that there is a significant delay in diagnosis in JHS/EDS-HT patients [Hakim, 2012] and that they are often disbelieved or even told their symptoms are psychosomatic [Bulbena et al., 2004; Baeza-Velasco et al., 2011]. By the time they reach the next medical professional, many JHS/EDS-HT patients are angry and resentful of the medical world and in many cases trust has broken down [Knight, 2013]. The patient frequently becomes cynical of the medical world—after all, they have already seen numerous doctors and other medical professionals, so why are you, doctor X, going to be any different? This particular group of ‘expert patients’ frequently presents knowing more about their condition than their doctors [Knight, 2013]. It is not unusual to see JHS/EDS-HT patients bringing copies of internet articles, copious medical notes, and even books to consultations. Many of them blog and are highly active on social media about their conditions. So just how should a doctor approach this type of patient?

Firstly, it is essential that the physician gain the trust of the patient. This is fundamental to the beginning of the relationship, as is the crucial need to

listen to the patient’s story. The need for narrative medicine in this patient cohort is absolutely vital. Time is necessary, which is a potential difficulty in the current environment of cost-cutting but this somehow should be negotiated when one sees an JHS/EDS-HT patient. Although this maybe a complication in terms of health economics, in the long-term it will prove to be far more beneficial. This may be more feasible in private practice, as opposed to the constraints of the (UK) National Health Service.

## PATIENT AS A RESOURCE

### The Bowen Technique

The Bowen Technique is a relatively young technique originally from Australia. At present there is a limited understanding about precisely how it works; but it aims to affect the connective tissues of the body, particularly the fascia. It also works on the muscle stretch-receptors and the muscle-spindle feedback mechanism [Knight, 2013; Wilks and Knight, 2014]; as well as addressing the sympathetic nervous system and taking the body into a deeper sense of relaxation [Knight, 2013]. It might, by virtue of its effect on fascia, have postural implications as well as potential changes to other bodily conditions [Wilks and Knight, 2014]. As a Bowen practitioner, who works predominately with JHS/EDS-HT clients, I now offer a two-hour initial consultation (including treatment time) because for some clients the need to tell the story almost supersedes the need for treatment. As a Bowen practitioner who also has the condition herself, and has written two books about JHS/EDS-HT, I have the advantage of to sharing the story with the patient. The patients know straight away that they will be believed without question, and that I will understand their plight—although it is important to stress that every person’s story is different and unique to them. Whatever my knowledge might be (both academically and experientially) about JHS/EDS-HT—I have not lived in my client’s shoes or walked

their life path. This means that for me narrative medicine is an essential part of my work. There is an expression that is most apt “*walk one day in my shoes and then you might understand.*” This would be a useful adoptive adage in terms of narrative medicine for all medical professionals.

### Medical Encounters

Many JHS/EDS-HT patients have visited doctors who really haven’t listened to them. They frequently leave dissatisfied by the consultation and there is no real way forward both in the relationship with that medical professional or in any particular treatment plan. However, when the reverse happens it can make an enormous difference. One patient on my facebook page wrote: “*One rheumatologist that I went to see, gave me so many pointers for my dysautonomia, every other Dr I have seen, including in A&E when being really ill because of it, just sent me away, as basically, in their eyes, I wasn’t having a heart attack, plus they had no idea what was going on, so just dismissed me. She really listened, and completely understood all the issues I have, not just with my nervous system, but with numerous other things. She was also sympathetic about how being in pain makes you really tired, and it just escalates. Nobody has ever had the time to sit there, with complete understanding, and total knowledge as she did.*”

Other comments included: “Last time a doctor properly listened to me about it all I burst into tears;” “It makes you feel validated, after so long of being doubted you start to doubt yourself!;” “Believed!!!;” “Amazed and like I want to cry with joy. Doesn’t happen often though (being heard);” “It’s amazing and such a relief!;” “Like what I have to say really is important and that the pain and symptoms are real and they care and want to hear about them.”

Allowing time for the patient to tell the story is important because apart from gleaning an understanding [Charon, 2001], you will start to gain their trust [Knight, 2013], and then a possible way forward for treatment, which often involves a huge variety of different medical expertise to account for the multisystemic nature of the

condition. Although physiotherapy is the evidence-based mainstay for management of JHS/EDS-HT [Simmonds and Keer, 2007], patients might need to be seen by podiatrists, gastroenterologists, urologists, gynaecologists, cardiologists, psychologists, and many others. The journey for patients can be immense [Knight, 2013].

### Educating Medical Professionals/Students

*“It is so valuable to hear your perspective of this condition. You have helped to bridge the gap between learning about a condition and truly imagining how it must be to go through the process of having it”* (Dr Malcolm Matthews, Consultant Anaesthetist). I was really touched to receive this personal review of my book [Knight, 2013], as it really encapsulated what I had wanted to achieve through writing about the multidisciplinary approach to managing JHS/EDS-HT. In fact, educating medical professionals of all disciplines and physiotherapists (and others) has become one of my missions in life.

Finally, doctors must also learn to communicate with each other—even if this means from different hospitals. There are a number of occasions when this would have been invaluable in my care—particularly in relation to gastroenterology matters. Doctors should not feel embarrassed if they don’t know the answer to everything, and when they don’t—it would be much better if they felt more prepared in some cases to liaise with JHS/EDS-HT experts or to ask the patient, who may know themselves!

### CONCLUSION

JHS/EDS-HT is a truly multisystem condition and involves an extremely wide range of medical experts from many disciplines. One of the most important things you can initially do as a medical professional is to listen to the story that the patient tells you, and to believe in them. Then trust in a patient-medical relationship can truly begin as part of an essential and ongoing holistic management, including talking to JHS/

EDS-HT experts. This, I cannot emphasise enough through my own journey.

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