Unit 2 – Research Paper

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Why am I still in pain?

Investigating how anatomical and physiological understanding of Ehlers Danlos Syndrome/ Hypermobility Spectrum Disorder (EDS/HSD) affects patient agency. Could art and artists help create a more accessible form of education such as interactive sculpture and thus contribute towards this understanding.

6,552 words

Introduction

This paper aims to look at how a greater anatomical and physiological (A&P) understanding of Ehlers Danlos Syndrome/ Hypermobility Spectrum Disorder (EDS/HSD) could be useful to some of the EDS/HSD community and how art might be part of creating this understanding through the use of interactive sculpture.

EDS/HSD is recognised as a complex multi systemic set of conditions where faulty collagen causes a multitude of painful, variable and disabling symptoms which require life long management. (The Ehlers Danlos Society, 2021) Currently patient care is usually divided into as many different teams and services as there are different sets of symptoms. Patients frequently report serious delays in diagnosis, along with disjointed and either absent or sporadic treatment. Patients frequently attribute this to a lack of etiological and pathological understanding expressed by clinicians and care providers. My extensive experience over 15 years in the health care system where I have met dozens of EDS families and clinicians has repeatedly thrown up consistently expressed issues with the A&P and the effect faulty collagen has on EDS/HSD A&P in particular. I have witnessed the enormous difference an in depth knowledge of the A&P differences in EDS can make to patient's understanding of their condition and how this leads to better a grasp of the multitude of potential symptoms, what causes those symptoms, why they hurt and subsequently the potential benefits and pit falls of possible treatments. With this understanding patients feel better able to co create, plan, manage and monitor their therapies and treatments.

This paper explores some of what currently hampers A&P understanding and looks at whether my experience and those reported to me over the years is indicative of the wider EDS

community. This involves also explaining more about EDS/HSD and why there is a need for greater patient support and agency along with some of the current treatment and management options available to patients.

Much of the information has been gathered via my own lived experience, those of my EDS family and EDS/HSD friends, extensive discussion with families and patients during inpatient admissions, rehabilitation clinics, on going out patients groups, national and international specialist patients groups, disability groups and questionnaires sent to patients and clinicians. It also draws on published medical research and the recent increase in EDS/HSD representation in social media. The initial focus on models informing aspects of physical therapy was a result of two main things. Firstly, physiotherapy currently is recognised as the mainstay of daily ongoing treatment and secondly the huge emotional implications of perceived patient non compliance and resultant the shame, guilt and judgement which then hampers patient agency. (Rahman, A. Daniel, C. & Grahame, R. 2014)

The paper looks at expressed problems with how current information is shared with EDS/HSD patients. Kinaesthetic learning methods are discussed as they are potentially one of the most effective ways for EDS/HSD patients to gain the required knowledge. This is partly due to the newly observed correlation between neurodiversity and the EDS/HSD community. Interactive sculpture could be an effective and efficient way to provide this A&P understanding as it uses kinaesthetic learning.

Art and art skills could be part of the solution as artists are well placed to communicate complex concepts due to having extensive understanding of physical materials and experience of creating 3D interactive works which support kinaesthetic learning and help anchor understanding.

Included are examples of art which has been used to educate kinaesthetically along with the specific knowledge and skill set that artists have that might be used to create these sculptures.

My experience and years of interaction in the EDS/HSD community has lead me to believe that health literacy is a vital step on the path to patient agency which is essential to managing long term health conditions. Described by James W Moore in his paper 'What Is the Sense of Agency and Why Does it Matter?' agency is 'when we make voluntary actions we tend not to feel as though they simply happen to us, instead we feel as though we are in charge. The sense of agency refers to this feeling of being in the driving seat when it comes to our actions.' This idea of being in the driving seat is essential for patients when it comes to management of long term health conditions. Anatomical models speak to both health literacy and patient agency.

Why EDS/HSD?

I decided to focus particularly on EDS/HSD because of my extensive personal experience as an EDS patient and having seen the damage a lack of understanding causes.

Ehlers Danlos Syndrome (EDS) is a group of 13 genetic connective tissue disorders. Due to the prevalence of connective tissues around the body EDS can have many differing manifestations potentially affecting most systems in the body. This can include musculoskeletal, cardiological, neurological, autonomic nervous system, gastrointestinal, ocular, psychiatric, haematological, and gynaecological issues. The most prevalent symptom being chronic/recurrent pain. (Castori, M. 2013)

Current medical thinking describes EDS/HSD symptoms being a result of missing proteins essential for collagen production. This results in the collagen not forming the normal strong but elastic structure needed to hold the body together. EDS effected collagen is often described as 'like an old rubber band', it can still stretch but it doesn't have the strength to bounce back to the original shape. This results in tears and injury to tendons, connective tissue and cartilage, bowls and internal organs, valves not closing properly resulting in digestive issues, varicosities and heart problems, prolapses and herniations, joint instability and dislocation amongst others. The faulty collagen is also now thought to possibly play a part in the over degranulisation of mast cells and even the development of the central nervous system and brain formation. (Afrin, L. Maitland, A. and Seneviratne, S. 2017)

The multi-systemic nature of EDS makes it notoriously 'elusive' to identify, (Castori, M. 2013) with patients regularly fighting for years for a diagnosis and often having to jump through hoops to get to the relevant specialist for treatment. In my survey all of the participants reported the diagnosis taking multiple years, with one participant reporting it took them 50 years and another reporting 30 years. This seems to be partly due to the lack of proper EDS/HSD education in the wider medical field.

The most common type of EDS, Hypermobile Ehlers Danlos Syndrome (hEDS) is categorised by joint hypermobility/instability (dislocations and subluxations) chronic/recurrent pain, fragile, stretchy and 'velvety' skin, unusual scaring, slow healing, often a resistance to painkillers and aesthetics, amongst many more symptoms. Hypermobility Spectrum Disorder (HSD) is also characterised similarly and largely manifests and is treated very similarly. "The essential difference between HSD and hEDS lies in the stricter criteria for hEDS compared to the HSD" (The Ehlers

Danlos Society 2017). This is predominantly due the concerted effort to find the genetic variant for hEDS as it's the only EDS diagnosis for which there is no identified genetic marker.

Currently the explanations of EDS/HSD given to or made available to patients are usually either very basic or far too complicated. They vary between not really providing real insight into the causes of the severe chronic and acute pain beyond the frequently used trope of 'your joints are just too hypermobile,' to extremely complex explanations. These often involve long, dense and medically heavy texts and webinars that, unless you are medically trained, are inaccessible. This does a massive disservice to the patients and health care professionals working with them. The phrase 'your joints are too hypermobile' does not give any real insight into how truly complex EDS/HSD really is. It does nothing to explain what it really means to have overly fragile, stretchy collagen and how it affects your ability to even stay upright or the long-term implications such as 'recurrent or chronic inflammations of soft tissues may lead to thinning and spontaneous ruptures of tendons and ligaments'. (Castori, M. 2013)

Artists are well placed to communicate complex concepts

Art and artists have historically played vital roles in the communication of science and medical education. Obvious examples include Grey's Anatomy and Leonardo Da Vinci's medical and mechanical drawings and designs.

Kim Amis, a sculptor and tutor at City & Guilds of London Art School, is a prime example of an artist creating work using their specific skill set in an educational and clinical setting. Amis works in collaboration with researchers and doctors at University College London to create 'tissue-equivalent Phantoms' for medical research

Fig1: Kim Amis, Phantoms (2006 - Present)

and training. (Amis, 2019) These Phantoms are particularly used to help get accurate brain scans and thus accurately target effective treatment of premature babies. This is essential because they 'often have abnormal brain oxygenation which can lead to brain damage.' (Amis, 2019). Depending on the type of scan, the Phantoms are made of a latex shell which is filled with a compressible polyvinyl acetate gel which makes a soft Phantom or a solid Phantom which is made using either epoxy or polyester resin. Both have 'scattering and absorbing substances' added to them which can mimic a brain bleed or damage.(Amis 2019) One of the uses of the Phantoms is to more accurately tune the scanner to babies' heads by putting the Phantoms in first to adjust how and where to focus the imaging.

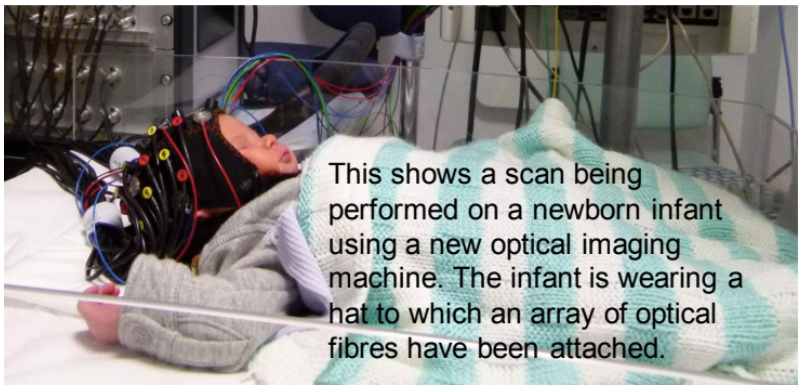

Fig 2 & 3: Kim Amis, Phantoms (2006 - Present)

As artists we are often used to visualising and translating ideas into tangible artworks. This along with the extensive material and technical knowledge of many artists means when making something like these proposed interactive sculptures we can approach them in creative ways, potentially thinking outside of the box with how they could be realised.

My art practice for the past few years has often included depicting anatomy, chronic illness, pain and biochemical structures and effects. I have experimented with and learned about materials and techniques that can represent these topics in a way that is accessible to me personally as

someone with Attention Deficit Hyperactive Disorder (ADHD) as well as people around me, many of whom are also neurodivergent. I have worked extensively with natural latex and other elastics, exploring how they degrade over time and the different properties they give at each stage. Latex for instance goes from being highly flexible and stretchy to more brittle and fragile. I anticipate potentially using natural rubbers and possible bioplastics to create part of these interactive sculptures in order to represent faulty collagen tissues.

Fig 4 & 5: Sorcha Jewell, Can you see my pain now? (2017)

Information gathering.

In order to find out if the information I gathered over the past 15 years from the aforementioned sources was still indicative of the wider EDS/HSD community, I also sent out some surveys, using google forms, asking several of the questions already discussed by both patients and clinicians.

The questionnaires were formulated using personal knowledge of EDS/HSD and knowledge of the EDS/HSD community, alongside input and authorisation from my research supervisor at the time.

The first survey aimed at Patients, Family and Friends, included questions designed to establish some the history of their journey and as much as possible about what influences their decision making regarding how they manage their conditions. I wanted to have a sufficiently broad area of enquiry so there was space for as many issues as possible to arise. It was important to leave room for new or surprising information and aspects of people's experience as that could effect how I to go forward. I decided to include questions about what the path to diagnosis and treatment was like for them, whether there is a need for better EDS/HSD education and if they felt anatomical interactive sculptures could help them understand their conditions better. There were also questions about whether participants felt they were given adequate support and information about EDS/HSD and where they got their information from. I asked if they felt their condition has improved since diagnosis along with whether they felt they understood why they are in pain. I also asked what has proved most helpful and unhelpful in the management of their EDS/HSD.

(For the full list of questions and answers please see Appendix A.)

List of questions

1. How did you first hear about EDS/HSD?

Most people report finding out about EDS/HSD from family and friends or other patients and this was mainly backed up in the survey.

2. Have you managed to get a diagnosis of EDS/HSD?

Although getting a diagnosis is reported to be very difficult and takes a long time most of the survey respondents did have a diagnosis.

3. Were you informed of why you are in pain?

Most people report taking a long time to find out anything to explain the pain and most survey respondents were not given an adequate explanation of their pain.

4. Do you feel you now have a good understanding of why you are in pain?

Most people still struggle to understand and the survey respondents mainly felt they did not.

5. How long was it between the start of your health problems and receiving what you consider to be an accurate diagnosis?

Whilst there is a growing awareness of EDS/HSD both in the health service and the wider community resulting in some reports of faster recognition, it seems it still takes years to get a diagnosis and the journey is traumatic and very hard work.

6. Was EDS/HSD fully explained in a way that you consider comprehensive and helpful?

Over the years I have never met anyone who was given a proper explanation at the point of diagnosis. This was reflected in the questionnaire with only two respondents saying they received proper explanations. Clinicians don't seem to check if the patient understands. It was suggested that this surprising almost comprehensive lack of explanation could possibly be because they lack the information themselves or because if a patient has got to the diagnosis stage the doctors assume they will have read everything there is to read in order to get there. The shortage of time due to huge clinic pressure and too many patients to too few clinicians is also a factor to consider and another reason health literacy and patient agency is so important.

7. Were you provided with adequate literature and support information?

No one was given this information. Most patients report getting this information from other patients either directly, via social media or via patient groups, medical publications or magazines.

8. As part of the journey to diagnosis treatment have you ever experienced the following?

I chose these descriptors in response to feedback from so many EDS/HSD patients over the years and I have seen the profound effect that these feelings have on patients ability to engage with treatment.

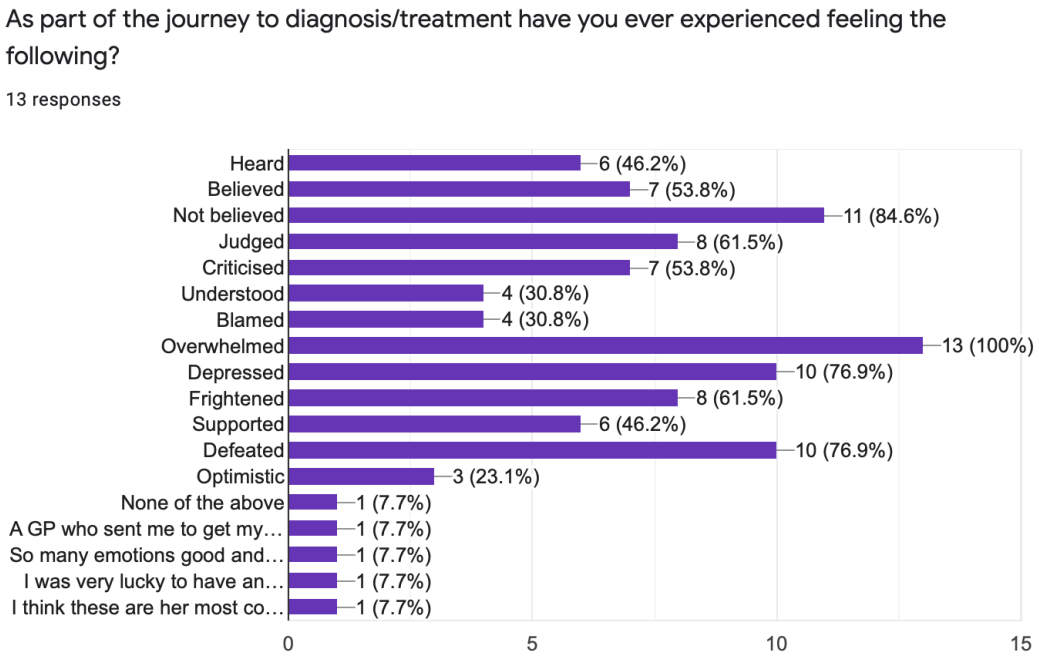

Fig 6: Sorcha Jewell (2021-22) Bar chart taken from patient, family and friends.

Disturbingly most respondents did feel overwhelmed, depressed, disbelieved and defeated. Which is in keeping with what most EDS patients have reported over the years. This result impacts on any further development of educational tools and particularly on how they could be best used. It highlights the importance of not adding to the stress patients already feel.

9. Following diagnosis/treatment has there been an improvement in your condition? If so how?

Surprisingly most people said they felt there wasn't any improvement. Perhaps because of the lack of accompanying information and support. However I now realise that I should have also asked if people felt better able to manage their condition following diagnosis?

10. What treatments or therapies have been offered? (Please add any specialist services in 'other')

Painkillers seemed the most frequently offered treatment. 9/14. It seems most people were only offered physiotherapy advice, only 6 respondents were offered short courses and shockingly only 4 were offered ongoing physiotherapy which is what's actually needed. Thus highlighting the need for patients to be A&P literate to enable them to develop their own physical therapy in order to empower them to self manage.

11. What treatments or therapies were provided by EDS/HSD specialists?

A small amount of pain management was offered or very limited physiotherapy. Most people were not given specialist care.

12. What do you consider you need more of?

Patients report needing more information, more physiotherapy, more specialist input and ongoing help. They need more accommodation at work and a deeper upstanding of their conditions from families and colleagues. More Hydrotherapy and multidisciplinary care with individual attention with time and following through.

13. What has proved the most helpful?

There was a huge variety of responses both anecdotally and from the survey. This is unsurprising as EDS/HSD symptoms are so varied and every one's experience is unique however some themes did emerge. Adaptive physical ongoing care from a variety of specialists and the importance of support, listening and mental health care. Having clinicians who take time and trouble with their patients. Heat for pain management and difficulty keeping warm is also a recurring theme.

14. What has proved the most unhelpful?

Patients report so many horror stories and traumatic experiences that it's hard to summarise. Some themes did however emerge. There were many reports of lack of clinical expertise resulting in inappropriate treatment and advice. Clinicians not adapting to the individual person and their circumstances, making inaccurate assumptions, not respecting or listening to patients. Clinicians not keeping up to date with current understanding of the EDS conditions, comorbidities, treatments and many adopting a 'one size fits all' approach. It is clear that when EDS/HSD patients get the wrong advice or treatment a lot of damage is done both physically and psychologically.

15. Were you asked about and informed about possible comorbidities or accompanying health issues? HYPERLINK "https://www.ehlers-danlos.org/what-is-eds/information-on-eds/conditions-linked-to-eds/"

On the whole but not exclusively people were not informed or only provided with very limited information.

16. Are you familiar with any of these comorbidities of EDS

It seems that EDS/HSD patients do a lot of research and find information out for themselves. However this impression is almost certainly skewed as people who respond to surveys or requests for interviews and discussions are obviously a more proactive selection of the relevant cohort.

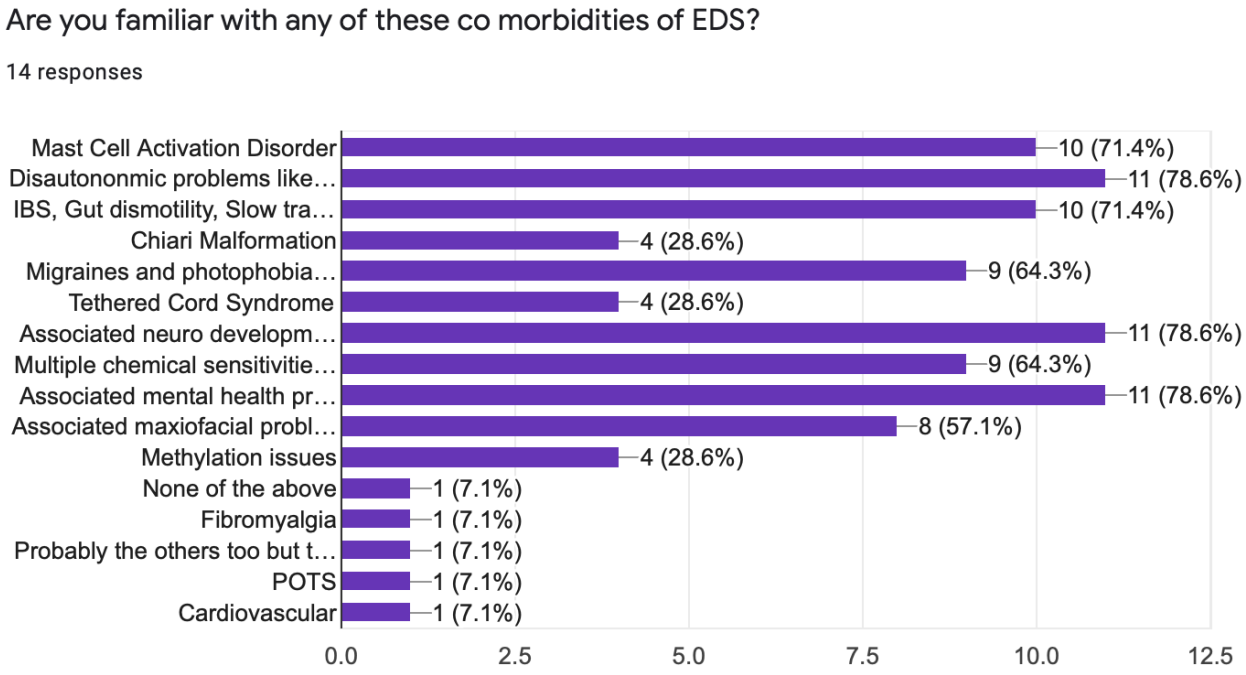

Fig 7: Sorcha Jewell (2021-22) Bar chart taken from patient, family and friends. survey.

17. What do you wish you had known sooner?

Again there was a lot of varying responses with some emerging themes. Most people felt that a comprehensive explanation of EDS/HSD and the accompanying comorbidities that they could access at the time of diagnosis and going forward would have helped enormously. Clinicians traditionally tend to err on the side of limiting information sharing apparently based on the misguided belief that patients will be unable to cope, where as most patients seem to feel forewarned is forearmed. Patients repeatedly expressed the opinion that if they knew what was going on in their own bodies they could care for them better. Overly optimistic predictions were found to be especially damaging and difficult for patients to cope with.

18. Do you ever find it is too hard to engage with physical therapy?(PT)

Most respondents and EDS/HSD patients did report difficulty engaging with physical therapy. Many people said it was because of pain, exhaustion, injury, fear of injury and not seeing benefit. Depression and overwhelm were also factors as was feeling fed up with being instructed by clinicians that 'don't get it' or were just handing out inappropriate instruction. All respondents felt there were obstacles when engaging with physical therapy. Not knowing how it could be beneficial and safe was a recurring theme.

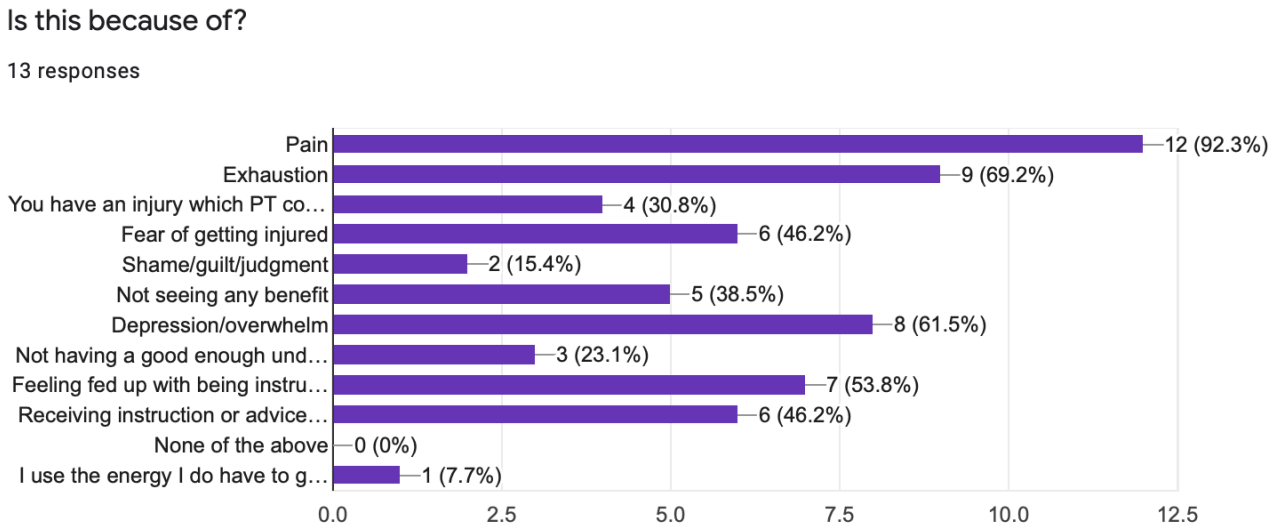

Fig 8: Sorcha Jewell (2021-22) Bar chart taken from patient, family and friends survey.

Options partly obscured on bar chart;

"You have an injury which PT could make worse or would irritate.

Not having a good enough understanding of exactly what helps and why

Feeling fed up with being instructed by people who don't 'get it'

Receiving instruction or advice which is inappropriate or even counterproductive"

19. What information do you feel would be most helpful and/or empowering?

Respondents and many of the wider EDS/HSD community feel that greater understanding of their condition and support with pain reduction would be most helpful. Support from others who struggle with the same problems and finding out what helps them. Recurring themes were in depth A&P understanding of EDS, it's comorbidities and an in depth understanding of the consequences of faulty collagen. Having up to date information and clinicians who are au fait with new developments. They want to be heard, understood and believed.

20. Where do you get your most useful information.

Most respondents and people I spoke with said they got their most useful information from other people with EDS/HSD. Either friends or family or via specialist patient groups and charities. Some patients said from the top specialists in the field. Most found out about them from other patients or via the patient groups online.

21. Could physical anatomical models of EDS/HSD joints and tissues that illustrate the differences between EDS/HSD and 'normal' ones help you to decide how PT might help? (please see bellow for example)

There was an almost universal 'yes' apart from one 'possibly'

They did feel the models could be useful and one person said they already use anatomical models to good effect. They confirmed the need for joined up care, specialist multidisciplinary teams and for far easier access to them. They also confirmed the need for more EDS/HSD education and the need for ongoing appropriate care rather than crisis management

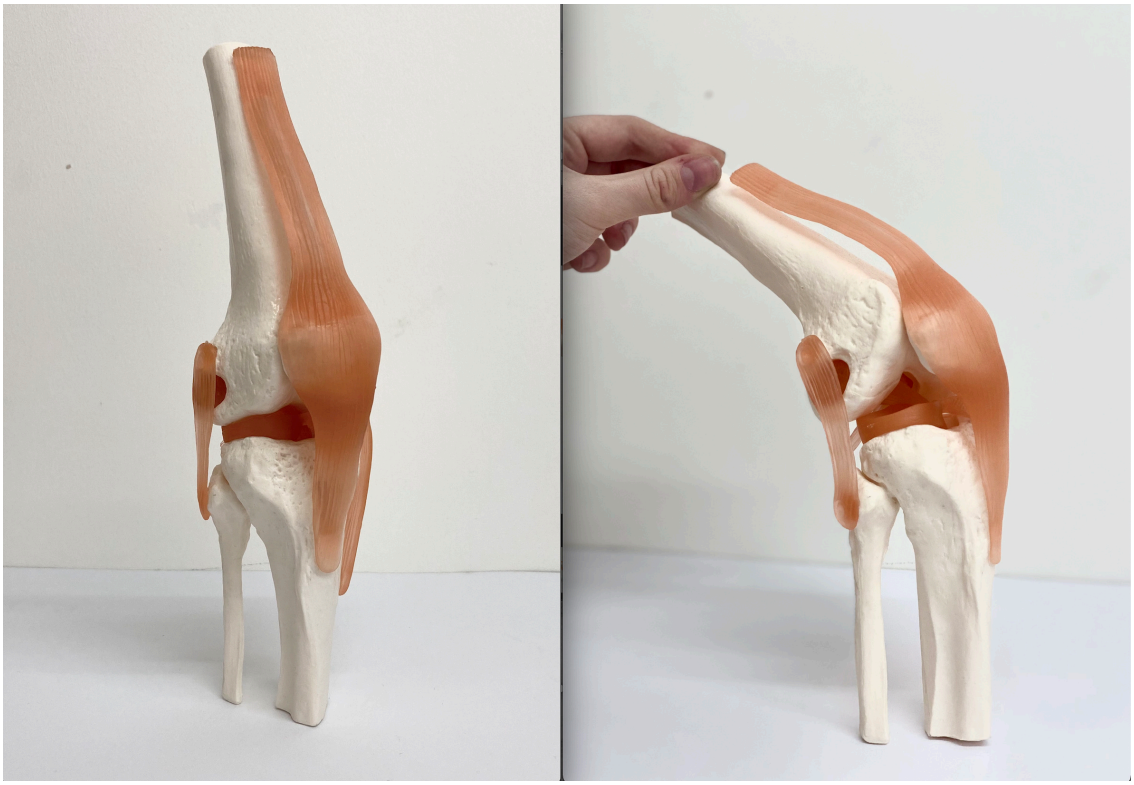

Fig 9: Sorcha Jewell (2021) Example of commercially available anatomical model of a knee joint

22. Might models be useful in deciding exactly what could help and how to adapt your therapy to your individual situation?

Nearly everyone said 'yes' with the odd 'possibly' response. Many respondents gave answers which support the observation that having kinaesthetically designed models would help anchor the information they were designed to illustrate.

For the second survey aimed at health care professionals, I wanted to understand their knowledge of EDS/HSD both currently and what was provided during their medical training. I asked if they felt their patients were able to engage with treatments, what they consider most helpful and unhelpful for patients and if they think that anatomical interactive sculptures demonstrating issues relevant to EDS/HSD would be useful.

Although I have discussed much of these matters to greater or lesser extents with lots of clinicians over the years only three of the survey respondents were relevant clinicians. However

they were three enormously experienced specialists whose input is therefore particularly significant and I am very grateful that they took the time and trouble at such short notice.

They did feel the models could be useful and one person said they already use anatomical models to good effect. They confirmed the need for joined up care, regional specialist multidisciplinary teams and for far easier access to them. They also confirmed the need for more EDS/HSD education and the need for ongoing appropriate care rather than crisis management

(For the full list of questions and answers please see Appendix B)

What supports or undermines patient agency?

An in depth understanding of the A&P involved in EDS could be described as health literacy which is an essential component of patient agency. The American Affordable Health Act defines health literacy as "the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions." (American Federal Government, 2010)

Patient agency could be described as the ability to make well informed decisions around our own care that are respected and acted on in a timely and supportive manner. 'People with long-term conditions are managing their health on a daily basis, but they may need additional help to develop their confidence in fulfilling their role as a self-manager.' (Coulter, A. Dixon, A. Roberts, S. 2013) When discussing patient agency it is necessary to understand what patients feel sabotages it.

In an interview with Jane (not real name) who was newly diagnosed with EDS/HSD in 2019, she described 'wanting to give up' her assigned physiotherapy program. This followed finding out that

she would not receive any actual 'in person' or even online physiotherapy. The combination of no contact with a physiotherapist and having a chronic hip injury, meant she felt unsure about continuing the program and was afraid it would aggravate matters and cause further injury. Without this essential initial support right after diagnosis and insufficient knowledge about her condition, she had no way of adapting and tailoring her program in order to safely continue it. Two years later she still has persistent hip problems and has recently felt her only option is to go to a private physiotherapist to receive the support she so badly needs.

The majority of respondents to the first survey reported experiencing overwhelm, depression and fear. (Fig 6) This not only supports all the anecdotal reports but goes some way to explaining the enormous resistance both patient and clinicians experience when realising that managing EDS is a life long commitment. Patient agency is clearly affected by how they are able to engage with the abject. Facing the reality of having an incurable condition that will need constant lifelong management and adjustment that will effect your quality of life is incredibly overwhelming. There is a long tradition of representing the abject in fine art. Perhaps as artists we can also help break up the abject into more manageable pieces?

None of the survey respondents felt they were provided with sufficient information, most not receiving any relevant literature or instruction where to find it. EDS/HSD patients frequently report that they feel undermined, disbelieved and discouraged as the people closest to them and often clinicians who they rely on don't understand the condition or what treatment involves. A more thorough understanding of how physiotherapy works, the potential draw backs, the compromises and the potential benefits would result in more realistic and achievable goals.

Anthony Gormley's Clearing VII (2004-19) is a good example of an artwork providing useful insight by confronting people with the abject reality of something stressful and exhausting in a

playful and engaging manner. Clearing VII first appears as an overwhelming maze of lines which is not passable and is definitely not accessible. However this changes as you walk through these huge structures of inch thick wire steel that weave all around the room. In methodically moving into the space you find more accessible openings in order to fully experience the piece. Climbing through it and interacting with it, there was no way to not touch it because you had to be aware of your surroundings in order to not fall over. The aim seemed to be to pull one into the present by coercing a sense of physical hyperawareness. The work was about experiencing being human through being present and being in the moment more than it was about observing the art.

Fig 10: Antony Gormley, Clearing VII (2004-19)

As 'EDSer', a term commonly used by those of us with EDS, there was a particular take I gained from the work as I have to navigate the world through this lens all the time anyway. I have to be hyper aware of my body in order to not injure myself. By making that self-awareness part of the work I didn't feel like I was constantly fighting to keep my concentration on the art because my body was a part of it. Able-bodied people can gain insight into how it feels to have to constantly be aware of your body in order to avoid injury. The exhibition catalogue described the work as a 'field that involves an effort of the whole body as you push past or step through, parting the swaying coils that tremble to the touch'. (Caiger-Smith, 2019). This interpretation of Gormley's

piece speaks to how an artwork can explain a complex and invisible experience felt by so many disabled people in a way that is subtle and nuanced.

Is 3D sculpture potentially the most effective way of increasing A&P literacy in the EDS/HSD community?

Interactive sculpture is indicated as potentially very helpful as such a large number of EDS/HSD patients are also neurodivergent. This is a rapidly growing but still very new area of research. Consultant Psychiatrist, the nationally recognised ADHD specialist and training director Dr Kustow, founding member of UKAAN (UK Adult ADHD Network) talks about the

“Increasing body of evidence that ADHD prevalence is significantly higher in those with EDS/JHS Kustow. J, 2020). in his recent presentation to the Ehlers Danlos Society.

This supports the need to make an explanatory tool that is as accessible as possible to the different ways in which EDSers learn. A physical interactive model that employs kinaesthetic methods of demonstrating the biomechanics involved would be the most inclusive and fastest way of sharing the relevant information.

What is Kinaesthetic Learning.

“Kinesthetics is the study of touch, space, and motion. Kinaesthetic learning, then, is learning through touch, space, and motion or learning by physically doing. [...] Kinaesthetic learning is a type of active learning that uses body movements with a hands-on approach. The cerebellum is much more active with motor movements involved in kinaesthetic learning.” (Craig, 2003)

“Kinesthetic learning is very brain compatible because of the high amount of sensory input that occurs.” (Craig, 2003)

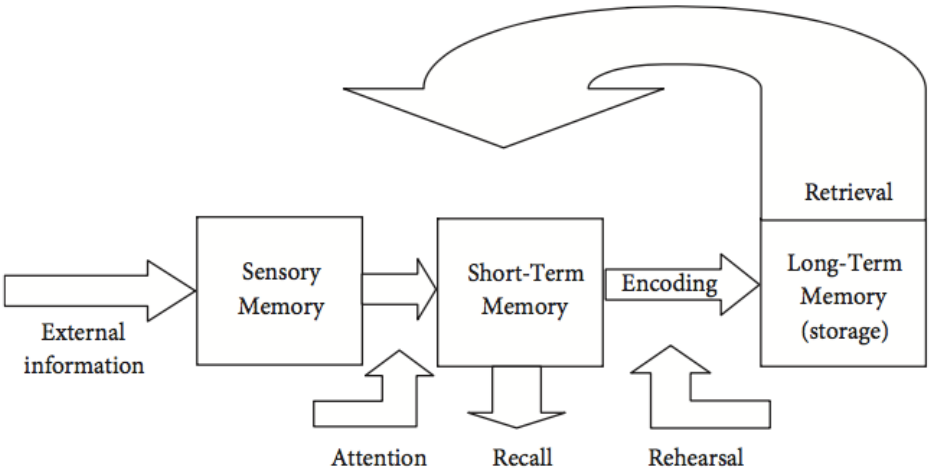

Fig 11: Richard C. Atkinson and Richard M. Shiffrin. The modal model of memory (1968)

In a healthy functioning brain memory storage works in stages. An experience containing information is initially processed in the sensory memory. This has all the 'detail and richness' of the experience but only for a short period, 'no more than three or four seconds' (Sutton, J. Harris, C. & Barnier, A. 2010) Most of the sensory information is lost after this. The information that receives attention from us is passed into the short-term memory, which usually lasts between 15 and 20 seconds. The information can then be 'encoded' into the long-term memory. The process of becoming permanently anchored happens through 'rehearsal' or action and recall of the information. The information stored in the long-term memory can be recalled into the future, years after the original experience. Accurate, functioning 3D interactive models could successfully incorporate all three learning styles, but could be considered particularly appropriate for Kinaesthetic learners. Whilst many EDSers describe themselves as Kinaesthetic learners, most people still also use visual and auditory queues as well.

Francis Wells uses patient's blood, surgical implements and the sterile paper they come wrapped in to give an 'instant replay' of his surgical procedures to his students while they're waiting for the patients heart to resume normal rhythm. (BBC, 2005) This visceral, tactile recalling

of the techniques used during surgery undoubtably helps anchor the information in the long-term memory for both Wells and his students.

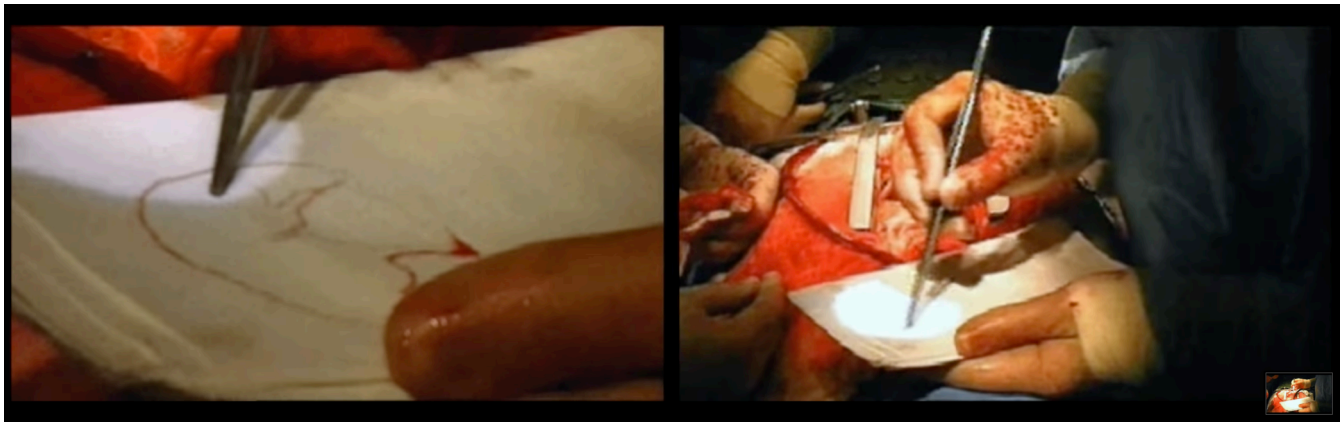

Fig 12 & 13: Stills from the BBC series "The Secret of Drawing" Episode 1: "The Line of Enquiry" (2005)

There are alternative ways people learn and research suggests that most people retain information most successfully if kinaesthetic methods are involved in their learning process. The anecdotal stories, reports and survey answers all confirm the need for these methods.(Craig, 2003)

In a follow up seminar after diagnosis Jane reported she was given a large amount of information on EDS/HSD in the form of a presentation by a physiotherapist. While she felt it was very helpful during the seminar, afterwards she stated that she wasn't able to retain the majority of the information "I couldn't remember most of it due to my struggling neurodivergent brain" "The delivery didn't feel accessible, I left in a state of information overload"

EDS/HSD often presents and is subsequently diagnosed during puberty (8-13 years) as symptoms can become more seriously disabling at this time due to hormone changes and rapid growth. This age group often learn engage through exciting play. (Conklin, H. 2015) It is an age

where there is often fascination with the body especially anything gory or going wrong. I remember at that age playing with anatomical models and having races to see who could complete them fastest. Organisations like Techniquest who use interactive models and create group kinaesthetic experiences are particular popular with children who report remembering the lessons learnt in great detail.

Fig 14: BBC, Image of Techniquest Cardiff taken from 'Techniquest in Cardiff: Fears for future after budget cut' article. (2016)

One of the most memorable pieces that clearly demonstrates the effectiveness of kinaesthetic education is an institutional installation that can be seen as an artwork. In the Volcanoes and Earthquakes gallery of the Natural History Museum there is one display that everyone wants to linger on. As you walk through the displays and diagrams of tectonic plates and molten lava there is an interior of a Japanese supermarket. Nestled in amongst the bread and soup there are monitors showing CCTV recordings of the moment when the magnitude 9 earthquake struck Japan in 2011. As you stand in this supermarket the floor starts jerking from side to side. The walls start wobbling and you can hear objects being thrust off the shelves and hitting the floor. As the onlooker physically experiences some of the recreated physical sensations and sees and

hears aspects of this multi-sensory installation the overall experience is lodged and anchored in a unique manner.

Fig 15: Natural History Museum, Earthquake Simulator (2014)

The Ware Collection of Blaschka Glass Models of Plants are another example of how 3D models have been used in education. Created from 1886 through to 1936 by Leopold (1822-1895) and Rudolf Blaschka (1857-1939) for Harvard Professor George Lincoln Goodale as educational models to aid him when teaching botany to students. While they were already using 3D models, these were 'crude papier-mâché or wax models' where as the glass models were able to provide a level of remarkable anatomical accuracy and detail unparalleled at the time. 'Since the Glass Flowers are always in bloom, tropical and temperate species may be studied year-round;' providing constant access to a complete 3D view of these plants. (Hmnh.harvard.edu. n.d) These glass models are not only practical but are stunning artworks now seen as 'one of Harvard University's most famous treasures' an 'internationally acclaimed' collection, with the Harvard Museum of Natural history offering paid tours of the recently renovated gallery space containing the models. (Hmnh.harvard.edu. n.d.)

Fig 16 & 17: Leopold and Rudolf Blaschka, Ware Collection of Blaschka Glass Models of Plants (1886-1939)

How could anatomical and physiological understanding improve treatment outcomes?

Physiotherapy is currently recognised as the mainstay of most treatment programs offered. This seeks to primarily strengthen muscles in order to stabilise the joints. (Rahman, A. Daniel, C. Grahame, R. 2014) Patients are often given the impression or even actually told out right that doing the physiotherapy will get rid of the pain. This can lead to enormous disappointment and mistrust when the pain either increases or doesn't abate. The vast majority of EDS/HSD patients report that, whilst there are many benefits to physical therapy and that it is an essential aspect of managing this condition, it does not reduce pain. Many report that it can be counterproductive and increase pain levels. (Fig 8) Stabilising joints and increasing strength can hugely improve stamina, fatigue levels and quality of life long term but it can also often increase pain as the EDSer is moving more. This commonly repeated misrepresentation has a huge effect on the EDSer's feelings towards physiotherapy and their view of the effectiveness of it. For example I felt extremely discouraged after having religiously followed my prescribed daily physiotherapy

program following an intense rehabilitation course at Great Ormond Street Hospital and found my pain levels weren't improving at all. Whilst my joints and strength did benefit resulting in fewer dislocations and increased stamina the increased pain meant I lost faith with physiotherapy until much later when I really understood why it was beneficial to me. This is a recurrent situation reported by many EDS patients many of whom give up physical therapy entirely as they have only ever experienced the draw backs and never the benefits. This can and often does result in a general decline in function as a result of de conditioning further exacerbating the patients misery. Hence this project's emphasis on exploring ways to support physical therapy.

Pain was cited as a recurring issue for patients. Unexplained increases in pain can be particularly frightening if you are being told it should be decreasing by the clinician treating you. It is easy to feel you are failing and getting it wrong. EDSers talk about feeling defeated and depressed if compliance with a program is having the opposite outcome from the one predicted. Pain is a complex neurological response and research indicates that communication and greater understanding plays a significant part in its reduction. (Henry, S. and Matthias, M. 2018) EDSers report that understanding their particular A&P significantly reduces fear and the damaging effects of pain.

Historically anatomical models have always been a vital part of medical training for doctors as has learning anatomy using the physical interaction of cadaver dissection. For some reason this essential aspect of interactive learning has seldom made the leap to doctors using it to teach patients. There is a huge variety of anatomical teaching models available including models designed to illustrate and explain various commonly encountered pathologies however I cannot find any illustrating collagen disorders. The models I am proposing could potentially include joints with ligaments and tendons which are detachable and or replaceable in order that they could be

interacted with. The tendons and ligaments could even be broken by each patient and then replaced for the next person. Hopefully this would support the patient with understanding the mechanics of how and why their joint is fragile and how muscle strengthening could help. It could illustrate for example how slow steady movement is safe where a jerky movement could tear fibres. This could also allow for comparison where normal tendons could be attached followed by EDS tendons so patients can see how movement and strength is affected.

Conclusion

The information gathered supports the need for physical models which are interactive such as the proposed anatomical sculptures. This would support enhanced health literacy, greater anatomical and physiological understanding and lead to improved patient agency with better informed decision making. There is evidence to show that the models could be useful both in a clinical setting and as tools to inform families and friends. EDSers repeatedly reported needing a greater understanding of the anatomical consequences of faulty collagen particularly at the point of diagnosis. Patients report needing the painful truth with frank and realistic information sharing accompanied by appropriate negotiated mental health support. There is convincing evidence of artists already representing complex information in ways that are authentic and accessible. Artists have a particular set of skills and experience both materially and conceptually which they can use to create the desired objects.

This greater understanding of the A&P particular to EDS/HSD is needed and would benefit patients and clinicians. It has become apparent that these models and accompanying A&P information would need to be repeatedly accessed over time partly to mitigate the effects of information and emotional overwhelm. Understanding seems to be an unfolding and evolving process both for the patients and their families. Having easy access to the models could also

help EDS/HSD patients explain the issues they face in order to negotiate the adaptations and accommodation they require. Ultimately having this understanding of why they are in pain could make living with EDS/HSD far less daunting and frightening.

List of illustrations

Fig 13: Stills from television program - The Secret of Drawing Episode 1: The Line of Enquiry (2005) BBC 2, 8th March

Fig 14: Image of Techniquest Cardiff taken from 'Techniquest in Cardiff: Fears for future after budget cut' article. BBC (2016)

Fig 15:, Earthquake Simulator, Natural History Museum (2014) Mixed Media

Fig 16: Ware Collection of Blaschka Glass Models of Plants, Leopold and Rudolf Blaschka, (1886-1939) Glass. Hmnh.harvard.edu. [online] Available at: <https://hmnh.harvard.edu/glass-flowers> [Accessed 18 January 2022].

Fig 17: Ware Collection of Blaschka Glass Models of Plants, Leopold and Rudolf Blaschka (1886-1939) Glass. Hmnh.harvard.edu. [online] Available at: <https://hmnh.harvard.edu/glass-flowers> [Accessed 18 January 2022].

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Appendix

Questionnaires

Appendix A: Questionnaire sent out to patients, their families and friends.

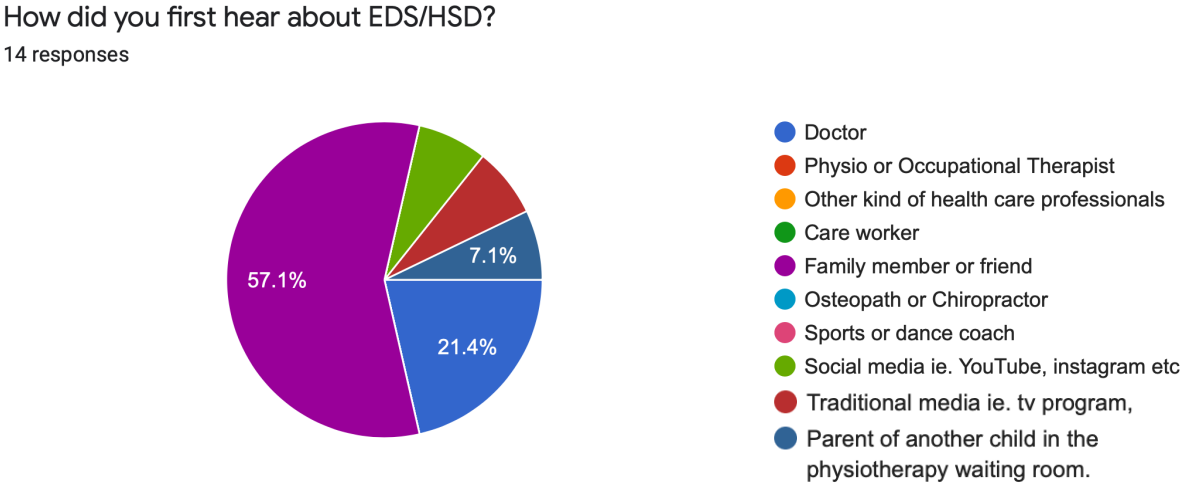
Ehlers Danlos Syndrome/Hypermobility Spectrum Disorder - patients and their families and friends experiences

I am an MA Art & Science student at Central St Martins UAL researching the experience of Ehlers Danlos Syndrome/Hypermobile Spectrum Disorder(EDS/HSD) patients and the experience of the health professionals supporting them. I am investigating the current support patients receive hoping to find ways to increase patient understanding and agency. As an EDSer myself with many of the accompanying co morbidities and over 15yrs in the system, I am particularly interested in investigating potential tools which could help communicate the relevant anatomy and physiology. These could potentially be particularly useful for those undergoing diagnosis and initial treatment.

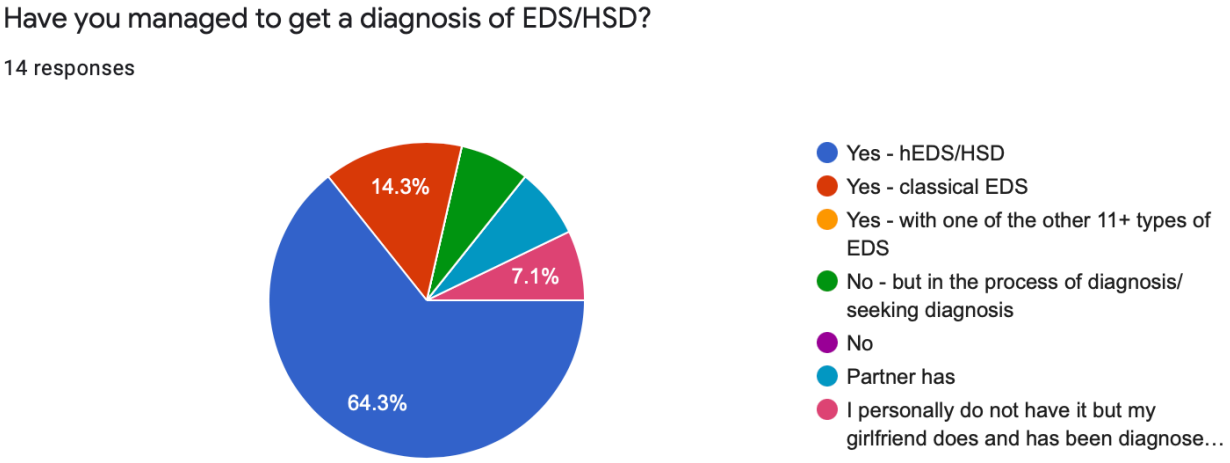
All responses and information provided will be kept confidential and anonymous.

If you would like to know more about me and my work here is where you can find me
Website - sorchajewell.com
Email - sorchajewell@gmail.com
Instagram - @sorchajewell

1. How did you first hear about EDS/HSD



2. Have you managed to get a diagnosis of EDS/HSD?



3. Were you informed of why you are in pain? (apart from 'your joints are too loose')

- Yes
- No
- No this was never explained to me
- Yes, I was told my collagen is weaker than others.
- Yes, first learned I was hypermobile when I was a teen, then in my mid twenties I started getting chronic pain/fatigue working a very physical job. Physiotherapist linked two.
- Sort of, it could've been explained more/better for sure
- We're give basic information that the ligaments weren't correct. Did more research on our own and doctor kept sending for tests. Later found out she also has fibromyalgia
- no
- I was very young, so I'm not sure. But for a while it was just called hip dysplasia
- I was told that I was in pain because my 'joints are too flexible for my muscles to support them'
- Not initially, the many varying clinicians have many varying explanations with equally varying degrees of accuracy.
- I don't think she was given a full explanation - just this general explanation, at least not until she investigated further herself personally

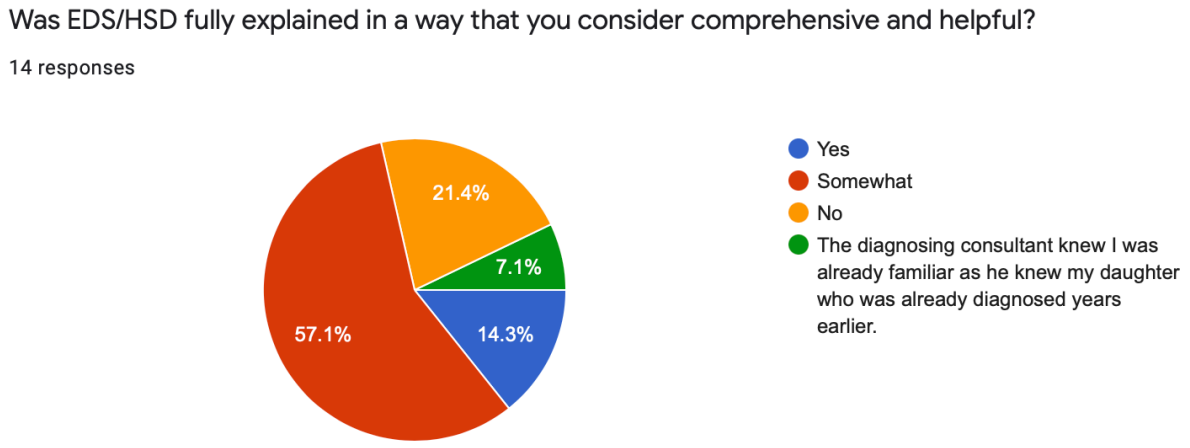
4. Do you feel you now have a good understanding of why you are in pain?

- Yes
- A better one but I would struggle to explain to someone else
- Not really, as I believe I may have other underlying conditions.
- I have a better understanding, but as I don't have a full diagnosis yet I feel that more answers will come.
- After speaking to a friend who knows a lot (lol you) as well as doing some of my own research I know more. There's still a lot I could understand better though
- somewhat
- No
- Somewhat
- Not fully
- As good as is possible given the available science.
- Reasonable.
- Yes she does - but as mentioned this is only because she has had some of the best doctors in the world (for the condition) and a great deal of self study

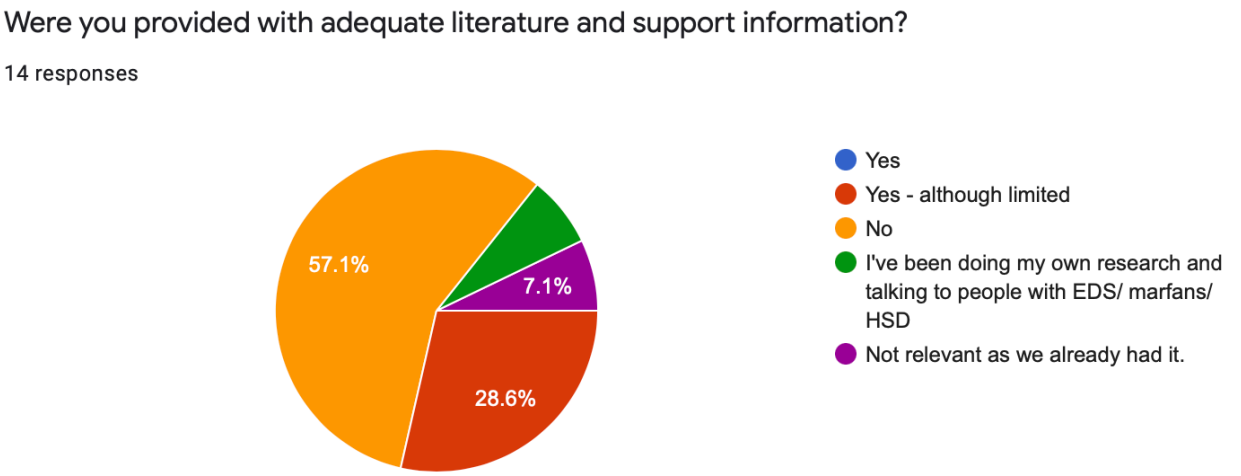
5. How long was it between the start of your health problems and receiving what you consider to be an accurate diagnosis?

- About 5 years
- About 2-ish years. Hard to tell
- No diagnosis yet, currently on a two year waitlist for genetic testing.
- I've always had health problems but they got a lot worse about 5-6 years ago. So either about 4 years or my whole life?
- Around a year until EDS diagnosis, another half a year before diagnosed with fibromyalgia. Think this was very much hampered by the COVID pandemic
- 9 years
- fifty years
- I had hip issues right from birth and got a diagnosis around 9 or 10 years old
- Been experiencing pain since I was a young child, and wasn't diagnosed till I was 29/30
- It took about two years from the onset of joint pain to a diagnosis of EDS. However I think that today there is a possibility I'd be diagnosed with HSD (the diagnosis didn't exist when I was diagnosed) since a lot of what seemed to indicate EDS (eg stomach problems) were explained by another condition
- A couple of years.
- About 30 years but that was partly because I was given another diagnosis so I stopped pursuing it.
- She was diagnosed quite young but even so I think it was years of her childhood before being fully diagnosed.

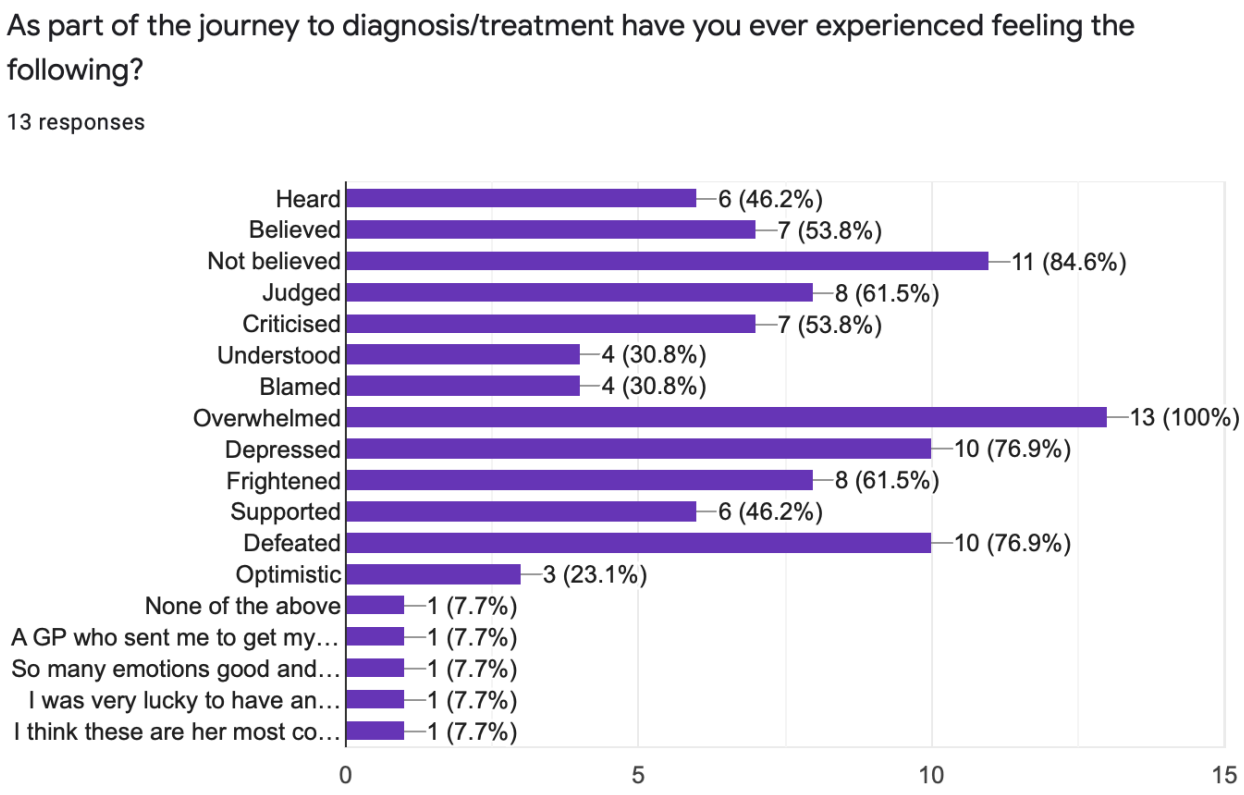
6. Was EDS/HSD fully explained in a way that you consider comprehensive and helpful?



7. Were you provided with adequate literature and support information?



8. As part of the journey to diagnosis treatment have you ever experienced the following?

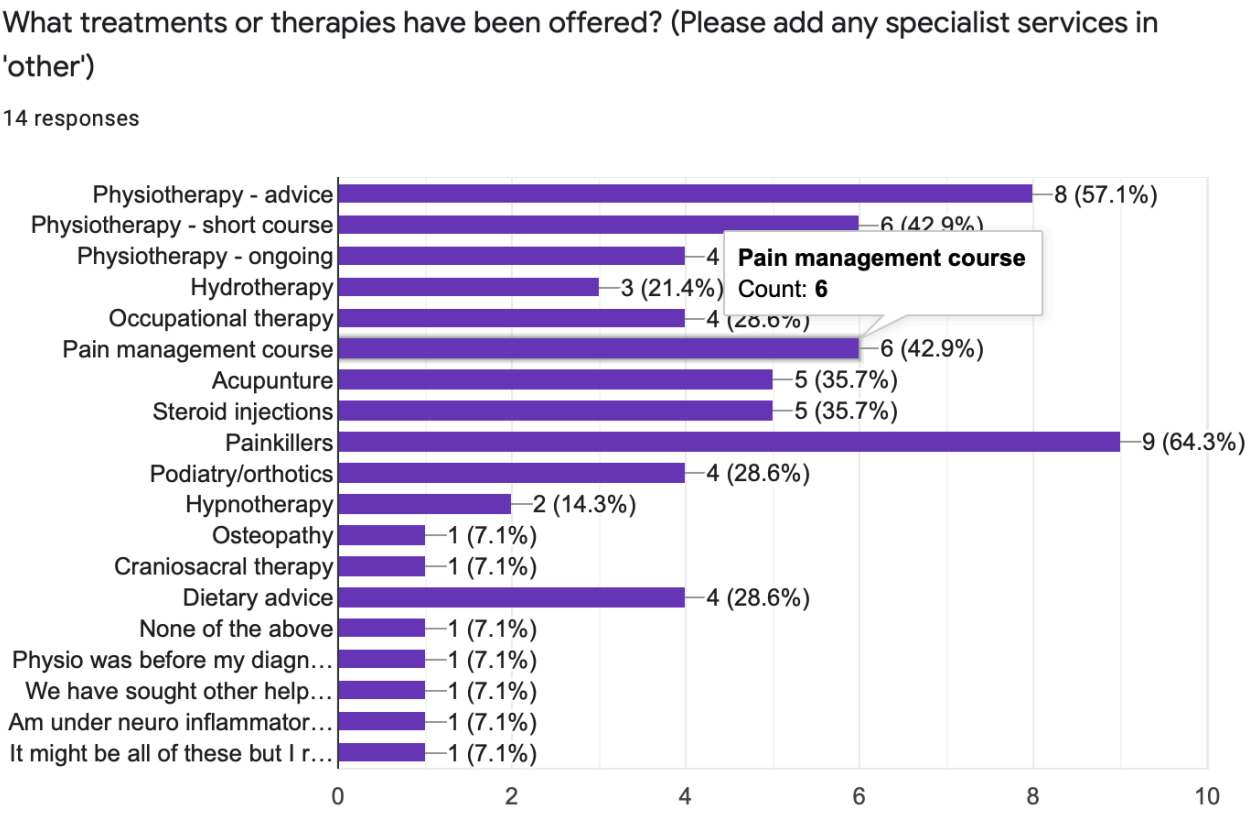


9. Following diagnosis/treatment has there been an improvement in your condition? If so how?

- Not really, I grew out of certain pains but I was refused rehab programs after my diagnosis so no improvement in my physical condition
- No improvement

- Just started using braces which has helped a lot and just started some physio exercises but will have to see how they help.
- Other than I know about certain things to avoid doing, and understanding sometimes I need to rest, no improvement, probably due to no actual treatment
- No, deterioration. Diagnosis of fibromyalgia followed and covid pandemic made things worse as they rarely leave the house now. My partner needed physio but all the appointments were on phone, absolutely useless and told her she was in too much pain to work with. Left her in a massive depression and not wanting to access help again. We have since gone to a private physio and had better results.
- She now walks with a stick, struggles with overall pain, especially back pain. Can't walk very far anymore. Doesn't leave the house much and struggles with daily tasks like showering and cleaning.
- No
- no
- I have had an operation to help my hips, but other than that no treatment. Currently my GP is helping me get back into the system as my pain is getting worse
- Somewhat. I'm on a medication, physical therapy, massage therapy routine that helps keeps things at bay, but never gives me a single day of relief.
- It improved without intervention as I got older, and although I'm still very flexible with lower muscle tone than most people of my size and activity level, I don't have daily joint pain anymore
- Yes, once we knew what we were dealing with we were better able to seek appropriate help and also the official diagnosis passported us to more help. It also helps with educational support and disability benefits.
- Yes, I can ask for particular considerations such as particular types of anaesthesia and be believed. This helps at the dentist and for operations. My physios who treat me for multiple sclerosis now factor in the EDS issues and adapt the exercises. My very wonderful NHS wheelchair was specially made taking into account the joint problems too.
- Yes and no. She had extremely bad digestive issues and still does but she manages them with Sodium Picosulphate and eating schedules that ensure she is able to digest. This seems to have improved for her in general but I think this is due to the managment and not the condition easing off. Otherwise muscle/skelatal issue continue - as the observer its hard for me to tell if this is worse or better than in the past but it seems to generall fluctuate depending on a multitude of things ranging from: tiredness/fatigue, hormones, outside stimulants (sound/light/smell/touch/heat/cold etc) as well as other things like mental state such as depression and anxiety. Anything and everything effects EDS since it is intrinsically and genetically connected to the structure of every cell in the body. Thus her EDS symptoms are particularly dependant on her mental and physical wellbeing.

10. What treatments or therapies have been offered? (Please add any specialist services in



11. What treatments or therapies were provided by EDS/HSD specialists?

- None I don't think
- No applicable, haven't seen a specialist yet
- The course thing I was supposed to do which offered some of these things couldn't properly go ahead due to covid. So instead I got videos, and two group zoom consultations
- Haha. That's funny. None
- Physical therapy and occupational therapy
- none
- None
- Physio after my operations
- PT and pain management only
- I was given physiotherapist exercises to complete daily
- Some were and some weren't. Often it was the clinicians willingness to listen and find out things that mattered most.
- None but I can go back to consultant if need be.
- I think the pain management course was one of the main ones, or at least of of the more memorable/truamatising treatments

12. What do you consider you need more of?

- Information, easy ways to understand & be able to explain what's going on on the inside, physio and rehabilitation techniques
- I need more understanding from people, mainly parents and certain peers.

- I need to see a geneticist for now. Probably more accommodation at work.
- Can I say everything? Physio I think is the most important for me. Also maybe just help and information
- Everything. She needs support in the house, mobility aids are expensive and we can't afford them. Painkillers don't hit her anymore. She hasn't had physio on the NHS in person we have to pay for it. She would hugely benefit from hydrotherapy but it's no offered here. She's interested in the pain management course but the waiting list is huge and services greatly reduced due to COVID. Unlikely to have in person support, exercises and massage that she desperately needs.
- Pain management methods
- warmth, scared of losing heat due to £££
- Longer lasting treatments, more support throughout life
- Need more knowledge around cardiology and a quicker reduction of pain. I want to function
- Education on managing chronic illness (which I was never given) and mental health support for the psychological aspects of stigma against physical disabilities
- Access to specialist ongoing regular physiotherapy and hydrotherapy. We need specialists who are clinically up to date, are willing to listen properly and make decisions based on what they have heard rather than their own often inaccurate assumptions.
- Hydrotherapy, physiotherapy,
- Ongoing physio and psychotherapthy

13. What has proved the most helpful?

- Talking to people with the same condition for my mental health. Heat is the only thing that helps any of my pain
- Limiting exercise.
- Physiotherapy, my braces, and having a friend with a diagnosis
- Chiropractor
- Massage and she's reccently tried TENs machine and that's helped her a lot.
- Family support
- heat and exercise
- Not much
- Constant physical therapy 2-3 times a week, dry needling, and massage therapy in combination with meds
- Physiotherapy and ageing
- Physiotherapy from specialists. Some highly skilled and motivated individual clinicians, patient groups consisting of highly skilled patients who are in contact with specialists from all over the world.
- My fantastic supportive and clever GP's, my amazing physio who listens and also finds stuff out, the forward thinking consultants who have pioneered new understandings and listen to their patients, the patient groups who share their extensive knowledge and experience . All the information I collected over the many years that my daughter has needed care.
- Physio I think

14. What has proved the most unhelpful?

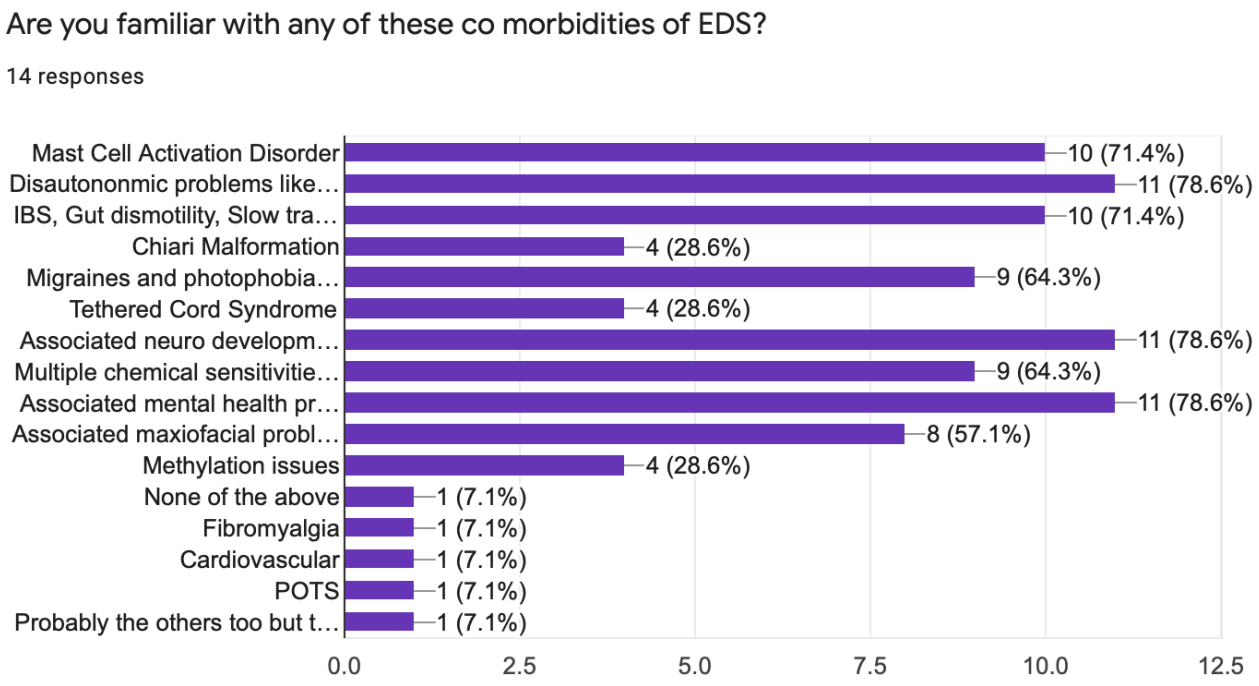
- Arrogant & ignorant doctors // peoples opinion on my disability
- Trying to build muscle strength through exercise, causing more pain.

- There's been a lot of nay sayers. I am hypermobile in some areas but I don't pass the Brighton scale so it appears to be normal.
- Not getting the help I was promised
- Throwing opioids at the situation until her tolerance went up. Also telling her she needs to improve her mental health
- Doctors who are unaware of EDS
- physio as it never goes on long enough
- Some doctors knowing nothing about EDS
- Acupuncture and dietary changes
- I was given a crutch when I dislocated my knee, which actually made the entire rest of my body worse
- Clinicians who are not up to date, who don't listen properly, clinicians who don't communicate efficiently and clinicians who generalise rather than adapting strategies and treatments to individuals and individual circumstances.
- Not being able to access physio and hydro. Clinicians who either don't listen, don't keep up to date or think they know better than the actual specialists and are unwilling to learn.
- I think the pain therapy clinic was actually very detrimental in that it actually cuased lasting damage to the body by forcing the confrontation of pain rather than manageing it in a healthy way.

15. Were you asked about and informed about possible co morbidities or accompanying health issues? - https://www.ehlers-danlos.org/what-is-eds/information-on-eds/conditions-linked-to-eds/

- Yes when I was diagnosed I was also tested for pots at the same time. No mention of MCAS or anything else though which I have later found out that I do have
- Somewhat.
- I already knew some were common due to my own research
- Just chronic fatigue
- She was warned that fibromyalgia can also be common alongside it. Not the others
- Somewhat
- no
- No
- Yes
- No
- No we had to find out the hard way. A group called the Elephant Project consisting of highly knowledgeable patients and the Canadian Mastocytosis society and some of the international consultants were most informative.
- Not relevant as already knew most of them.
- I think she knew of some but I don't think she was told all of it from the start.

16. Are you familiar with any of these co morbidities of EDS?



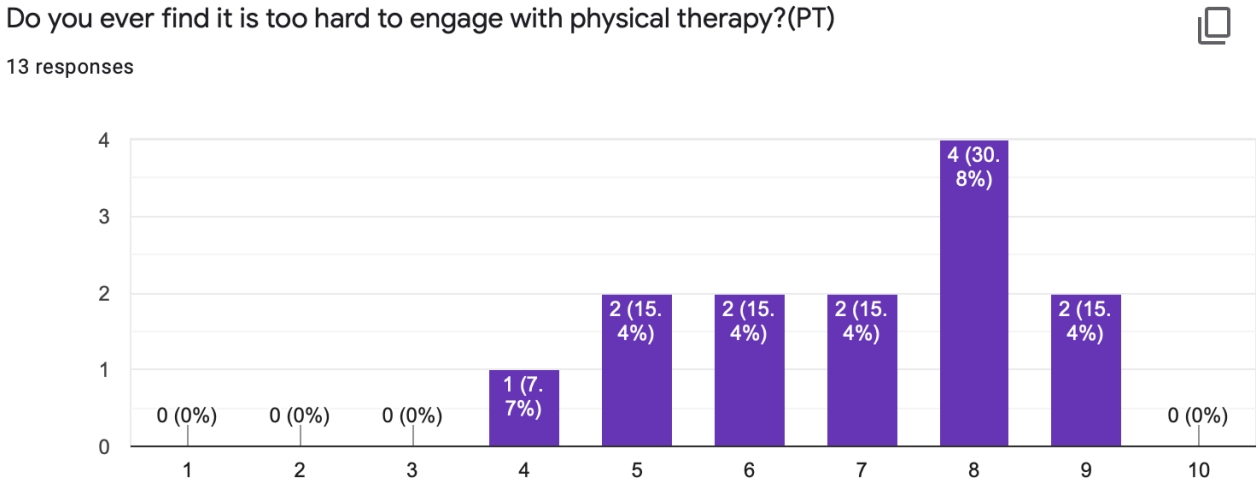
Options obscured by bar chart
Disautononmic problems like POTs, flushing, syncope, vertigo etc
IBS, Gut dismotility, Slow transit and gastrointestinal complications of EDS/HSD
Migraines and photophobia and visual disturbance
Associated neuro development disorders, for example ASD, ADHD, ADD?
Multiple chemical sensitivities, food and chemical intolerances and allergies
Associated mental health problems
Associated maxiofacial problems, dental problems and speech and language problems.

17. What do you wish you had known sooner?

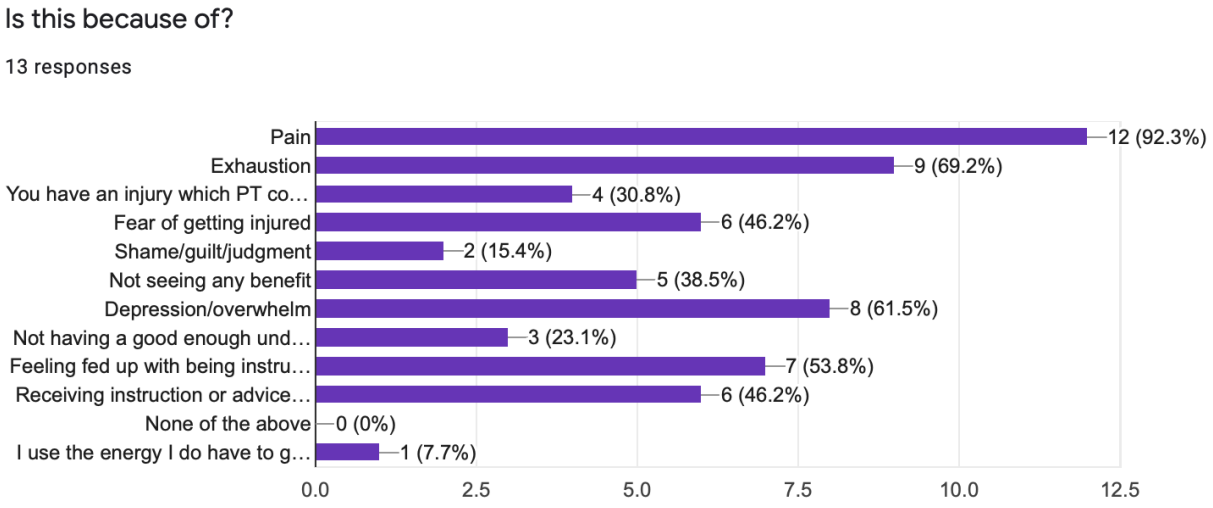
- Enough about what was going on / ways to explain it so I could explain properly to people/ doctors who just think I'm making it up and being lazy. Wish I could make a dr feel inferior by explaining what they don't know about eds in detail and make them feel uncomfortable for once lol
- I wish I had known how difficult it is to explain my issue to people, and I wish I had known that it will get worse.
- That the hypermobility was going to be an issue. I was told it in passing so I never thought much of it until I was already in pain.
- 100%
- I wish she had known sooner so we could have had a chance to do more exercises and keep her strength up. Instead doctors really got her down and depressed and she no longer wanted to do anything due to pain and depression with her diagnosis.
- Quality of life when symptoms worsen
- that I had the condition
- About the other Co morbidities associated
- I wish I had known why I was always in pain sooner and as least set my body up for success years earlier. As we age, things only get worse and harder to maintain an even platform.

- The links with ASD - I was diagnosed in my late 20s (after several people throughout my life had suggested I may be on the autism spectrum). If I'd known it was correlated with EDS I'd have probably been diagnosed much younger
- Knowledge of the possible co morbidities would have saved months even years of suffering and potentially less residual damage and disability.
- That I had EDS!! Would have made managing my life easier.
- I think the biggest one for her is ADHD, if she'd know this sooner she could have had it treated with ongoing medacine much sooner.

18. Do you ever find it is too hard to engage with physical therapy?(PT)
    Scale of 1to 10 - 1 meaning never 10 meaning every time



19. Is this because of?



Options obscured by bar chart

You have an injury which PT could make worse or would irritate
Not having a good enough understanding of exactly what helps and why
Feeling fed up with being instructed by people who don't 'get it'
Receiving instruction or advice which is inappropriate or even counterproductive.

20. What information do you feel would be most helpful and/or empowering?

- In depth but easy to understand sculptures/cards or just explanations not just for other people but so I can actually understand what my body is doing and why
- Information from people who have EDS/HSD on how they best manage their condition.
- Feeling heard and being told that the doctors will find out what's wrong.
- Not even sure where to begin
- Support from others who struggle with the same thing and what helped them
- You are your best advocate
- EDS specific exercise that's fun
- Having someone actually understand and help
- Things you can do at home to help reduce pain
- Information on the types of accommodations that can be made in workplaces and learning environments, and how to advocate for yourself to get those out in place. I was constantly pushed to neglect my needs and try to be 'just like everyone else' and it made my condition worse
- Knowing how the connective tissue is different and the subsequent consequences with a view to adapting physical therapy appropriately. Having a better understanding of how to manage the pain and fatigue and how to keep fit without injury. Access to knowledge specialists. Comprehensive current access to relevant research. Not via social media.
- Recent research is starting to look at some of the common denominators such as methylation issues, the effects of defective collagen and the differences in the subsequent anatomical brain and tissue development. This is fascinating and I would like to know more.
- An exhaustive list of the possible side effects and related conditions that EDS can give someone. And a visual representation being it a poster/book/model of what each of these things looks like or feels like when in relation to your own body so you can know 'why' it happens and why it may hurt or make you tired

21. Where do you get your most useful information?

- Susie & Sorcha Jewell
- Medical articles, and people on EDS/HSD forums.
- My physiotherapist and my friend with EDS
- You :') (which is silly because it's not your job)
- From friends with similar conditions. A friend with cerabal palsy has reccomended some good treatments and what to expect
- The Ehlers-Danlos Syndrome Foundation Website/medical journals
- from friends
- Various Internet sites
- EDS site or Instagram EDS posts
- I actually got the most useful information first from my friend who told me my joint issues could be EDS (she had a diagnosis herself and noticed a lot of similarities). I think other people I meet who have EDS often have the most useful information
- The elephant project, EDS and MCAS charities and support organisations, pub med and various research organisations, individual consultants, Prof Seneviratne, Prof L Afrin, Prof Graham, local specialist physios, Fragile Links, friends who are scientists with relevant knowledge.

- Specialist consultants, physios, OT's patient organisations, and research scientists but most of all....other patients.
- Probably the EDS UK website - at least thats how I read about it first and I think friends have started there too

22. Could physical anatomical models of EDS/HSD joints and tissues that illustrate the differences between EDS/HSD and 'normal' ones help you to decide how PT might help? (please see bellow for example)

- Yes
- Yes I think they'd be very useful
- Possibly
- Maybe, but my minor was biology so I think I understand anatomy already fairly well. (I might not be the target audience)
- YES. The only person who does this is my chiropractor, I find it extremely helpful. But would be great if there were specific models for EDS/HSD
- Absolutely
- definitely
- Absolutely! I'm a kinesthetic learner and seeing what is 'supposed to be' and what is would help my engineering mind better adjust to different scenarios.
- Yes, after having several scans and check-ups to figure out why a knee joint was so painful I couldn't walk on it, a doctor actually took some some objects and used them to show what was happening to my knee when I put pressure on it, why it was causing pain, and what exercises I should and shouldn't do, and it really stuck with me!
- Yes. Especially in those first years when my daughter was a child in terrible pain and so very ill. We could have adapted appropriately and she would have understood more about why she was being encouraged to engage with what must have felt like pointless torture.
- Yes, manipulating models informs my body and brain together this helping me to imagine ideas that just my brain alone wouldn't have come up with.
- Yes definitely

23. Might models be useful in deciding exactly what could help and how to adapt your therapy to your individual situation?

- Yes
- Definitely
- Yeah
- Perhaps!
- I believe so
- My partner often doesn't know when she's over flexing until I tell her to stop. I think having the chance to see what she's doing from a medical standpoint would benifit her hugely
- possibly
- Back, knee, neck, arms and fingers
- Yes, really useful.
- Yes, same reason as above.
- Very - it can go a long way to explain visually what is happening.

Appendix B: Questionnaire sent out to health professionals.

Ehlers Danlos Syndrome/ Hypermobility Spectrum Disorder - Health professionals experiences

I am an MA Art & Science student at Central St Martins UAL researching the experience of Ehlers Danlos Syndrome/Hypermobile Spectrum Disorder(EDS/HSD) patients and the experience of the health professionals supporting them. I am investigating the current support patients receive hoping to find ways to increase patient understand and agency. As an EDSer myself with many of the accompanying co morbidities and over 15yrs in the system, I am particularly interested in investigating potential tools which could help communicate the relevant anatomy and physiology. These could potentially be particularly useful for those undergoing diagnosis and initial treatment.

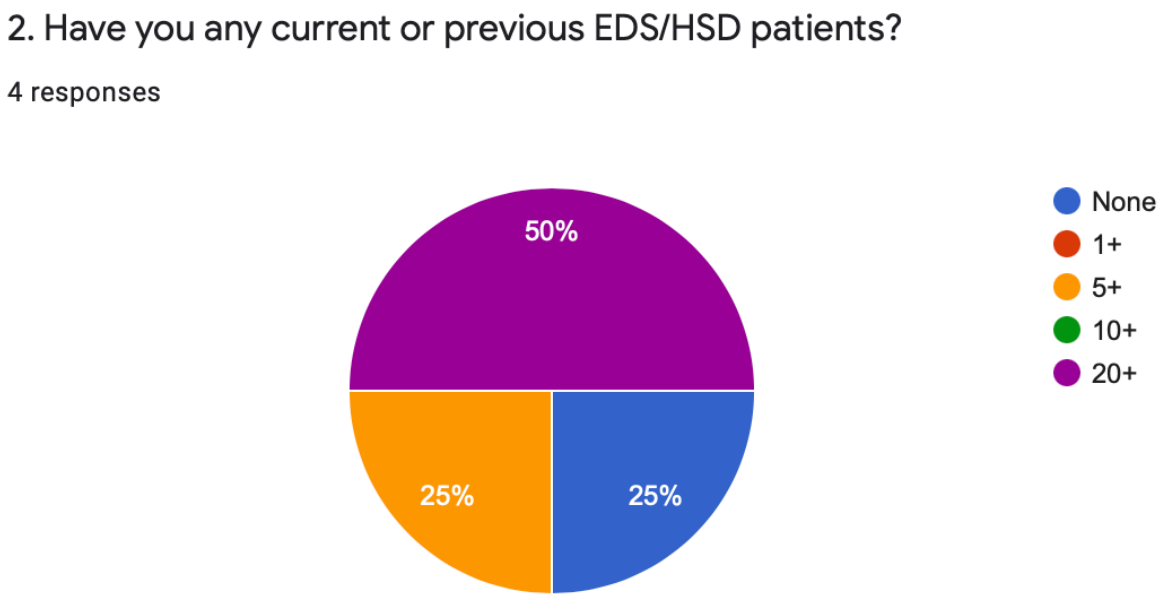
All responses and information provided will be kept confidential and anonymous.

If you would like to know more about me and my work here is where you can find me
Website - sorchajewell.com
Email - sorchajewell@gmail.com
Instagram - @sorchajewell

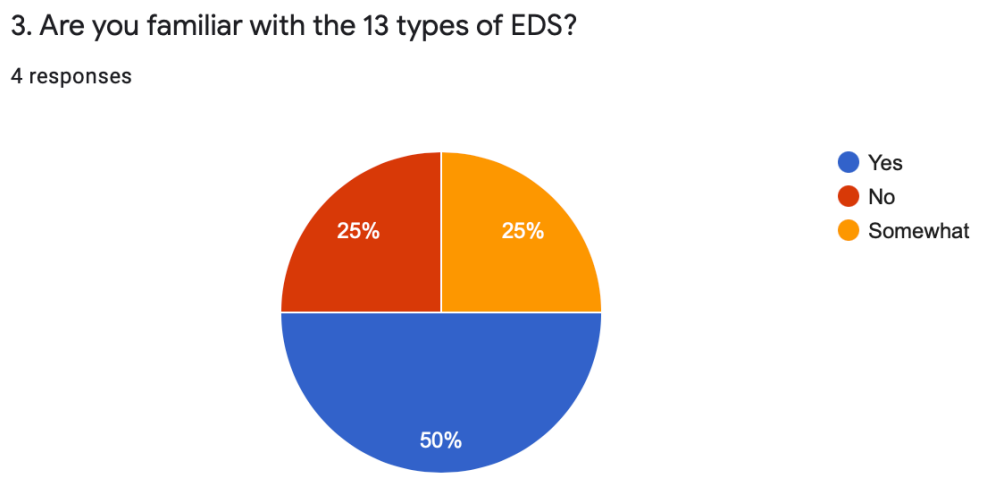
1. What is your profession?

- General Manager Print Company
- Doctor
- Paediatric Physiotherapist
- Paediatrician

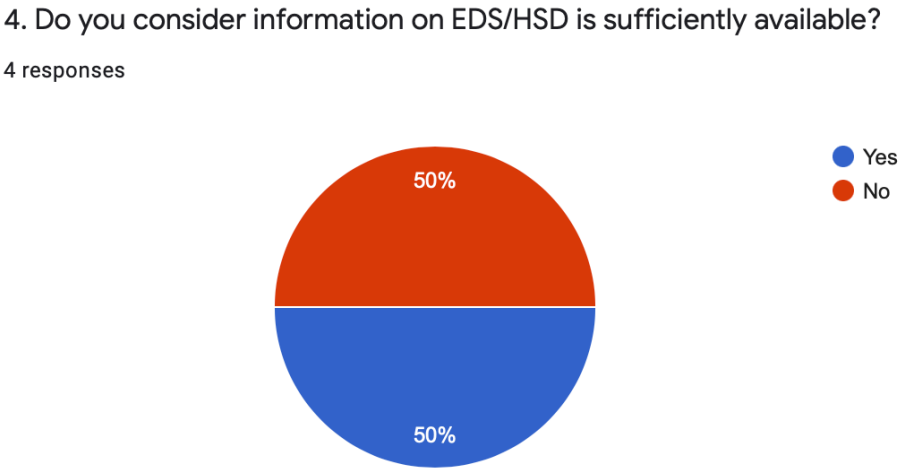
2. Have you any current or previous EDS/HSD patients?



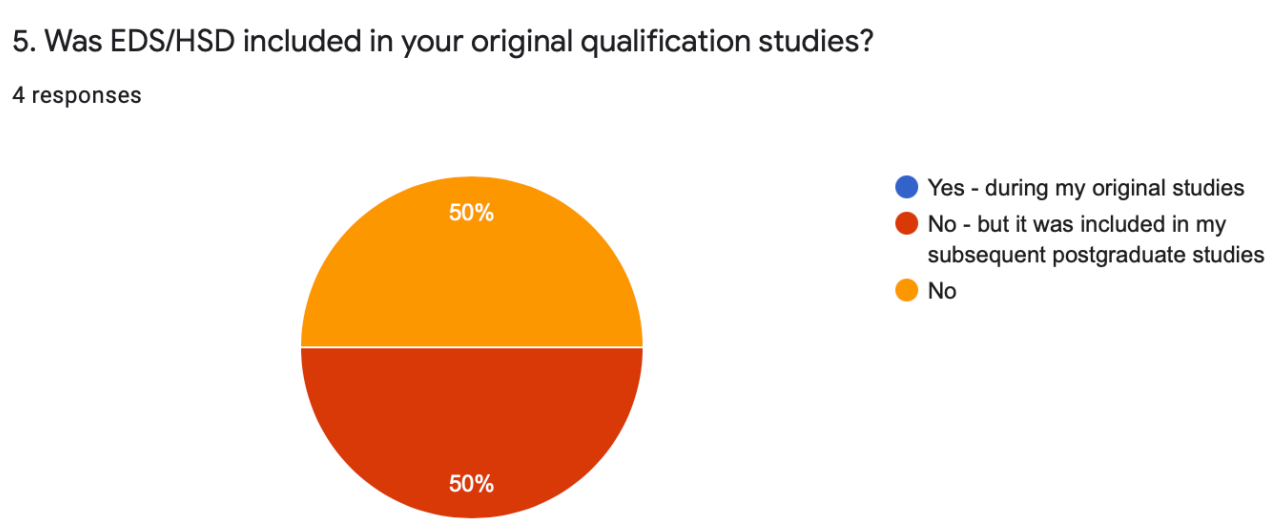
3. Are you familiar with the 13 types of EDS?



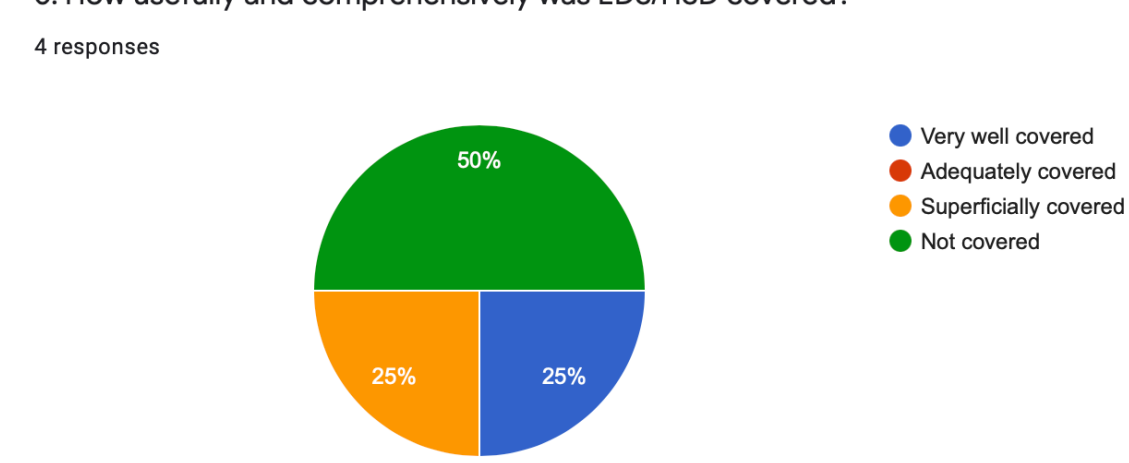
4. Do you consider information on EDS/HSD is sufficiently available?



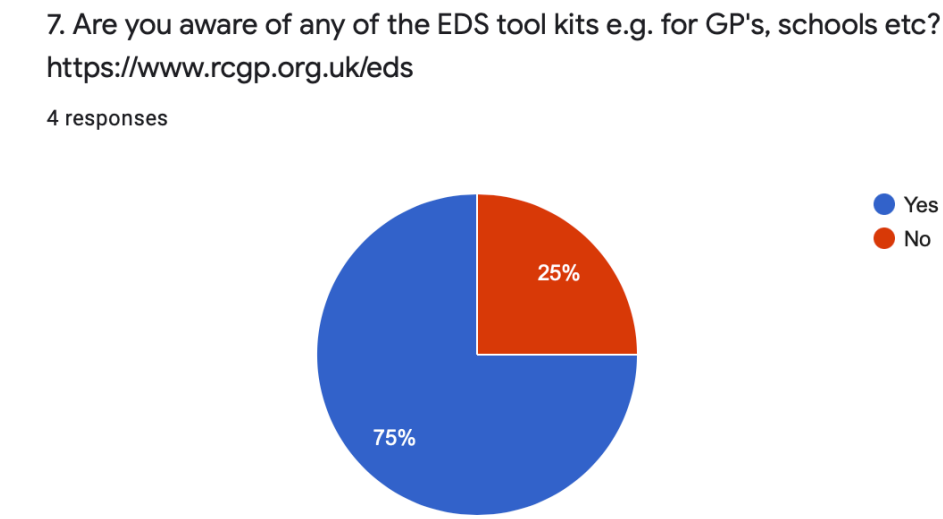
5. Was EDS/HSD included in your original qualification studies?



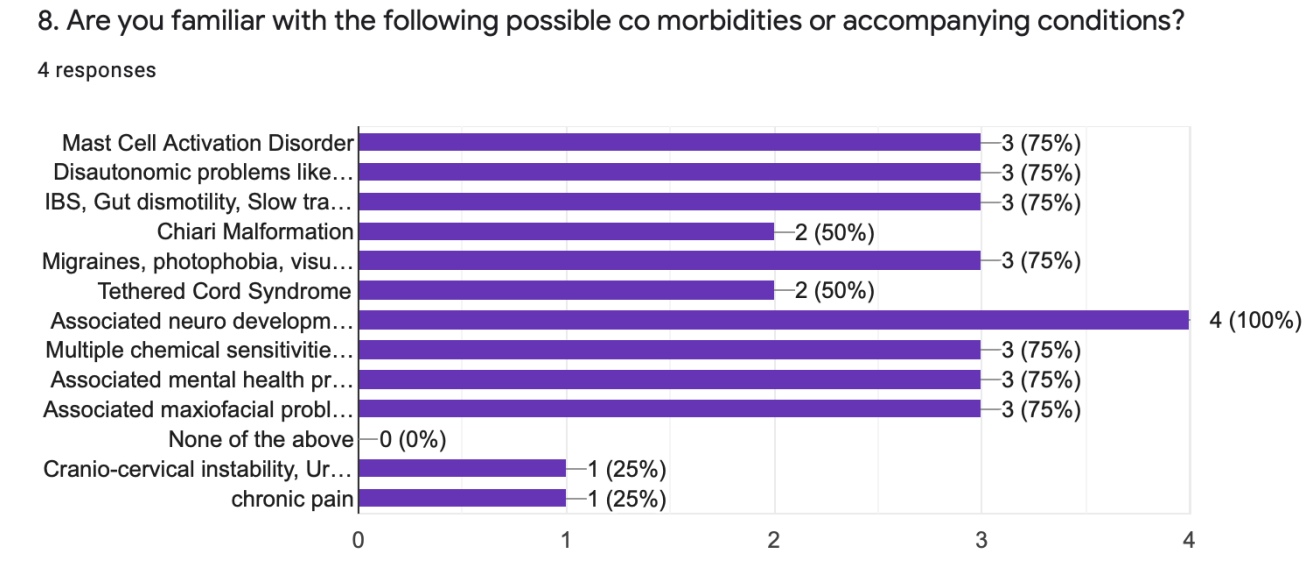
6. How usefully and comprehensively was EDS/HSD covered?



7. Are you aware of any of the EDS tool kits e.g. for GP's, schools etc? "https://www.rcgp.org.uk/eds" https://www.rcgp.org.uk/eds



8. Are you familiar with the following possible co morbidities or accompanying conditions?



Options obscured by bar chart

- Disautonomic problems like POTs, flushing, Syncope, vertigo etc
- IBS, Gut dismotility, Slow transit and gastrointestinal complications of EDS/HSD
- Migraines, photophobia, visual disturbance and opthalmic problems
- Associated neuro development disorders, for example ASD, ADHD, ADD
- Multiple chemical sensitivities, food and chemical intolerances and allergies
- Associated mental health problems
- Associated maxiofacial problems, dental problems and speech and language problems
- Cranio-cervical instability, Urological

9. Do you feel that your EDS/HSD patients are able to fully engage with prescribed or suggested treatments, therapies and support?

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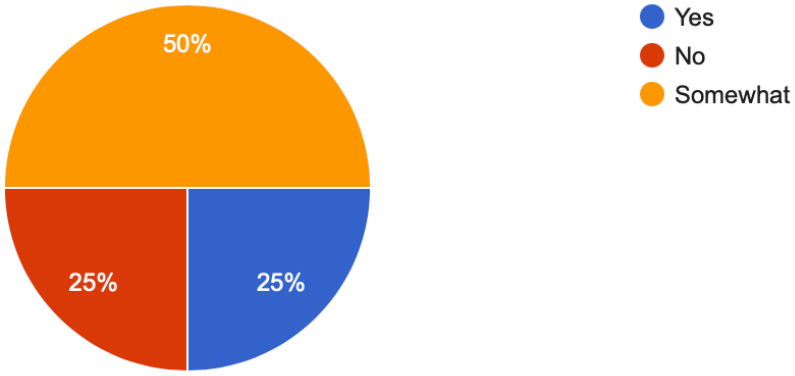
4 responses



10. What do you consider most helpful?

- An MDT team including (but not limited to) physiotherapists, psychologist, paediatrician , pain team , patient/ family support groups
- Access to hydrotherapy pool
- Analgesics, Physical therapies, and Comorbidity treatments can all improve outcomes

11. What do you consider most unhelpful?

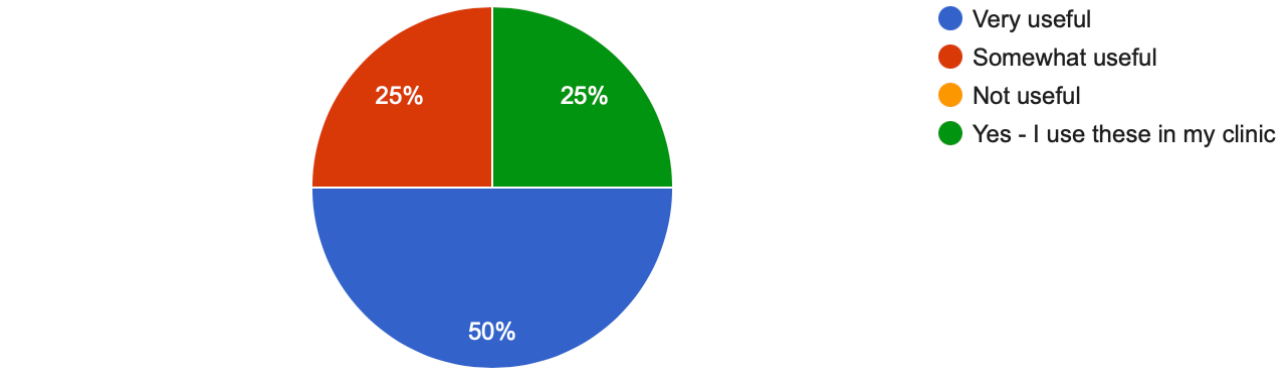
- Lack of knowledge generally about co- morbidities. Lack of access to professionals.
- Lack of mental health input for this patient group
- anti-depressants either as mood stabilisers or neuropathic analgesics

12. What do you consider is most needed to help your patients?

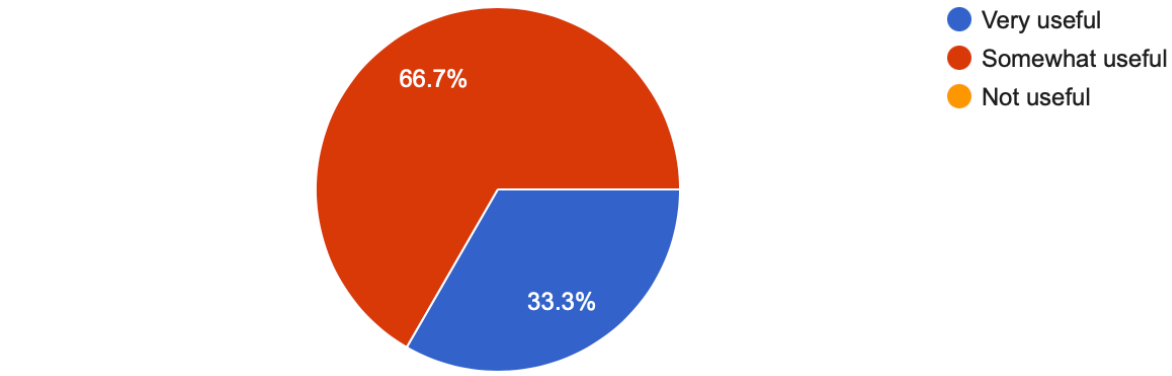
- Improved resources- primarily personnel (psychology and chronic pain services particularly)
- Multidisciplinary clinics in NHS for diagnosis and treatment
- Properly integrated local / regional MDT

13. Would physical models demonstrating the anatomical issues relevant to EDS/HSD be a useful addition to explaining the following?

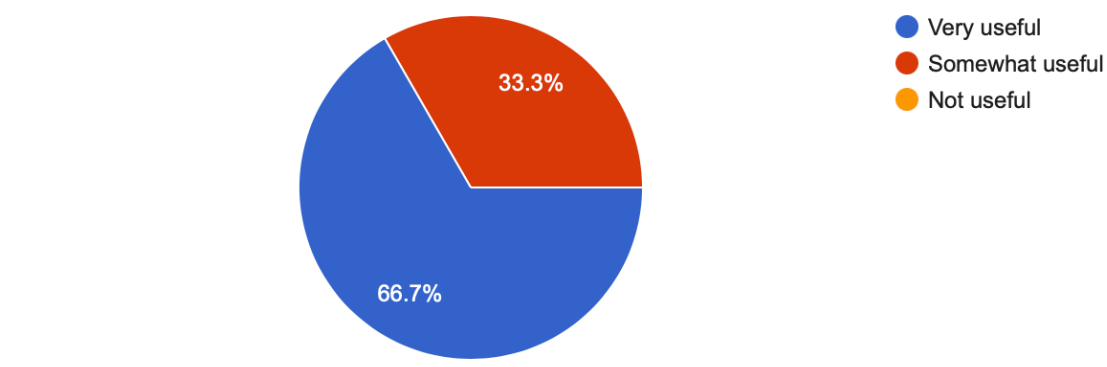
13.a. Explaining what is happening physically?



13.b. Explaining what is causing pain?



13.c. Explaining how therapy can help?



13.d. Supporting patients with engaging with therapy?

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3 responses