Feedback on Health and Social Care Services from Adults with Hypermobility Syndromes across Yorkshire and the Humber

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Our work at a glance

This project was a collaborative piece of work by local Healthwatch across Yorkshire and the Humber. It was led by Healthwatch Calderdale and included:

Healthwatch Barnsley

Healthwatch Bradford

Healthwatch Calderdale

Healthwatch Doncaster

Healthwatch East Riding of Yorkshire

Healthwatch Kingston upon Hull

Healthwatch Kirklees

Healthwatch Leeds

Healthwatch North Lincolnshire

Healthwatch North East Lincolnshire

Healthwatch North Yorkshire

Healthwatch Rotherham

Healthwatch Sheffield

Healthwatch Wakefield

Healthwatch York

OUR WORK
at a glance

What was the issue?	Healthwatch Calderdale began to hear of difficult NHS and social care experiences from adults with hypermobility syndromes. These experiences were from people residing either in Calderdale or further afield. As a result, it was decided that Healthwatch Calderdale would lead a collaborative piece of work with all local Healthwatch across Yorkshire and the Humber to collect feedback from adults with hypermobility syndrome across the entire region.
What did we do?	We ran three focus groups in February 2018 where we asked adults with hypermobility syndromes about their NHS and social care experiences. Themes from the focus groups were then used to compile a survey, which was open from early August 2018 until the end of October 2018.
What did we find?	The majority of the responses we received related to NHS care. We heard many examples of difficulties in NHS care specifically regarding obtaining a diagnosis, referrals and waiting times, misdiagnosis, partial diagnosis or stereotyping, the reaction of health professionals to symptoms, communication between health professionals, the lack of knowledge among many health professionals regarding hypermobility syndromes and inadequate or lack of NHS care. We also heard some examples of good NHS care and suggestions from adults with hypermobility syndromes about what would make current care better. We heard from people about the significant life impacts of their NHS experience specifically the loss of employment, relationships, work/education, mental ill-health as well as the loss of function in the long-term. In terms of social care, people reported a lack of knowledge among professionals, which led to problems at needs assessments as well as cases of parents being wrongly accused of fabricating illness in their children.
How will we use people's feedback?	The findings from the surveys form the basis of this report which we will share with the public via our website. We will also be contacting various organisations representing health and social care services in Yorkshire and the Humber and nationally to ask them how they plan to address the issues identified.
Who will we contact?	• Primary and secondary care organisations across Yorkshire and Humber • Members of Parliament across Yorkshire and Humber • Members of Parliament/other professionals known to have an interest in hypermobility syndromes. • All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions • Ehlers-Danlos support UK (national charity) • Hypermobility Syndromes Association (national charity) • Postural Tachycardia Syndrome UK (national charity) • Association of Directors of Adult Social Services • Association of Directors of Children's Services • Healthwatch England • NHS England
How will we report service improvements?	We will publish the responses from the organisations alongside this report on our website: **https://www.healthwatchcalderdale.co.uk/our-work-4/hypermobility-syndromes-project** and follow up with the above named organisations at 3 and 6 months.

Foreword

This report is based on patient experiences. From the 183 people who have received a diagnosis, 141 (77.05%) reported that the process of obtaining the diagnosis was difficult or very difficult with 128 (69.95%) reporting the diagnostic process as leaving them with negative feelings about themselves, the NHS or certain medical professionals.

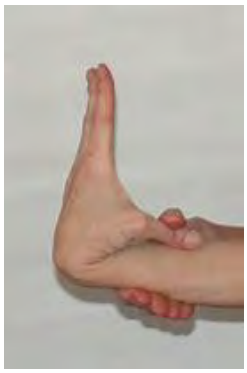
In the qualitative data analysis similar proportions of negative experiences were described by the participants.

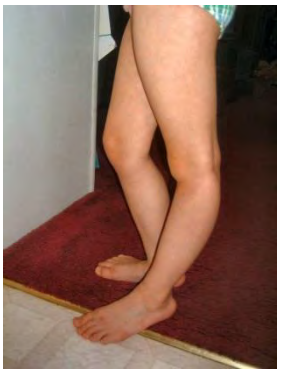
The report presents the results and the authors recognise such an overwhelmingly negative experience makes for difficult, if not, challenging reading. It is not our intention to be provocative or to hold any professionals to account. The aim of the report is to provide a starting point for developing and improving as many aspects of these NHS and social care experiences in the future.

Hypermobility

What is Hypermobility?

Hypermobility is the term used to describe the ability to move joints beyond the normal range of movement. Have a look at the photos showing hypermobility below:





Joint hypermobility is common in the general population, especially in childhood and adolescence, in females, and in people of Asian and African-Caribbean descent. In many people joint hypermobility is not problematic. It can even be a bonus, especially for sportsmen and women.

HOWEVER

This report is neither about athletes NOR party tricks. **It's about hypermobility linked to chronic ill-health. People who experience hypermobility with problematic and chronic symptoms can be described as having a hypermobility syndrome.**

Hypermobility Syndromes

Hypermobility syndromes refer to the group of conditions in which symptomatic-hypermobility is recognised as a common feature. The most common of these is Hypermobility Spectrum Disorder (HSD). Other conditions of hypermobility include heritable disorders of connective tissue such as the Ehlers-Danlos syndromes, Marfan syndrome, Osteogenesis Imperfecta and Stickler syndrome. Whilst these are all conditions in their own right, hypermobility syndromes are complex conditions frequently associated with co-morbidities which require multi-disciplinary health care teams for their diagnosis, treatment and management (Hypermobility Syndromes Association (HMSA), 2017).

It is not clear how many people in the United Kingdom are affected by hypermobility syndromes. Conditions of hypermobility are thought to be widespread though there is no up-to-date information regarding the exact frequency in which they occur. Hypermobile Ehlers-Danlos syndrome (hEDS), is thought to be the most common genetic connective tissue disorder (Ehlers Danlos Support UK (EDS UK, 2017). Hypermobility is often misdiagnosed as fibromyalgia,

osteoarthritis, seronegative arthropathy, psychogenic rheumatism, depression or chronic fatigue syndrome.

Why have we focussed on this issue?

Observations gathered by a Healthwatch Calderdale staff member at a Management and Wellbeing conference in September 2017, run by the charities HMSA and EDS UK, highlighted that health services for people with hypermobility syndromes are often disjointed with no clear pathway available. There were approximately 300 delegates from around the United Kingdom in attendance at this conference. Many of these people also reported that medical professionals often lacked knowledge about hypermobility syndromes, resulting in delayed diagnosis for many, a lack of access to appropriate treatments and poor health and social care experiences, which in turn impacted upon people's functionality and increased their psychological and social issues. Similar observations were collected by the same staff member in October 2017 at The Northern Patient Day run by the charity, Postural Tachycardia UK (PoTS UK) and EDS UK, which was attended by around ninety people.

Around the same time, Healthwatch Calderdale also began to hear from individuals with hypermobility syndromes via its signposting and NHS Complaints Advocacy services. These people wanted support in complaining about their NHS care for hypermobility and/or requested signposting advice on how to obtain a diagnosis. This feedback, together with the stories from people with hypermobility syndromes at the aforementioned events, prompted Healthwatch Calderdale to engage with people further on this subject. Given that Healthwatch Calderdale had heard from people both inside and outside its locality, it decided to engage more widely than in Calderdale on this matter. It has existing links with other local Healthwatch across Yorkshire and Humber so therefore asked all local Healthwatch across this area whether or not they would be interested in participating in a collaborative piece of work so as to collect feedback from adults with hypermobility syndromes across the entire region. All local Healthwatch across Yorkshire and the Humber agreed to participate in the project.

What did we do to investigate?

Focus groups

In February 2018, staff from Healthwatch Calderdale ran focus groups with members of EDS UK support groups in York (10 February 2018) and Leeds (24 February 2018) as well as with people from the PoTS UK support group in Sheffield (13 February 2018). The total number of focus group participants was 23.

Some of the focus groups were conducted face-to-face whilst others were run virtually since a number of members of these support groups were too unwell or unable to attend a focus group in person. Participants for the virtual groups were identified and recruited through the closed Facebook EDS UK Leeds group, as well as via support group coordinators.

Type of focus group	Number of participants
Face-to-face	14
Virtual	9

Table 1: Number of participants per focus group type

All these focus groups comprised participants with a diagnosis of one of the Ehlers-Danlos syndromes, other hypermobility syndromes or undiagnosed symptomatic hypermobility.

All focus group participants were asked the following questions:

- How long has it taken to get to diagnosis?
- What was the process?
- How does your experience make you feel?
- What is the life impact of your health/social care experience?
- What worked well in your health/social care journey
- What would have made your experience better?

The data from the focus groups was then thematically analysed and these themes were used to construct a survey.

Survey

The survey had five sections (see appendix 1 for full details), covering both health and social care experiences of adults with hypermobility syndromes:

A. Clinical background – about symptoms and diagnosis
B. Experience of getting a diagnosis
C. NHS experience
D. Social care experience
E. What worked well in participant's health/social care experience and what would have made the experience better

It was open for participants to complete online between the beginning of August 2018 and the end of October 2018. Participants also had the option of completing the survey over the telephone.

There was also an opportunity in the survey for participants to tell us anything else that they felt was relevant to their experience of their condition.

The survey was promoted on social media (Facebook, Twitter) by local Healthwatch across Yorkshire and the Humber. The charities EDS UK, the HMSA and PoTS UK also agreed to help the project reach more people affected by hypermobility syndromes by spreading the word about the project through their networks, specifically via;

- Social media
- E-newsletters
- Member's magazines (Fragile Links and the HMSA Journal - see appendix 2 for these articles)
- Closed Facebook groups
- Regional members' lists

A promotional video introducing the project also linked to the survey and this was also circulated by the local Healthwatch involved as well as by the aforementioned charities.

Analysing the data

In total, 252 questionnaires were returned to Healthwatch Calderdale. Of these, one respondent had not given consent to use their data or share the project's findings with other organisations. This response was therefore discarded.

Of the remaining 251 responses, 78% were from respondents with a formal diagnosis of a hypermobility syndrome, 14% were from participants with no formal diagnosis and 8% were from people who did not clarify whether or not they had a formal diagnosis.

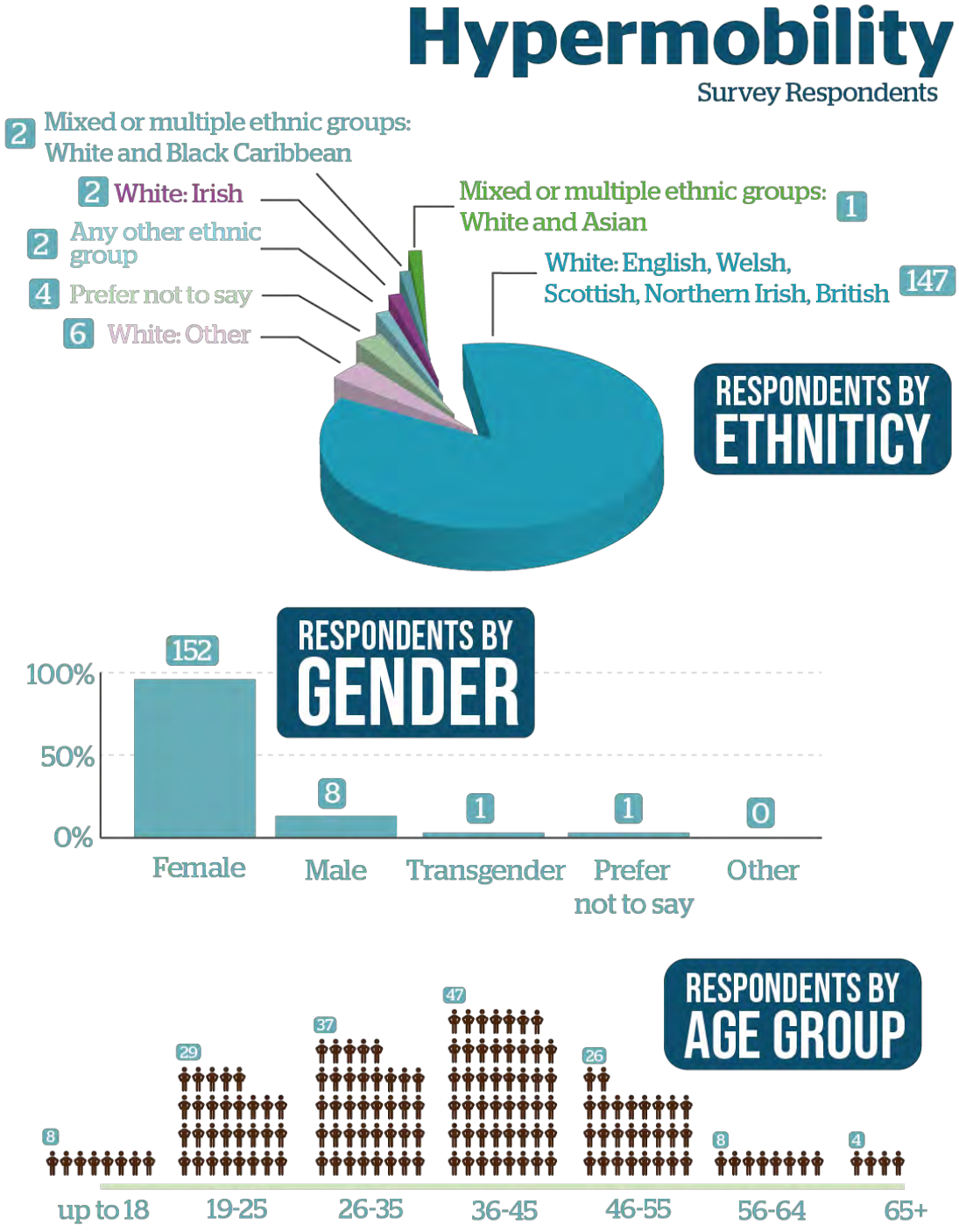
Sorting the data according to IP address identified 15 duplicate entries, arising most likely from errors and false starts. These were deleted from the main dataset. A total of 21 surveys were not fully completed. These were retained in the dataset. In total 236 surveys were completed partially or in full.

Data was analysed using the following software packages:

Software package used	Type of data
Microsoft Excel	Quantitative
QDA Miner Lite	Qualitative

Table 2: Software packages used

Demographics of respondents



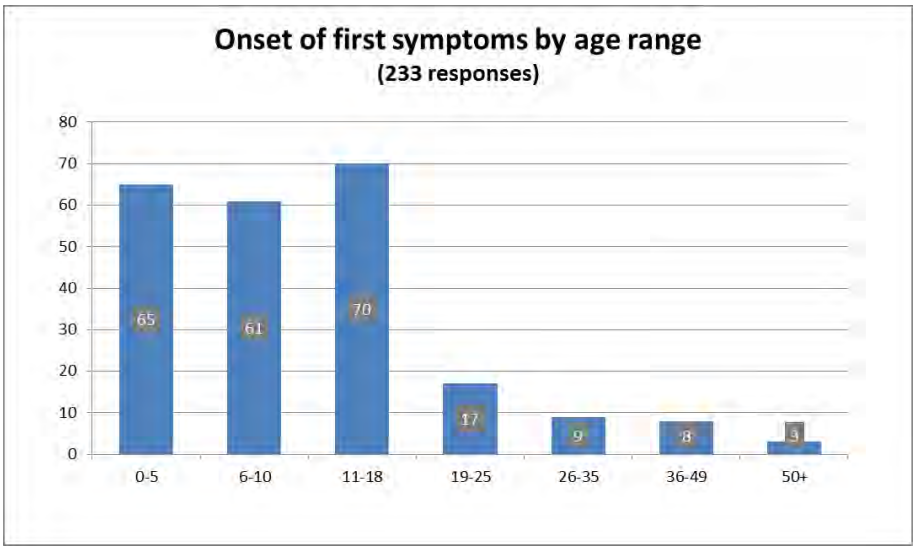
The exact breakdown of these demographics can be seen in appendix 3.

What did we find?

Clinical background: symptoms

Symptom onset

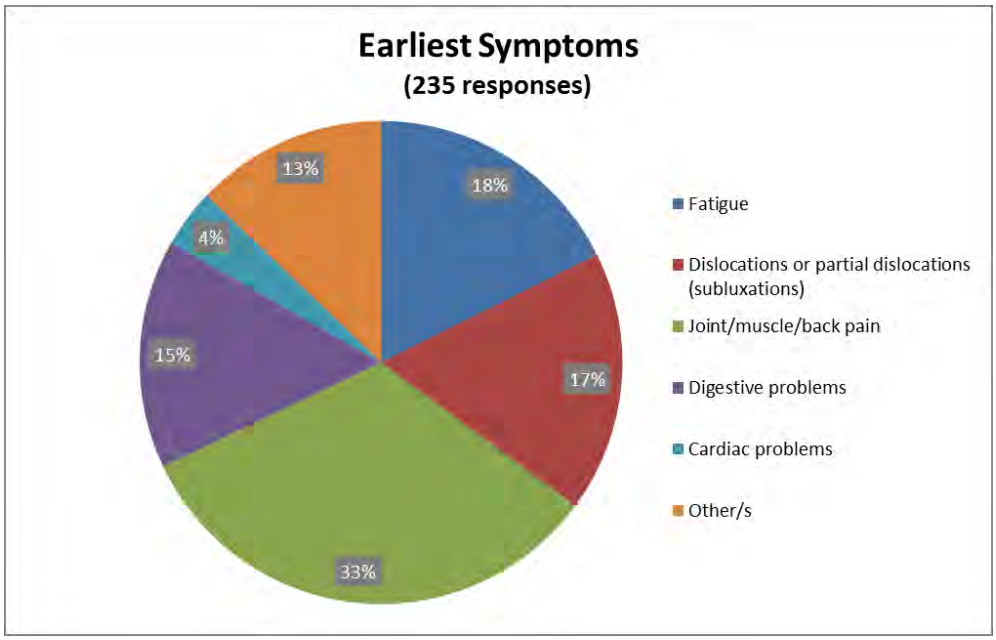
In terms of onset of symptoms, 84% of people who answered this question reported that they first had signs of hypermobility before the age of eighteen.



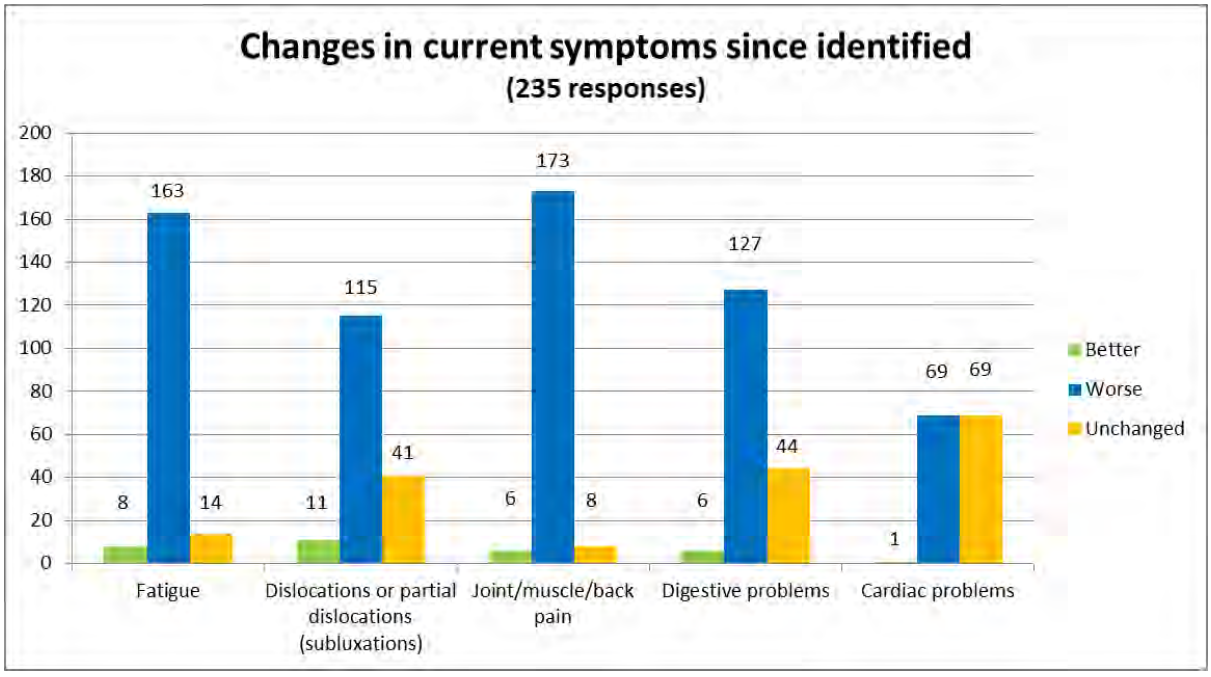
The average (mean) age of symptom onset was 12 years old, whilst the most common age (mode) for symptoms to begin was 5 years old.

Earliest symptoms

The most commonly cited earliest symptoms included joint/muscle/back pain, fatigue, dislocations, digestive problems and cardiac problems. Most people reported multiple symptoms, averaging 2.41 symptoms per person.



Most people (86%) reported that their symptoms had changed (improved or worsened) since they first began; with the majority of people (76%) reporting that their key symptoms had deteriorated over time. The table below highlights exactly how the symptoms had changed. Most people reported more than one symptom:



Health professionals consulted prior to diagnosis

The number of health professionals people consulted prior to diagnosis ranged from 1 (for a participant, who was diagnosed at birth) to 7 with an average of 2.6. This does not reflect quality or repeat interactions. The most commonly consulted medical specialists with which respondents had contact prior to diagnosis are represented in the word cloud below; the larger the text the more frequently the medical specialism was mentioned by participants.

Many respondents also indicated that they had sought advice from other medical specialisms. These are listed below in order of frequency with which they were mentioned:

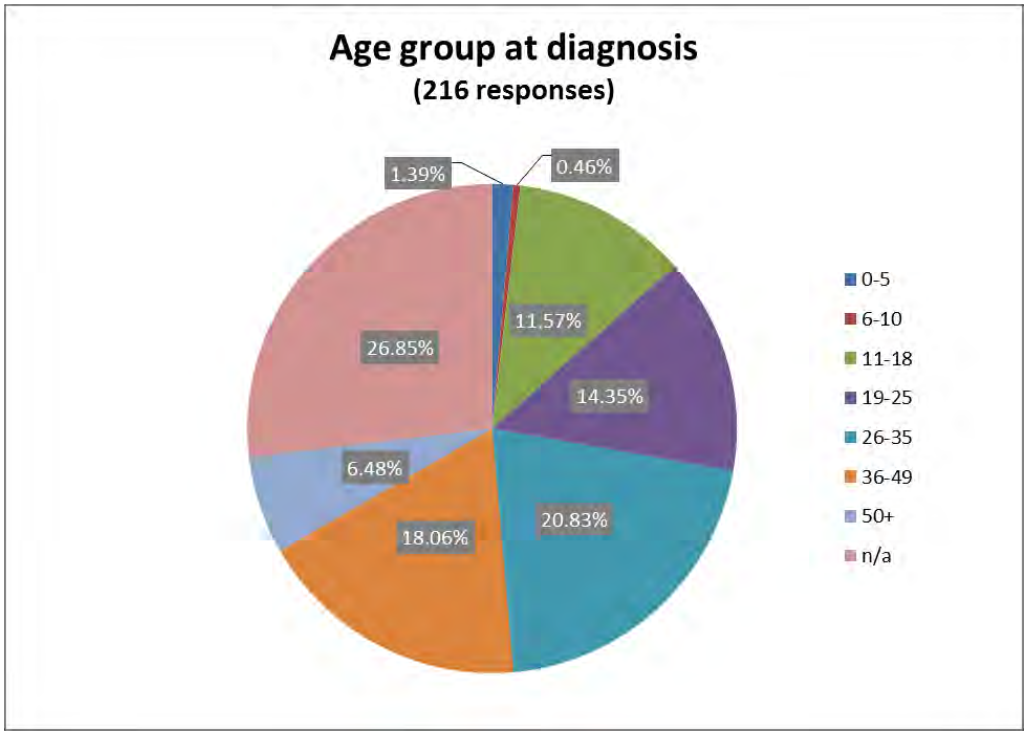
- Orthopaedics
- Gynaecology
- Paediatrics
- Immunology
- Ophthalmology
- Pain clinic
- Podiatry
- Occupational Therapy
- Psychology
- Dermatology
- Dietetics
- General surgery
- Haematology
- Hepatology
- Myalgic Encephalomyelitis (ME)/chronic fatigue syndrome clinic
- Musculoskeletal Clinic
- Urology
- Accident and Emergency
- Radiography
- Dental surgeon
- Ear, nose and throat
- Endocrinology
- Respiratory clinic

Respondents had also sought help from a range of alternative practitioners including osteopaths (5 participants) chiropractors (4 contributors) homeopaths (2 respondents) as well as from an acupuncturist, massage therapist, craniosacral therapist and a faith healer (1 response per therapist). It is not known from the data whether or not people have consulted these alternative practitioners from a basis of personal values or out of desperation/frustration with the NHS process.

Clinical background: diagnosis

Age on diagnosis

The majority of respondents were diagnosed in adulthood (60%). The most common age ranges for diagnosis were between 26 and 35 years old (21%) and between 36 and 49 years old (18%).



Many respondents commented that it had taken a long period of time between reporting the symptoms to a health professional and obtaining a diagnosis.

One older respondent remarked:

> 'In the 1960's and 70's joint pain treated as strains and sprains. X-rays, bandaging, resting limbs. At this time, I don't think there was a name for the condition often referred to as double jointed.'

Diagnosis given

In terms of diagnosis, participants reported a variety of different diagnoses. Joint hypermobility syndrome was the most common diagnosis among participants. The second most common diagnosis was Ehlers-Danlos syndrome with most reporting a diagnosis of hypermobile Ehlers-Danlos syndrome, four respondents reporting

classical Ehlers-Danlos syndrome and two people reporting vascular Ehlers-Danlos syndrome.

Diagnosis	% of Participants Reporting Diagnosis
Joint hypermobility syndrome	43.28
Ehlers-Danlos syndrome	36.13
Hypermobility Spectrum Disorder	6.72
Marfan syndrome	0.84
Stickler syndrome	0.42
Other	12.61

Table 3: Diagnosis reported by respondents

The "other" diagnoses reported included fibromyalgia, gastro-oesophageal reflux disease, mast cell activation syndrome (MCAS), hereditary alpha tryptasemia syndrome and postural tachycardia syndrome (PoTS). People also commented on (temporomandibular joint) disorders (TMJ), chronic pain, marfanoid habitus, juvenile onset degenerative disk disease, lax ligaments.

Health professionals involved in giving diagnosis

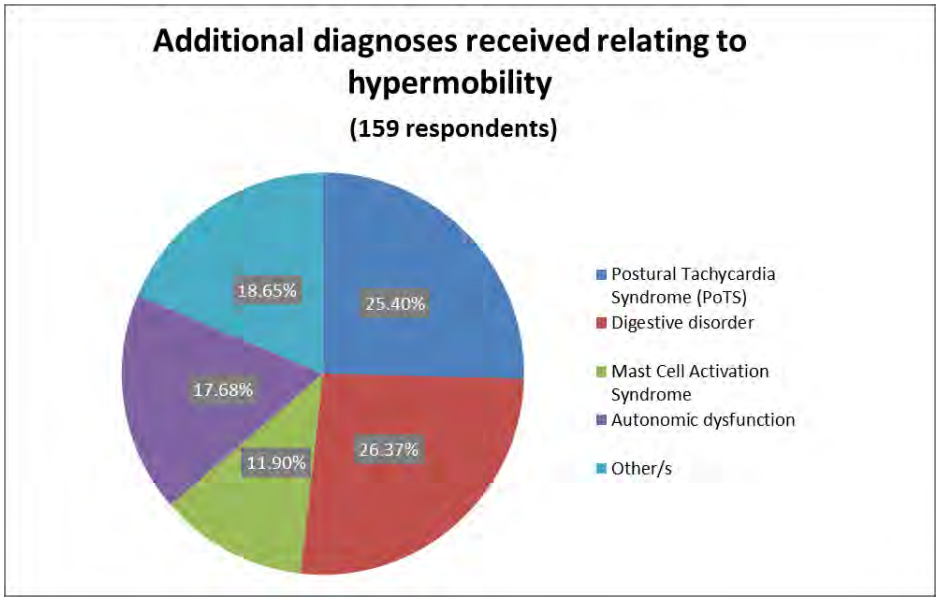
Participants reported that between one and six health professionals were involved in their diagnosis with an average of 2.3 professionals per person. Many different health professionals were cited as being involved in making people's diagnosis (see appendix 4 for details)

Most commonly, General Practitioners (GPs), rheumatologists and physiotherapists, and to a lesser degree clinical geneticists and cardiologists, were named as having a role in the diagnostic process.

Some other non-NHS professionals were also cited as having played a role in the diagnostic process, specifically a chiropractor, an osteopath, integrated medicine and biomechanics practitioners.

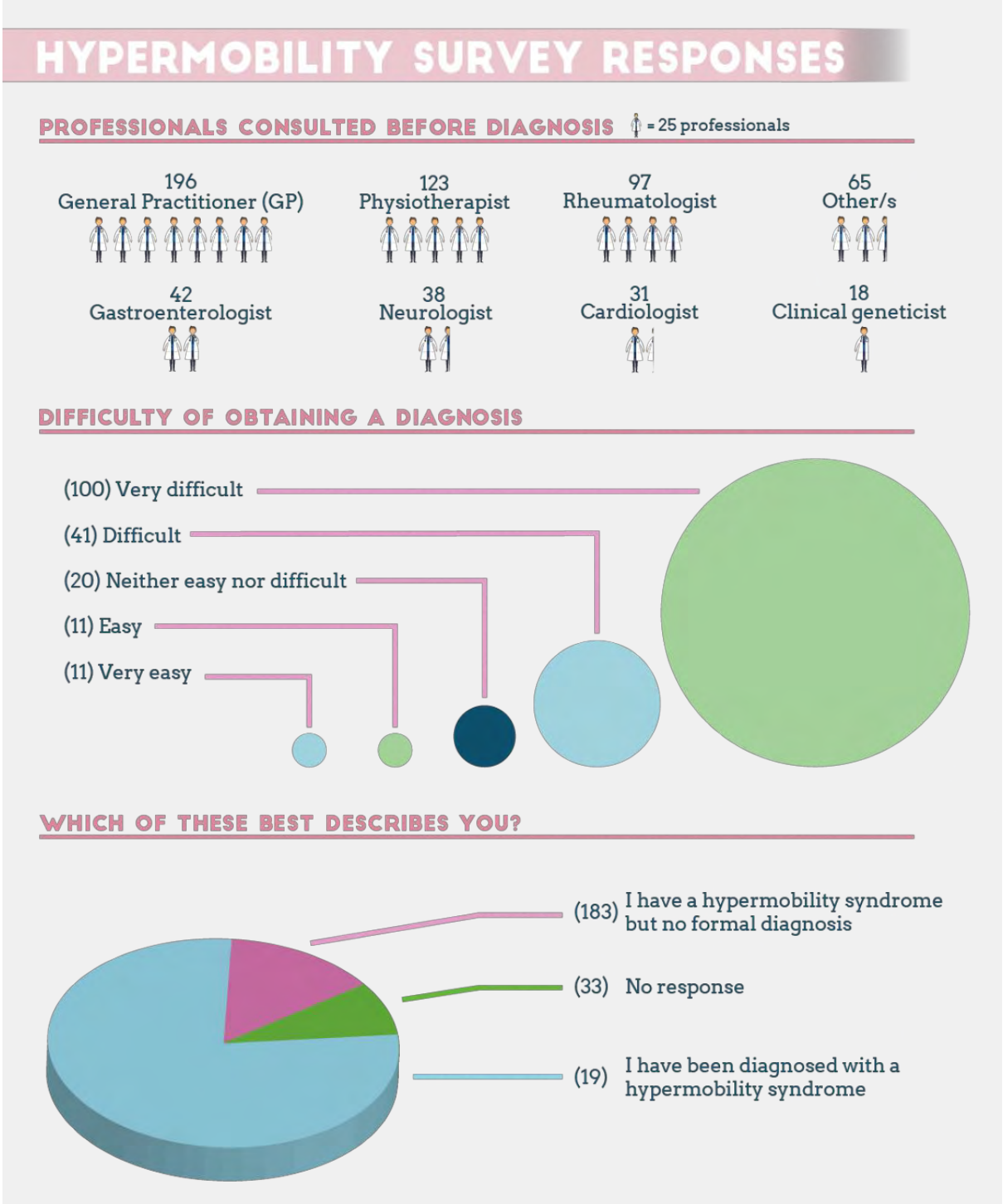
Diagnoses linked to hypermobility

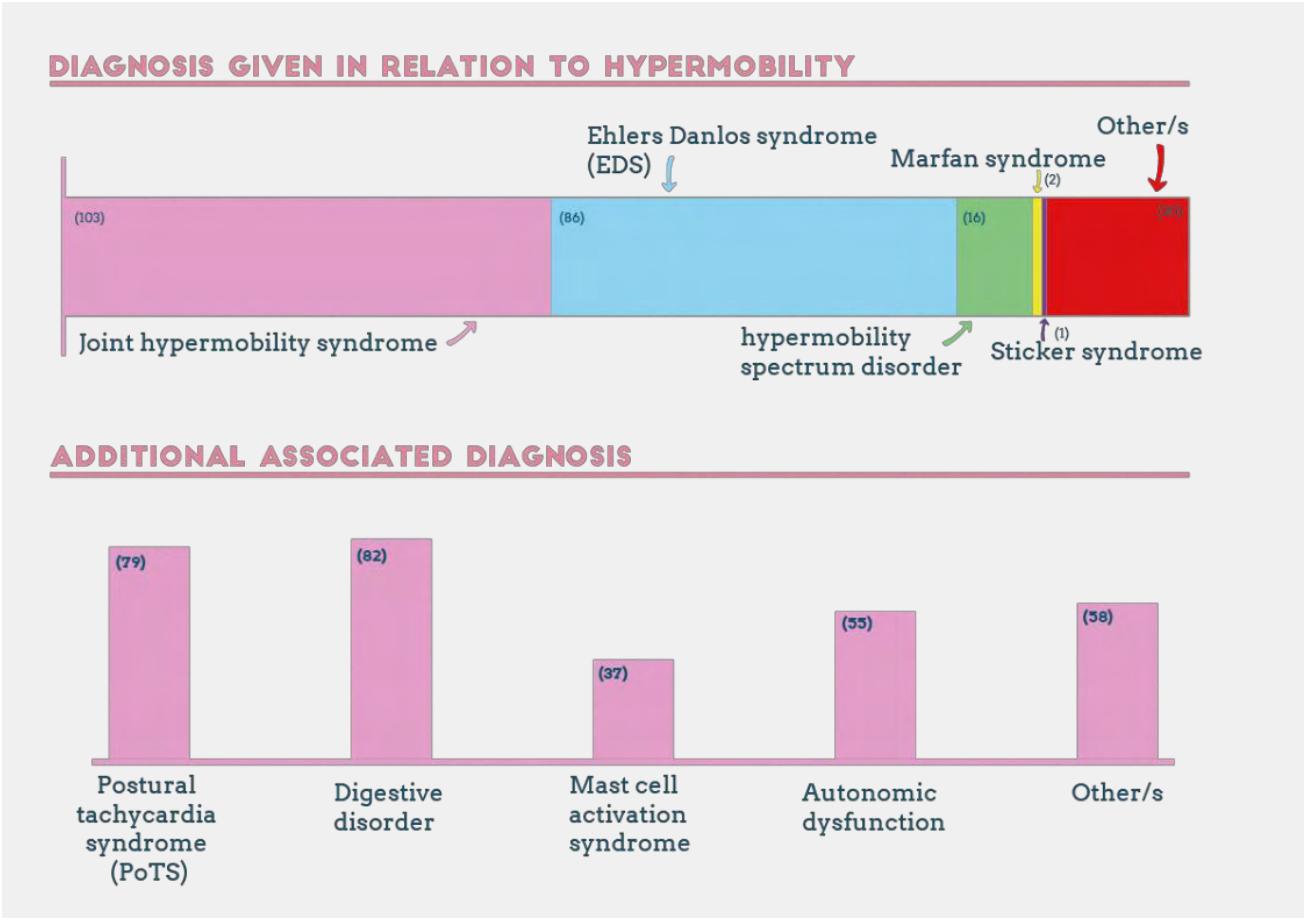
Participants also reported diagnoses of various conditions linked to hypermobility syndromes (12%).



A total of 58 participants said they had received “other” additional diagnoses. Altogether 62 other conditions were named (see appendix 5 for full list), with fibromyalgia, Myalgic Encephalopathy (ME)/Chronic Fatigue Syndrome (CFS), Raynaud syndrome, and temporomandibular joint disorder (TMJ) being reported most frequently. Again, some respondents reported against more than one of these “other diagnoses”.

Experience of obtaining a diagnosis





Only 7% of respondents described their experience of obtaining a diagnosis as “very easy”, with a further 6% stating it had been “easy” to obtain a diagnosis. However, there was a theme that indicated that it was often dependent on a particular individual.

The majority of respondents (76%) indicated that obtaining a diagnosis had been challenging, with 22% describing the process as difficult and 54% stating it had been very difficult.

Several recurring factors led to an overwhelmingly negative experience for many people. These included the apparent lack of knowledge amongst some health professionals, possible misdiagnosis, diagnoses based on only the presenting symptoms and not taking previous symptoms into account and in some cases what may be considered inappropriate or unprofessional reactions by some health professionals. Some of these are presented in more detail later in the report.

The combined effect of these factors is a prolonged diagnostic journey for many people resulting in significant impacts on them as individuals and their views of health services.

The impact of the diagnostic process

Frequently people described the process as leaving them feeling depressed, alone and isolated as a consequence of the lack of understanding that appeared to be the norm amongst professionals. This and the level of disbelief by professionals

also led to people doubting themselves despite their symptoms and experiences. Common terms used included feeling like a liar, a fraud and that they were going crazy. The word cloud below is a culmination of the terms respondents used when asked about how the diagnostic process made them feel.

In contrast, getting a diagnosis generated feelings of having been vindicated or relieved at having an explanation of their difficulties. These positive feelings are represented by the word cloud below.

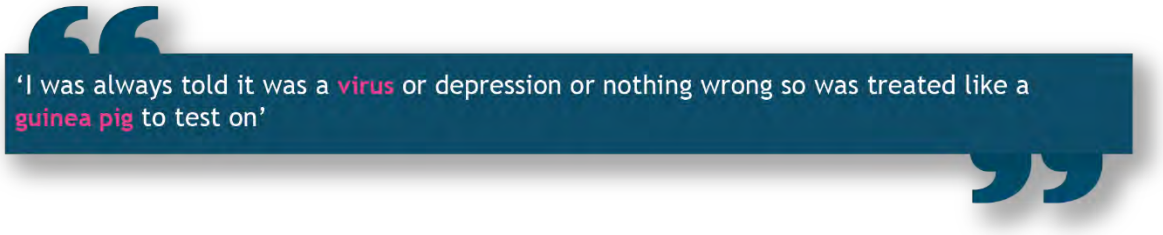
Tests in support of diagnosis

On the road to diagnosis the following tests and procedures were commonly performed, sometimes repeatedly, sometimes in isolation and sometimes in conjunction with the others listed (ranging from one other procedure/test to many):

- Electrocardiogram
- Blood tests
- Scans (magnetic resonance imaging, ultrasound, computerised topography, bone)
- X-rays
- Family history
- Physical examination
- Psychiatric evaluation
- Personal history including symptomology

The experience of respondents varied in terms of the number and types of procedures and tests carried out and the timeframe in which this was undertaken.

Many people reported having many blood tests, scans and/or x-rays. A number of respondents spoke of being tested/scanned/x-rayed exhaustively, often over years, in order to determine the cause of their symptoms. One person for example talks of being "treated like a guinea pig to test on".



In some cases, this led to the identification of specific aspects of the problems, e.g. "an MRI which showed the split disk, prolapse and the disk degenerative disease". For some people, this was a route to diagnosis of a hypermobility syndrome and supportive interventions but for others this resulted in prolonging the diagnosis of hypermobility syndrome, misdiagnosis and delayed support.

Many reported that their blood test results were normal and led to no conclusions in terms of diagnosis. Others reported having a few routine blood tests to rule out certain conditions, together with scans/x-rays, a focus on family history, reported symptoms and physical examination (including Beighton[1] scoring or Brighton criteria[2]).

For others, there was also a common thread regarding being diagnosed by health professionals who recognised the symptoms of hypermobility as opposed to simply looking at the test results.

[1] The Beighton scoring system measures joint hypermobility on a 9-point scale. The joints assessed are knuckle of the little/fifth finger, base of the thumb, elbow, knee and spine. Where applicable, range of movement is measured using a goniometer, an instrument that measures the joint angle (The Ehlers-Danlos Society, 2019). This scoring system is used in 2017 international diagnostic criteria for Ehlers-Danlos syndromes.
2 The Brighton criteria is a now defunct scoring system for the Ehlers-Danlos Syndromes in which the patients had to meet either two major criteria, one major and two minor criteria, four minor criteria, or two minor criteria and a first-degree relative (parent child or sibling) who had been diagnosed with hypermobile Ehlers-Danlos syndromes. A new international diagnostic criteria was introduced in 2017.

Where a physical examination took place, this seems in many cases to have been undertaken alongside other tests rather than independently by a therapist who was part of a treatment team or management pathway. This latter scenario appears to have been more successful in terms of diagnosis as several people reported that this was how the diagnosis was reached.

Such a pathway would mean that patients are not unnecessarily exposed, via scans, to radiation and its potentially harmful side effects. A pathway would not only be beneficial to patients but it would also reduce the costs and associated wastage to the NHS of unnecessary blood tests, scans and/or x-rays, which are often carried out on a repetitive basis as they are not giving the anticipated result. These are often expensive procedures. Some wastage also arises from a failure in effective processes (for example scanning) and inappropriate referrals. The respondents are aware of the potential costs to the NHS.

Of concern amongst these comments are references by some people to psychology or mental health referrals, sometimes for depression or anxiety but in a few cases for eating disorders or somatisation.

Professionals involved in the diagnosis

Comments about the professionals involved in the diagnosis (as opposed to prior to diagnosis) are frequently described positively. This may be as a result of their specialism relating to hypermobility or because of their support throughout the process of getting the diagnosis. In other cases, it was the professional's approach that made the difference for the people involved.

For some people the process seemed to hinge on a single particular person, either because of their approach as mentioned above or because they recognised or accepted the problems.

It is important to note that there isn't any specific specialism or clinical discipline that is consistently mentioned as by participants as being better than any other. Rheumatology, physiotherapy, cardiology and GPs are all described both positively and negatively throughout the survey, possibly reflecting the variability of knowledge, experience and acceptance of the condition across the NHS.

NHS care - what is not working well?

Qualitative data, such as that analysed in the survey, can highlight certain recurring themes within the responses. In this survey the following themes have emerged from the data:

- Knowledge among health professionals
- Misdiagnosis/diagnostic overshadowing
- Partial diagnosis
- Reactions of health professionals to symptoms
- Interpersonal communication issues
- Poor process
- Treatment and care

These are discussed in more detail here.

Knowledge amongst health professionals

The majority of respondents referred to health professionals either not being aware of, not knowing about or not believing in the wide range of symptoms and the impact of hypermobility on people. Comments were not restricted to any particular clinical profession. Many people reported that the dearth of knowledge regarding hypermobility amongst medical professionals has a demoralising effect upon them and leaves some of them unwilling to seek any further help.

The lack of knowledge about the range of symptoms and effects is particularly difficult for some people.

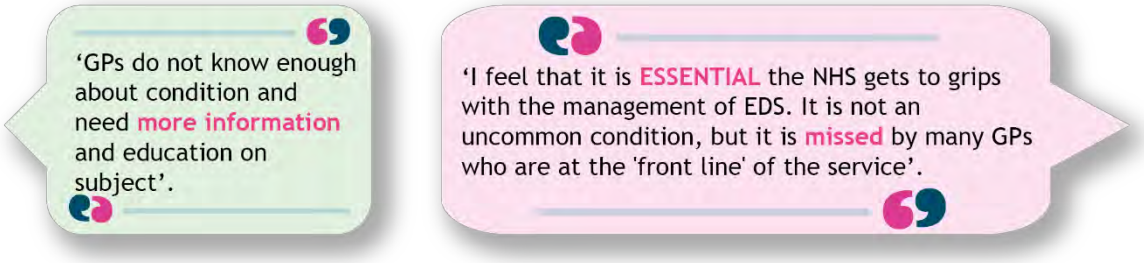
We collected many comments from respondents describing health professionals as "most certainly lacking in adequate knowledge", "very unaware", having "little knowledge", being "uninformed on hypermobility" or not having "any idea what they were dealing with".

There are variations within clinical professions within the comments for example, rheumatologist and physiotherapists received mixed feedback with some respondents stating that they had inadequate knowledge of hypermobility syndromes, whilst others stated they were knowledgeable.

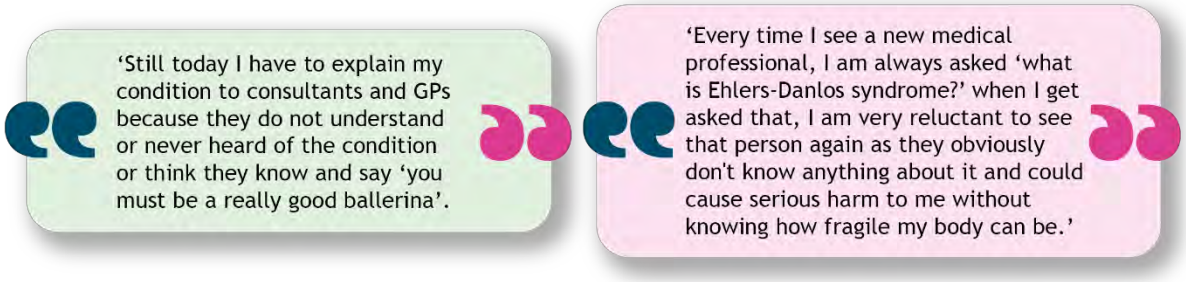
Others talked about the need for medical professionals to be educated with regard hypermobility syndromes making comments such as "doctors need to be educated more on these type of illnesses (hypermobility syndromes)" and "doctors need more information". While many respondents referred to health professionals generally when talking about the lack of knowledge within the medical community of hypermobility syndromes, a significant number of people stated that GPs specifically lacked knowledge of hypermobility syndromes.

In the instances where participants reported that there was some knowledge of hypermobility syndromes among health professionals, respondents stated that this was still inadequate.

In addition to the lack of knowledge problem, respondents were consistent in their view that GPs particularly need more knowledge about the conditions, perhaps because they are the first point of contact. The amount of knowledge needed has not been quantified but seems to range from 'awareness of' to 'understanding the range of issues'



People commented that medical professionals had no understanding regarding the severity of their symptoms. Also linked to inadequate knowledge on the part of health professionals, was the need to repeatedly explain the conditions to health professionals, which many found frustrating.



Respondents also spoke of interactions with some health professionals who were not aware of the extent and seriousness of the symptoms of hypermobility syndromes. One person for example reported that many medical professionals she had seen did not accept that it is possible for a joint to dislocate or subluxate without the person experiencing "trauma or screaming in agony". Others mentioned that medical professionals were not aware of the digestive problems linked to hypermobility syndromes. Inadequate or an absence of knowledge among health professionals regarding the symptoms of fatigue, pain, postural orthostatic tachycardia syndrome (PoTs), mast cell activation syndrome (MCAS) and hypermobility were also trends among the comments in this section.

Some respondents spoke of receiving a diagnosis/diagnoses in response to their symptoms, whilst others spoke of misdiagnosis, inappropriate treatment or management. Some of the people, who had a diagnosis also talked of medical professionals disbelieving the conditions, despite diagnosis.

While understaffing and underfunding of the NHS is acknowledged, there is a view among the respondents that lack of knowledge amongst health professionals is a significant factor in healthcare shortcomings. This has led to failures to provide a good care plan, inappropriate referrals and inaccurate scans/X-rays being taken. Advice or treatments offered have either been inappropriate, e.g. "exercise your way out of pain" or led to mental health concerns being explored in preference to physical symptoms being addressed.

Diagnostic overshadowing and bias

Diagnostic overshadowing refers to a prior diagnosis leading professionals to disregard further tests, diagnoses or choices of treatment. When this occurs for people with hypermobility syndromes it can have damaging effects as well as making the diagnostic journey harder altogether.

Other diagnoses given included irritable bowel syndrome (IBS), Myalgic encephalomyelitis (ME) and fibromyalgia but these were only in terms of one of the symptoms, not necessarily looking at the case as a whole. Often people's many, systemic symptoms were not linked together. Sometimes this led to inappropriate treatments, e.g. exercises that have exacerbated the problem, steroids making

symptoms worse or surgery that was unsuccessful as well as aggravating the condition.

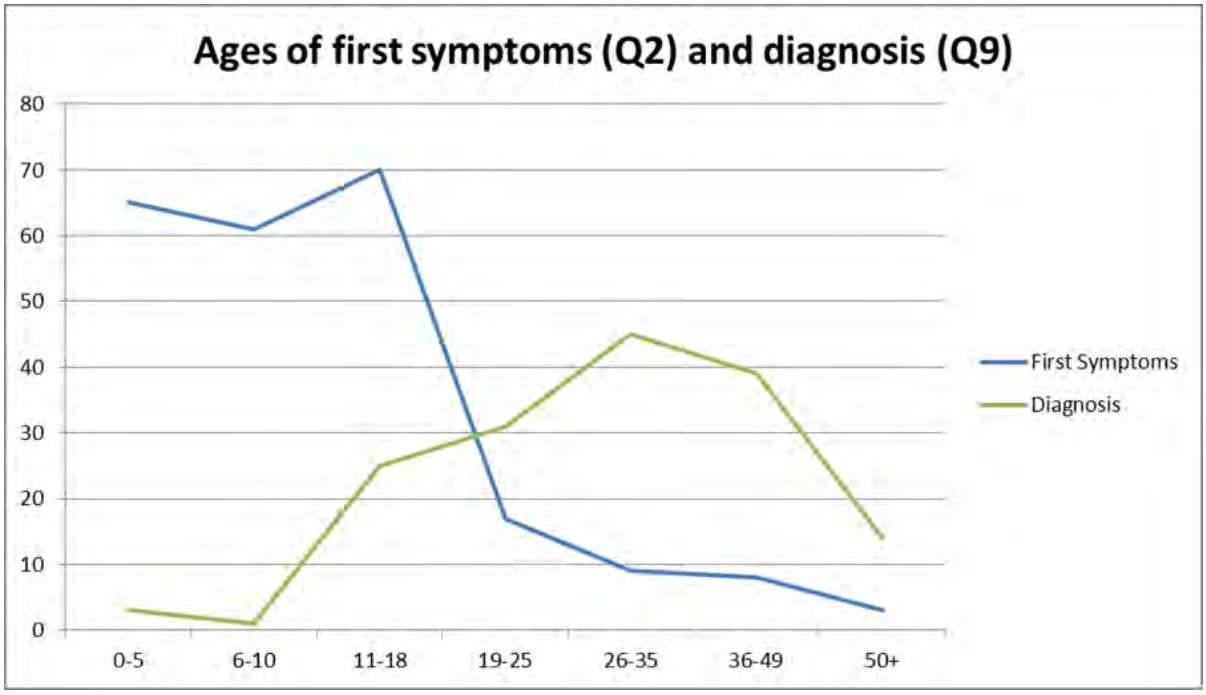
Setting aside the experiences of some people having their symptoms simply denied by the medical professionals, e.g. “it’s all in your head” or assuming people were after drugs rather than genuinely being in pain, there are other issues to be considered.

In the responses there were issues of the aforementioned but not just restricted to medical diagnoses; some seemed to have been the victim of what might be termed “medical stereotyping” as a form of diagnostic overshadowing. For example, a number of people were diagnosed with “growing pains” despite concerns about the level of pain being experienced.

Other causes considered may relate to the greater prevalence of hypermobility amongst women than men (see demographics in appendix 3). Some patients were told their symptoms and difficulties related to hormones, pregnancy or being too active in pregnancy, childbirth, post-natal depression or the menopause.

A number of female respondents reported being dismissed by health professionals without good reason or justification, one recalling being told that “lots of young ladies have it”, and fatigue/other symptoms being attributed to menstrual problems (“women’s problems”) or the menopause.

Some of these cases may be indicative of the pattern of first symptoms in childhood but no diagnosis until adulthood (see chart on following page).



Partial diagnosis

One significant theme of these responses generally is the failure of medical professionals to link together the variety of symptoms and health issues being reported and the focus on the presenting symptom only. One person for example stated that health professionals 'had no idea what was causing all the symptoms', whilst another said that health professionals were 'dismissive, carried out tests but seemed unwilling to connect the group of symptoms as being related'.

'My GP wanted to treat me symptom by symptom rather than looking at the symptom cluster as a whole. Different specialists don't talk to each other'

'They treated everything as a separate issue if they treated it at all'

'They did not look at me as a whole and consider my vast array of symptoms together.'

'Dismissive, carried out tests but seemed unwilling to connect the group of symptoms as being related'

'It took over 20 years of having lots of different things wrong before they linked it all together'

This complexity has led to many people being told their symptoms are related to mental illnesses such as depression, anxiety or stress.

Reaction of health professionals to symptoms

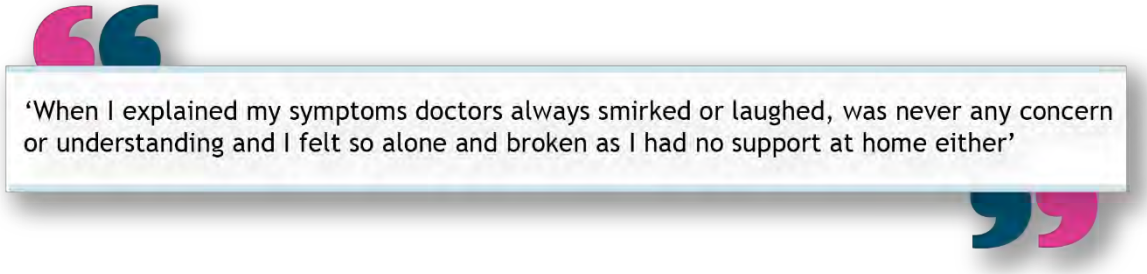
Whilst a small number of people reported helpful and supportive attitudes on the part of the health professionals whom they encountered both pre-and post-

diagnosis, a larger number of respondents stated that they had had mixed or negative responses to their symptoms from health professionals. In general people seemed to have had a range of negative experiences with health professionals.

In terms of the difficult encounters with health professionals on their journey to diagnosis, people talked of several key issues.

Many respondents told us that they had received dismissive responses from health professionals towards them and their symptoms both pre-and post-diagnosis.

People spoke of being laughed at, not being listened to, taken seriously or understood by health professionals.



Whilst some people described the response of health professionals to their symptoms as simply ‘unhelpful’, others elaborated:

> ‘Most of the doctors that I saw when I was younger and growing up for the past 10 years were incredibly unhelpful. Some were outright unprofessional and rude and did not believe me. Whilst others who were courteous and believed me clearly did not know enough about the conditions I had and simply ran blood tests then told me it seemed there was nothing wrong, not a single doctor in 10 years performed a basic physical examination’

Others also spoke of:

- a lack of treatment, care, advice and/or support offered
- a complete absence of interest in the symptoms
- a dismissive approach of giving people exercises to do
- ignoring any references to chronic conditions or pain

Many people also reported that health professionals disbelieved them when they informed them of their symptoms. This left people feeling upset, patronised and dejected by health professionals and also led to feelings of anger, frustration, and defeat (“giving up”).

> ‘I was referred to a physiotherapist who said hypermobility can't cause pain so my pain must be due to being "so unfit and overweight". When I explained I was exercising she said that meant I didn't need any help. I was upset so she grudgingly gave me a sheet of basic strength exercises and some resistance bands, which was not useful’

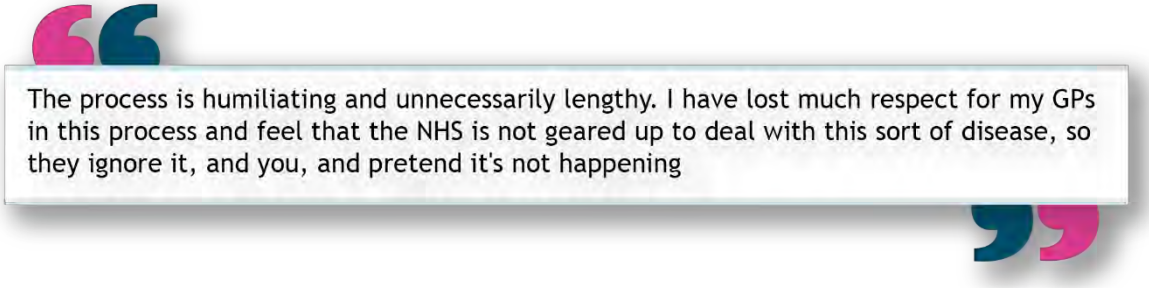
In one case, the lack of belief on the part of health professionals as to the extent of one person’s knee hypermobility led to plans for minor surgery only. However, once the operation was underway, and the extent of the hypermobility was finally acknowledged by the surgeon, the operation was changed to a much more extensive procedure (in terms of the surgery itself and time) than had been planned.

Others reported that they were disbelieved when they reported their symptoms or that their symptoms were not considered to be a cause for concern. People also reported that health professionals had ascribed the symptoms of hypermobility to excess weight, clumsiness or a lack of physical exercise. Some respondents reported being told by health professionals that they were too young to experience the pain they were reporting. In others, hypermobile joints were acknowledged but not seen by medical professionals as problematic making comments such as “it’s not a problem”,” it is normal”, you are “lucky to be so flexible”, “you’re just hypermobile”. Flat feet were seen by health professionals as nothing more than a physical variation.

Alongside the lack of understanding shown by many health professionals, respondents comments indicated there are some concerns about elitist attitudes promoting a dismissive approach, as well as arrogance about patients who have had to research their own illness.

Poor process

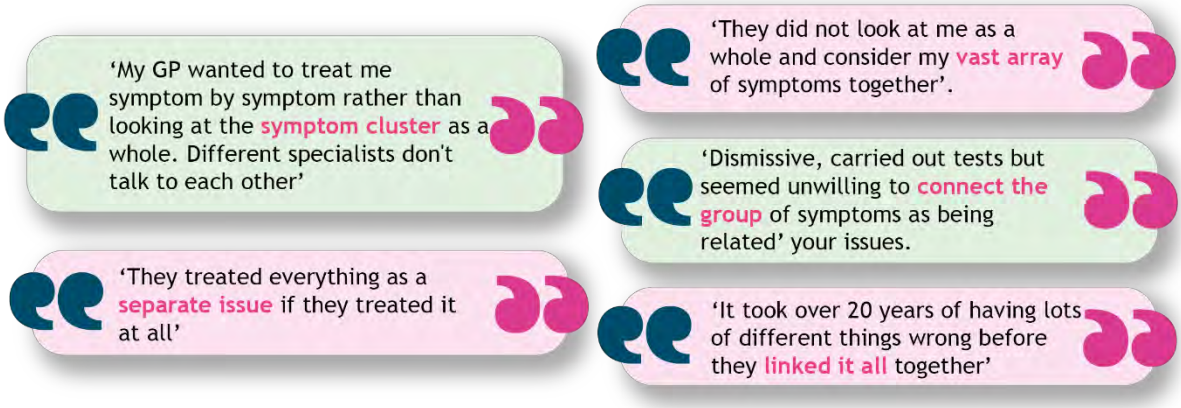
Most of the comments in this section were of a negative tone.



People told us of difficult experiences on their journeys to diagnosis, specifically being laughed at, multiple referrals, disparate responses from different health professionals, being seen as 'an impossible puzzle' or having too many symptoms to make sense of, and anomalous or 'normal' results leading to alternative diagnoses despite the symptoms being described.

In one case, the respondent's multiple symptoms began in childhood leading to her mother being accused of fabricating the symptoms in her child.

People talked of the inability or willingness of medical professionals to connect their many symptoms and this resulted in delays to diagnosis.



Several respondents spoke of the challenges they faced in persuading their GPs to refer them to a consultant for an opinion on hypermobility. In these cases, people spoke of having to make multiple visits over years in order to obtain a referral. This, coupled with the time taken between the referrals and the actual appointments was commented on as causing frustration, impacting negatively on the confidence the respondents had in the medical professionals and leading to delays in receiving help and treatment. There are several experiences of referrals taking far in excess of the 18-week maximum waiting time for non-urgent consultant-led treatments. One respondent spoke of a wait of two years to see a physiotherapist, whilst another stated that they were still on the referral pathway six years on.

Additionally, respondents spoke of being unable to access NHS medical professionals with experience of hypermobility syndromes and the related comorbidities, who were "out of area", reporting that they had been informed that waiting lists were closed to patients who did not live in the geographical area where the service was located. A number of respondents also referred to the fact that follow-up appointments were often missed.

> ‘Follow-up appointments are a joke as supposed to be seen every 6 months but have had to keep phoning for an appointment which I should have had a year ago!’

The complexity of hypermobility syndromes and their co-morbidities are exemplified in comments regarding diagnosis relating to either the time taken, the number of tests and the range of clinicians and consultants involved. There are also references to some of the difficulties this causes.

In terms of diagnostic consultations, common elements in these responses include the need to take time over a consultation, for observation, physical examinations and a more holistic approach. Again, the experience of respondents differs with some reporting having received comprehensive consultations involving a physical examination, symptomology and family history prior to a diagnosis being given, whilst others refer to much less thorough consultations.

Of the respondents, there were several referrals for psychiatric evaluation. Patients reported being referred to psychiatric services when medical professionals could not find a physical cause for their symptoms. These referrals resulted in little gain for the patients. Perhaps the phrase coined by Dr Heidi Collins should be adopted more widely “if you can’t connect the issues, think connective tissues”?

Communication between medical professionals was also a theme of these responses, with people also talking of how some doctors do not accept other professionals’ opinions which can have a detrimental effect on the diagnostic process causing delays and having negative impacts on the patients’ lives.

Treatment and support

Many respondents stated that they felt they did not have any NHS care or that there wasn’t any treatment available for their hypermobility syndrome. Other participants had received some NHS care but felt it was inadequate. When asked to describe their, NHS care, many of these respondents simply answered that they had received “nothing”. Others used words and phrases such as “none”, “very basic”, “lacking”, “inadequate”, “barely existent”, “not received support”, “not much”, “not a lot”, “never had any treatment as such”.

> ‘I went to a rheumatologist with multiple problems. Asking for help, what I got was a diagnosis (finally) but no help. Have had to go private because care is inexcusably non-existent’

> ‘Non-existent. I was discharged with my diagnosis with no advice or follow up’.

> ‘I have no NHS care for my hypermobility, discharged from rheumatology and basically advised to get on with it as it's not life threatening’

> ‘I have no management for it at all’

> ‘I don't get any. I was diagnosed, no more. Have been left to deal with it’

There were a significant number of people who spoke of having some NHS care, specifically physiotherapy, pain management, acupuncture, occupational therapy, hydrotherapy or orthotics.

People reported varying degrees of inadequate or unhelpful care from physiotherapists remarking that they had little or no awareness of hypermobility problems, that they focused on acute or specific injuries only as opposed to taking a whole body holistic approach. Several people commented that the way in which physiotherapy is generally provided by the NHS (a set number of sessions only) does not suit a person with a chronic condition such as a hypermobility syndrome. One person had been offered group physiotherapy, which she felt was inappropriate for her condition. Others described physiotherapy as a recurring referral with little benefit or even harmful consequences.

For some people, the only care they received was pain management often without review; there are several examples of respondents being prescribed opium or "strong" medications but they said without adequate medical support.

A number of people had been placed under the care of their GP for the hypermobility syndrome and their comments demonstrate that they thought this care to be inadequate.

> 'Symptoms managed by GP but due to complex issues symptoms are never controlled'

A number of people also opted to pay for private health care and equipment, as a response to the lack of empathy from NHS professionals or inadequate/overstretched NHS services. In some cases, this private care supplemented the NHS care provided, whilst in others it replaced the NHS care. Sometimes this private health care was funded by private medical insurance, whilst at other times people self-paid for the care. Where people paid for the care themselves, this was funded from retirement savings or benefits, often causing financial difficulties and restricting the amount of care and treatment that can be taken up. Several people stated that they had found private healthcare professionals to be more knowledgeable than those in the NHS and therefore opting for private treatment resulted in having one less battle to fight.

> 'For example, my NHS-supplied wheelchair and crutches are **no longer suitable** for my needs but are all I can be provided with, so I have had to **borrow money** to buy suitable alternatives.'

> 'Have had to go **private** because care is inexcusably non-existent'.

> 'For decent care I have to pay **privately** out of my benefits'

> 'The care is adequate now it is supplemented by my **private** physio and my own extensive research'

> 'This has included providing at my **own expense** various orthotics because off-the-shelf orthotics do not work.'

A significant number of the respondents feel that they are unsupported and have been left to manage their hypermobility syndrome alone. Sometimes they may have been given some exercises to do or prescribed pain medication but other than that many feel disappointed and alone in their situation. Some respondents talked of the self-management skills they had developed (for example going to Pilates, doing exercises at home, lifestyle adaptations, advice from peer support), whilst others simply stated that they "cared for themselves" with varying degrees of success. People feel they have to manage their own cases, sometimes without fully understanding it themselves, and research the condition so they can then ask for what they think might help.

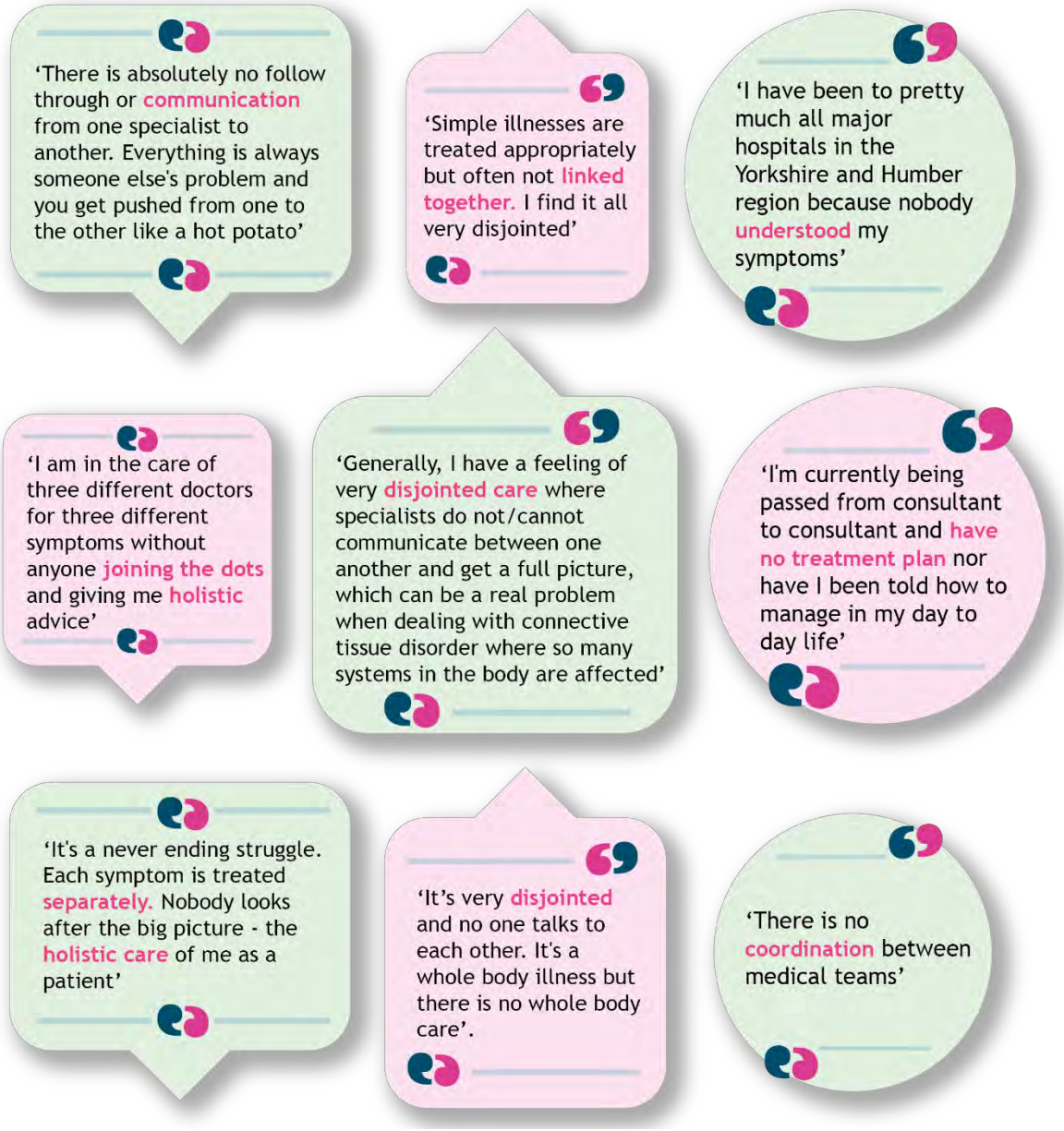
Managing their own cases and self-advocating was often stressful for the respondents, the stress creating further problems for these people. It is perhaps not surprising that given these responses and difficulties that people report they don't bother going to see their GP or to the hospital anymore because they don't see the point or expect to get dismissed and see it as pointless.

Some people acknowledged also that NHS care varied not just between specialities but also around the country and internationally. One person for example remarked that she had received worse care in Portsmouth than she had in either Liverpool or Huddersfield. Another person mentioned that she felt the UK lagged behind the United States of America and other countries in Europe in the way in which it diagnoses and treats hypermobility syndrome and the common co-morbid conditions.

Participants talked of difficulties with appointment systems, either the time taken to get an appointment, being discharged by accident or having to have a new appointment for each injury despite them being part of a bigger issue. Referrals generally are felt to take too long and, again, there may be separate referrals.

There are several reports of the care being disjointed, separate referrals being made for separate issues so that individual symptoms are treated but the condition as a whole is not. There was a feeling among respondents of being passed from one medical speciality to the next (pillar to post) with no positive treatment outcome. Communication between professionals is not consistent; communication failures occur frequently and conversations are repeated at consultations. This experience

is described as exhausting and demoralising. Additionally, people reported that medical professionals do not look at the issues holistically. One response illustrates this particular problem very well when referring to an elbow issue arising from the use of walking aids but the holistic view of mobility and avoiding elbow strains is not considered.



NHS care - what is working well?

Some people reported having had good experiences of NHS health professionals but this appears generally to be after moving around the country or changing GPs, hospitals or specialists. Again, this has usually occurred over a period of time. Only two respondents reported that they felt their NHS care was adequate. Positive NHS care appears to be dependent on a number of factors, specifically regular appointments, timely referrals, having had recent care as well as specialist knowledge and positive and supportive attitudes among health professionals. There are also a number of comments suggesting that a diagnosis of hypermobility syndrome was key to NHS care working well.

Knowledge

It is clear that there is significant inconsistency regarding the knowledge of NHS professionals regarding hypermobility syndromes. Where the majority of people have stated that knowledge of the syndromes is inadequate in the NHS, some respondents acknowledged that there are some professionals in the NHS with knowledge of hypermobility syndrome. Some comments showing that some specialists were very knowledgeable and helpful, and were able to provide expertise when working in their field.

The circumstances in which NHS care worked well focused largely around having access to at least one health professional who had knowledge of hypermobility syndromes. People felt that the impact of this knowledge made a difference to their NHS care.

Rheumatologists, GPs and physiotherapists are mentioned most commonly. There are also references to orthotics being very helpful; the overall view is that the care is good or adequate in different geographical areas.

Other health professionals also mentioned, albeit less frequently, included specialists in pain management, occupational therapy, gastroenterology, podiatry, orthopaedics and cardiology. This suggests a need for a wider knowledge base across different specialisms generally.

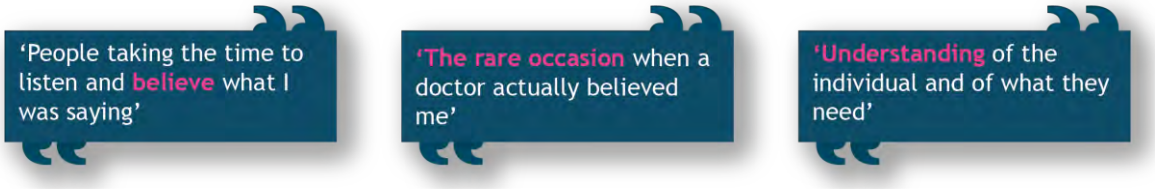
Some health professionals recognise the need for more research. Others appear prepared to learn more about hypermobility syndromes.

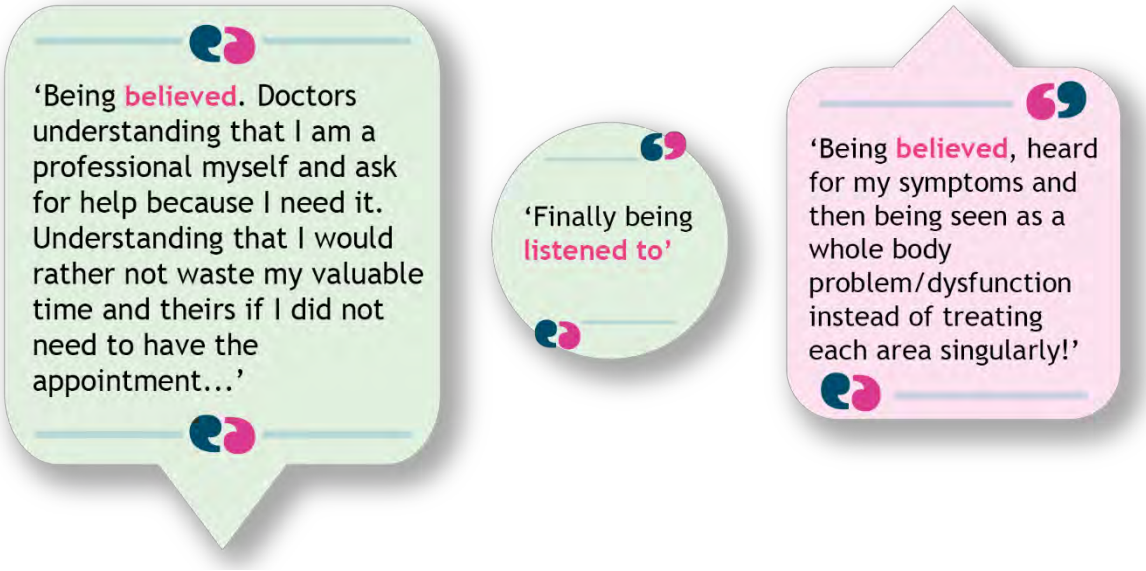
Communication

As well as knowledge being key to good NHS care, positive experiences of NHS care also generally involved the health professional/s:

- being open
- listening to the patient
- taking the patient seriously
- believing the patient
- understanding the patient
- being willing to help

The above are the most frequently identified positives in people's experiences of NHS care, sometimes coupled with the phrases "on the rare occasion…" or "finally…".





Respondents also indicated that feeling supported by at least some NHS teams was imperative to good care, even if the professionals involved had little knowledge of hypermobility syndromes. GPs in particular were identified as being very important as they are the gateway to other specialists. One person described how writing a letter to their GP impacted positively on the GP's response to them, resulting in the GP finally taking them seriously.

Comments indicate that some NHS staff have been exemplary in their approach and others have been helpful and supportive, even if they are lacking knowledge regarding the nature of the conditions. Not only are these people recognised by the respondents, but their help is very much appreciated

A few people commented on the communication between professionals as being positive contributions to what worked well for them with regard to their NHS care, with one person remarking on the importance of health professionals communicating with one another so that the correct care and support is provided.

Specialisms and procedures

37 people responded in terms of specialisms that had worked well. While there is not any one specific specialism that is noted, rheumatologists, physiotherapists and orthotics are frequent in the responses. Pain management clinics, cardiologists, podiatrists, occupational therapists, gastroenterologists are also mentioned.

A few people reported that surgical procedures they had undergone had been helpful in addressing specific parts of their difficulties. Several people commented on the care they had been given as being important in helping them continue with their lives or having the potential of helping reclaim parts of their lives. It may be important to note that the treatments and care are not curing the condition, which was openly commented on by one person, but ways of managing the impact of the condition, e.g. physiotherapy to strengthen joints, pain relief or pain consultations, and hydrotherapy.

Finally, people voiced their gratitude and thanks for the NHS generally and for some staff in particular. Notably the paramedics and Accident and Emergency staff have been praised and nurses and phlebotomists have been described very positively. One person specifically mentioned an optician who was described as the only medical professional she had encountered who really knew about hypermobility syndromes. People are able to differentiate between the quality of care provided and the level of funding for the NHS compromising what is available; there is a clear focus on the latter being inadequate contributing to many of the problems encountered.

Social care

It should be noted that not many people commented on social care experiences and this in itself may reflect the lack of involvement and awareness of the issues amongst social care staff.

A few people have received some care or support via social care; most frequently reported were aids and adaptations for the home such as grab rails, bathing/showering and toileting equipment (shower/bath seat, bath board, toilet frame, commode), kitchen aids (perching stool, kettle tipper), household supports (grab, rails, stair lifts, wheeled trolleys) and seating equipment (chair raisers). Some people have also been given additional support around personal care and social support.

There were a number of people who answered this question who reported that they receive no support from social services; the main difficulty reported here relates to the means-tested approach to funding social care interventions and support. One person stated that savings had effectively disqualified them from qualifying for any support as they had been deemed able to afford it themselves but found this impossible. Others said that they had undergone council financial assessments to determine how much they could afford to pay towards their care and support costs but felt they were unable to afford this contribution so felt they had no option but to refuse the care.

> I was entitled to a PA but I have a few saving so I don't get it I just struggle on because I need my savings to pay for all the lack of (NHS) care

There was a cohort of respondents who either seemed to be unaware of how to get support or had not been referred by anyone for support.

As with NHS care, there are significant issues regarding knowledge of hypermobility syndromes in social care. Staff appeared as if they didn't understand or didn't want to understand the overall impact of the condition being explained to them. There are also significant time delays in the assessment process that may mean people have to wait nearly a year between contacting services and getting the package of care and/or support.

The view expressed by the few respondents indicates that social care was poor overall.

NHS and social care - what would make the experience better?

Whilst we asked respondents what would make both NHS and social care experiences better, the majority of responses to this question relate to healthcare. Some people simply answered that they would like to receive some help, advice, treatment and/or management. Others spoke of the need to be listened to, understood and supported by healthcare professionals.

Knowledge

By far the most commonly commented on improvement suggestion was greater knowledge and awareness amongst NHS professionals. Respondents talked about the importance of medical professionals having not only knowledge of what hypermobility syndromes are but also awareness of how these conditions can affect people, what the commonly associated comorbidities are (for example, postural tachycardia syndrome, mast cell activation syndrome) and how to treat them. GPs are seen as key to this as the first point of contact but responses were not restricted to any one group. The desire seems to be for more knowledge across the whole of the NHS.

Coupled with the need for improved knowledge amongst health professionals is the need for professionals to be willing to admit they don't know about a condition but are willing to learn from the patient or anywhere else that would be helpful as opposed to brushing it aside or dismissing the condition entirely.

Some greater awareness amongst the general public or some leaflets to share with people would also be beneficial. One person reported their family children and friends would benefit from this.

Care, treatment and support

Among other suggestions about improvements was the wish for ongoing support by phone or via drop-in for example so that people could access health professionals when problems arise, rather than having to wait for lengthy periods of time until an additional appointment/new referral could be arranged. Some people also said that greater capacity to existing services would be an improvement. Physiotherapy and hydrotherapy services specifically mentioned here in terms of being limited as far as their current format is concerned; a desire was expressed for example for longer term physiotherapy as opposed the short courses that the NHS routinely provides.

Respondents also said that having appointments by telephone or online applications (for example by Skype) would save energy thus limiting the fatigue that many people with hypermobility syndromes experience. Support for mental health such as counselling was mentioned as something people would benefit from overall.

Responses also indicate that care could be improved by focusing on time. Reducing the waiting time for referrals for diagnosis and treatment would improve healthcare for these people. Also having time to listen to patients was identified as being important.

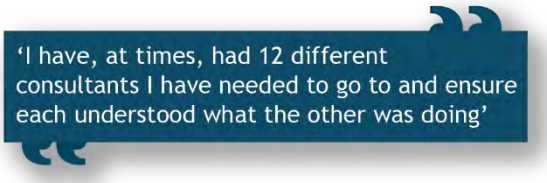
People also stated that continuity of health and social care was important when moving from one local authority to another; several respondents experienced difficulties in their care when moving from one geographical location to another (for example those in the forces, or following university).

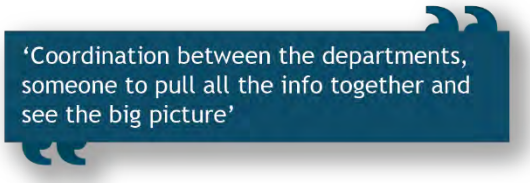
Communication

In terms of communication, being listened to by health professionals was the second most desired improvement; people need to be listened to and believed. The accounts we collected from people with hypermobility syndromes suggest that there are too many professionals at present who adopt an inappropriate attitude leading to people feeling patronised or dismissed.

Some people called for more professionalism amongst the staff providing healthcare. A few people reported care that suggested the staff did not care or at least didn't care properly and were not interested in the person they were caring for.

Improved communication, coordination and information sharing between health teams and professionals and between hospitals, and between health and social care would be a great benefit to people, either as part of a specialist service or simply as good practice.





Specialist care

A significant number of people expressed a desire for a dedicated care pathway with faster referrals and/or specialist service of some form for hypermobility syndromes. This, people felt, would help to address the current fragmented care that many people are receiving for hypermobility syndromes. Ideas proposed include a higher level of GP service (with for example quicker access, longer appointment times with a named professional), a coordinated service for complex

multisystem disorders, a specific hypermobility syndromes service or a regional specialist centre. Overall, a single point of contact would be an improvement.

Case management

Better case management is seen by some as an improvement that needs to happen. A single point of contact for a case, whether through a specific team in rheumatology or some other location, would enable better support to be developed. A single comprehensive care plan could be a part of the approach. It would also help to promote better communication across specialisms and improve the information sharing that often is absent in current care and which many people have commented on previously.

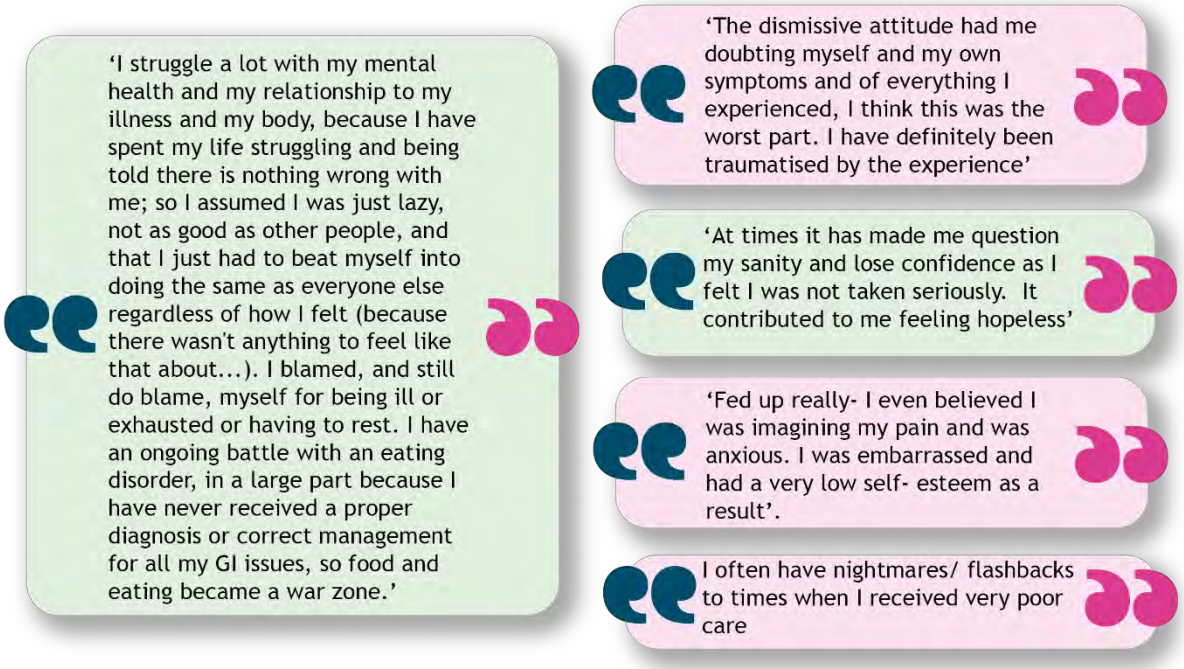
Life impact

People told us that difficult NHS experiences had impacted negatively on their mental health. The most common words in these responses are frustrated, angry, disappointed, sad, bitter, anxious, tired, invalidated, dismissed, exhausted, alone, and unheard.

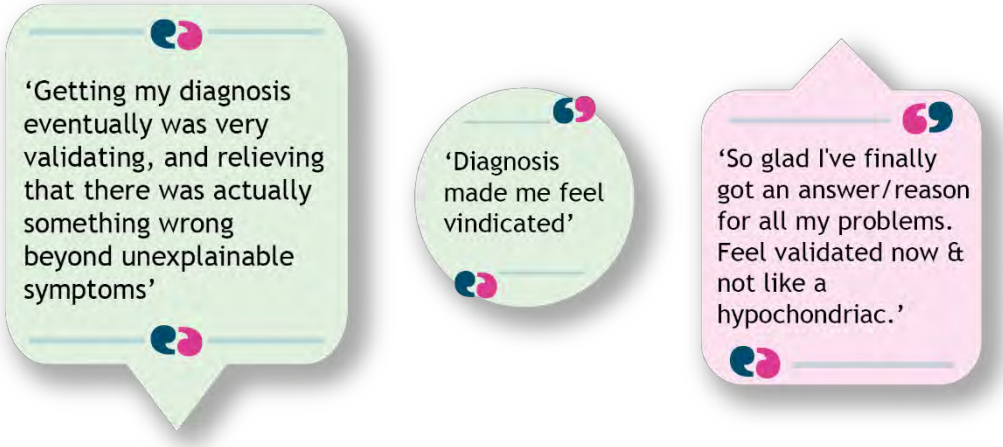
Negative mental states were described as resulting from self-doubt, the fact that health professionals had suggested or implied hypochondriasis, depression or low mood. People also talked of feeling ashamed, embarrassed or disbelieved. Some people's NHS experience, specifically being repeatedly disbelieved and questioned by medical professionals with regard to the symptoms, led them to have doubts about their own sanity. Issues of no longer able to trust doctors are commented on and derive from being belittled, laughed at, being told they were being overdramatic about issues or being told it was something they had to cope with. Several people refer to feeling suicidal.

The experiences of some have left them extremely distrustful of the NHS and medical professionals in general. Appointments induce anxiety, fear or an expectation of being told there's nothing wrong with them. Several people reported issues regarding the traumatic experiences they have had with the NHS and medical professionals.

One describes the equivalent of post-traumatic stress disorder (PTSD) symptoms and another expressed how the difficulties have led to anxiety and eloquently describes their experience empathising with others. It has impacted on people's self-esteem and confidence, leaving many with feelings of self-blame, isolation or loneliness. The impact on others around them should not be ignored; one person describes how her depression has left her son at greater risk of mental illness as well.



Where people finally received a diagnosis of hypermobility syndrome, the most consistent responses were those of being relieved, vindicated or validated. In addition to feeling better for having a reason for the problems, one person went on to say that being understood and cared for has enabled them to rebuild their confidence.



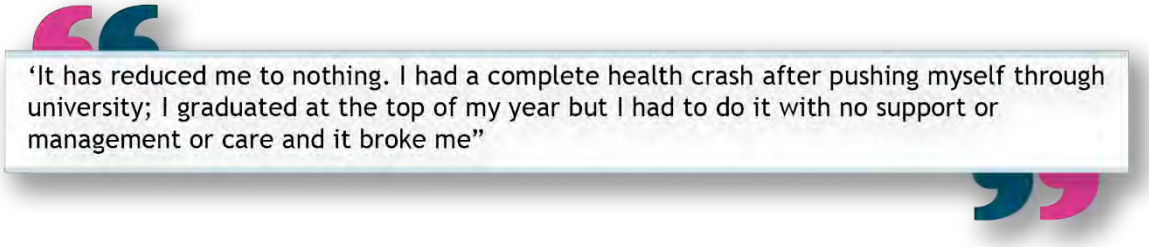
For some people NHS care has become a battle and people talked of being exhausted by the healthcare process as it took up a lot of time and energy. Respondents talked about the exhaustion resulting from attending many different appointments but also about that which came from constantly having to educate health professionals about their condition.

This may be exacerbated by the fact that NHS services are often not available outside normal working hours. Several people commented on the amount of time they have to take off work or studies as a result of their appointments.

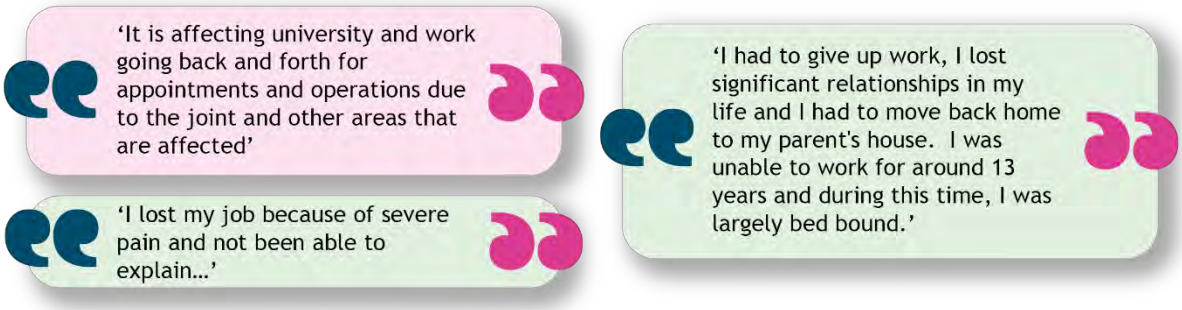
People also describe the profound impact of what they consider inappropriate and risky NHS treatments and medications resulting in long lasting and negative physical implications such as the loss of function. In particular, one person refers to the impact of a doctor when they were much younger on their current status and the reduced likelihood of regaining muscle usage.

As a result of issues with NHS care (lack of care, long waiting times), the hypermobility syndrome itself or often the two together, people reported a range of significant life impacts and difficulties including the loss of employment as well as a negative effect on education.

Several people have either reduced their hours of work or more frequently lost their job or retired on medical/ill health grounds. This then has a knock-on effect regarding family relationships and financial management problems. Where people have persevered without a diagnosis this has caused difficulties at work or led to significant problems at university.



Social and family relationships such as becoming isolated from family members, the near destruction of family life and marriage breakdown were also cited as significant life impacts.



Following her own diagnosis of hypermobility syndrome, one respondent's children also received similar diagnoses. As result this parent was threatened with the removal of her children due to allegations of fabricated illness; another respondent talked of her fear they will be removed by social care services.

The lack of an accurate diagnosis or being told by health professionals the condition is mild can have similarly significant effects on people's lives in terms of limiting their function, affecting family relationships and causing massive stress. People have lost years from their lives as a consequence of the impact and getting a diagnosis can mean having to rebuild their lives from scratch. In one case, obtaining a diagnosis had taken twenty years of a person's life.

Our conclusion

The key overarching findings from the engagement are that:

Current NHS care

- People with hypermobility syndromes are experiencing difficulties obtaining a diagnosis. Medical professionals are frequently not recognising that the complex and multifaceted symptoms being reported are linked and for many people this leads to significant delays, often spanning years, in the diagnosis of a hypermobility syndrome.
- Some people with undiagnosed hypermobility syndromes are inappropriately referred to mental health services when medical professionals cannot find a physical cause for their symptoms.
- People experienced multiple referrals, inappropriate referrals and difficulty persuading their GPS to refer them to consultants, lengthy waiting times both pre-and post-diagnosis and an absence of follow-up appointments. Respondents, were often unable to access NHS professionals with knowledge hypermobility syndromes/related comorbidities, outside their area, due to waiting lists for being closed to patients living outside the locality in which the service was provided. A significant amount of NHS money is wasted on inappropriate referrals, and in the case of people with undiagnosed hypermobility syndromes, exhaustive testing (blood tests, scans).
- People with hypermobility syndromes are often misdiagnosed, partially diagnosed or stereotyped notably when symptoms are considered in isolation.
- The reaction of health professionals to symptoms is mixed. Largely people encountered unhelpful and unsupportive attitudes both pre-and post-diagnosis.
- Communication between health professionals is often poor both between departments in the same service and between one medical facility and another.
- People state that there is inadequate knowledge among health professionals regarding hypermobility syndromes. GPs were specifically mentioned in this regard. Rheumatologists and physiotherapists received mixed feedback in terms of knowledge.
- Most people who responded to our survey stated that they had either no NHS care or inadequate NHS care for the hypermobility syndrome.

- Positive NHS care is dependent on having regular appointments, timely referrals, recent care, specialist knowledge and positive and supportive attitudes amongst the health professionals involved.

Future NHS care

- In terms of what could be improved in NHS:
    - people would like there to be focus on improving the knowledge and awareness of hypermobility syndromes and the associated comorbidities (e.g. postural orthostatic tachycardia syndrome, mast cell activation syndrome) among NHS professionals. An improved knowledge of these issues among health professionals, may go some way to addressing the current issues identified by respondents (e.g. disbelief) in the way many health professionals currently respond to people with hypermobility syndromes.
    - Ongoing NHS support for example by telephone, drop in services or longer treatment programmes so that problems can be addressed soon after they have arisen would also greatly improve current NHS care for people with hypermobility syndromes. Physiotherapy and hydrotherapy were both mentioned in this regard. Alternative ways of conducting appointments such as via Skype, other conferencing/telecommunication software, or telephone would also help people with hypermobility syndromes pace their energy by removing the requirement to be physically present at the appointment.
    - Reducing waiting times for referrals for both diagnosis and treatment would also help people with hypermobility syndromes as would giving more time in appointments so that the complex nature of the problems presented by hypermobility syndromes can be understood and linked together.
    - Improved communication, coordination and information sharing between health and social care, between departments within the same hospital and between treating professionals in different hospitals would be of great benefit to people, either as part of a specialist service or simply as good practice.
    - A specialist pathway for referrals and care or at the very least a single point of contact would greatly improve the NHS care for people with hypermobility syndromes.
    - Other improvements suggested by respondents include case management and care planning.

Social care

- The most commonly reported assistance via social care was in terms of specialist equipment to help with all areas of daily living. There was an apparent dearth of knowledge about hypermobility syndromes among social

care staff and a lack of awareness on the part of the respondents in terms of what is available. Respondents reported difficulties in being able to afford the financial contribution towards their social care.

Life impact

- People stated that their difficult NHS experiences had resulted in significant life impacts, notably the loss of employment, difficulties with or dropping out of education, problems with social relationships, the breakdown of families, financial problems, issues regarding the removal of children from families by social services. People also stated that the lack of or inappropriate NHS care had resulted in long lasting and irreversible physical problems. Challenging NHS experiences had also impacted on people's mental health whereas more positive NHS interactions resulted in more helpful feelings of vindication, being understood.

Our recommendations and next steps

We will publish this report on the Healthwatch Calderdale website, and ask that the local Healthwatch organisations across Yorkshire and Humber, which also took part in the project publish this report on their websites.

We recommend wider dissemination of the Royal College of General Practitioners (RCGP) Ehlers-Danlos syndromes toolkit across all GP practices within the Yorkshire and Humber region:

https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx

Healthwatch Calderdale will also contact Pennine GP alliance, a federation of all GP practices in Calderdale, the primary-care lead at Calderdale Clinical Commissioning Group as well as the Yorkshire and Harrogate Health and Care Partnership.

We ask that all local Healthwatch across Yorkshire and the Humber contact the following organisations in this regard:

- local primary care alliances across Yorkshire and the Humber
- relevant primary care lead/s in local Clinical Commissioning Group/s

With regard to secondary care, Healthwatch Calderdale will forward this report to the Yorkshire and Harrogate Health and Care Partnership and the West Yorkshire Association of Acute Trusts, recommending that consideration be given to increasing the awareness of hypermobility syndromes among other medical professionals, in the first instance among rheumatologists and physiotherapists but also among staff who work in the areas linked to the comorbidities of hypermobility syndromes such as gastroenterology, cardiology and immunology. Healthwatch Calderdale will also contact Calderdale and Huddersfield NHS Foundation Trust in this regard and would recommend that all local Healthwatch across Yorkshire and the Humber also contact the acute NHS hospital providers in their area.

In terms of social care, we recommend that knowledge of the symptoms and nature of hypermobility syndromes as well as its associated comorbidities be improved among social care professionals for both children and adults. We hope that an improved knowledge of hypermobility syndromes will ensure that the needs of people with hypermobility syndromes are correctly understood by professionals conducting assessments. We also hope improved knowledge will mean that that the symptoms of hypermobility syndromes in children are not mistaken for child abuse or fabricated illness, as can happen currently where a child has hypermobility syndrome. We will contact the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS) in this regard. We will also contact our local adult physical disability social care team.

This report will also be forwarded to Healthwatch England and NHS England for comment as it is clear from the project findings that adults with hypermobility syndromes across a wide geographical area are experiencing difficulties with their NHS care. The majority of people who shared their experiences of NHS care for hypermobility syndromes with us expressed concern about their NHS care and described difficulties in accessing appropriate NHS medical services and care. These findings concur with earlier observations by Healthwatch Calderdale at national/regional conferences for people with hypermobility syndromes.

Healthwatch Calderdale will provide the project toolkit and resources for other local Healthwatch across England wishing to collect the experiences of adults with hypermobility syndromes.

This report will also be shared with the national charities for hypermobility syndrome, EDS UK, HMSA and PoTS UK. It will also be sent to Dr Emma Reinhold, GP and Clinical Champion for Ehlers-Danlos syndromes.

Healthwatch Calderdale will forward this report to its local Members of Parliament. Other Members of Parliament, outside Yorkshire and Humber, with a known interest in hypermobility syndrome will also receive the report from Healthwatch Calderdale

This report will also be forwarded to the All Party Parliamentary group on Rare, Genetic and Undiagnosed Conditions asking them to provide written comment to Healthwatch Calderdale on the report.

We recommend that the feedback included in this report is used to help design and commission better services for people with hypermobility syndromes for both the diagnosis, treatment and management of these conditions.

To summarise, the report will be sent to the following NHS and social care organisations and Members of Parliament with the following requests to be completed by the beginning of November 2019:

Organisation name	Who will make contact with the organisation?	Actions and questions	Response due date
Pennine GP alliance Calderdale Clinical Commissioning Group (Primary Care Lead) Calderdale Local Medical Committee West Yorkshire and Harrogate Health and Care Partnership	Healthwatch Calderdale	Action: To ensure that all GPs across Calderdale are made aware of the Ehlers-Danlos syndromes toolkit produced by the Royal College of General Practitioners: https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx Questions: How will your organisation improve the knowledge of local GPs regarding hypermobility syndromes? How will the feedback in this report be used to improve the delivery of care for adults with hypermobility syndromes?	November 2019
Primary care alliances (via local Healthwatch across Yorkshire and the Humber)	Local Healthwatch across Yorkshire and Humber	Action: To ensure that all GPs across the region are made aware of the Ehlers-Danlos syndromes	November 2019

Clinical Commissioning Group across Yorkshire and the Humber (Primary Care Leads)		toolkit produced by the Royal College of General Practitioners: https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx Questions: how will your organisation improve the knowledge of local GPs regarding hypermobility syndromes? How will the feedback in this report be used to improve the delivery of care for adults with hypermobility syndromes?	
West Yorkshire and Harrogate Health and Care Partnership West Yorkshire Association of Acute Trusts Calderdale and Huddersfield NHS Foundation Trust	Healthwatch Calderdale	Action: to increase awareness hypermobility syndromes among health professionals in the first instance among rheumatologists and physiotherapists but also gastroenterologists, cardiologists and immunologists. Question: how will the feedback in this report improve the delivery of care for adults with hypermobility syndromes with regard to: • Process	November 2019

		• Treatment and support • Communication between healthcare professionals	
Acute hospital Trusts across Yorkshire and the Humber	Local Healthwatch across Yorkshire and Humber	Action: to increase awareness hypermobility syndromes among health professionals in the first instance among rheumatologists and physiotherapists but also gastroenterologists, cardiologists and immunologists. Question: how will the feedback in this report improve the delivery of care for adults with hypermobility syndromes with regard to: • Process • Treatment and support • Communication between healthcare professionals	November 2019
Association of Directors of Adult Social Services (ADASS)	Healthwatch Calderdale	Action: to increase awareness of hypermobility syndromes among Adult Social Care professionals	November 2019
Association of Directors of Children's Services (ADCS)	Healthwatch Calderdale	Action: to increase awareness of hypermobility syndromes among Children's Social Care professionals	November 2019
Healthwatch England NHS England	Healthwatch Calderdale	Questions: How can Healthwatch England help Healthwatch Calderdale escalate the issues with NHS care for people	November 2019

		with hypermobility syndromes to NHS England? How can Healthwatch England help raise the issues in this report at a national level?	
NHS England	Healthwatch Calderdale	Question: how will the feedback included in this report be used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019
Members of Parliament for the Calderdale are and with a known interest in hypermobility syndromes	Healthwatch Calderdale	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019
Members of Parliament across Yorkshire and the Humber	Local Healthwatch	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for people with hypermobility syndromes in the future?	November 2019
All Party Parliamentary group on Rare, Genetic and Undiagnosed Conditions	Healthwatch Calderdale	Question: what action will you take to ensure that the feedback in this report is used to help design and commission better services for	November 2019

		people with hypermobility syndromes in the future?	

Acknowledgements

A big thank you to everybody who took part in this project, either via the focus groups, the survey and/or the case studies.

On behalf of all local Healthwatch across Yorkshire and the Humber, Healthwatch Calderdale would like to thank Dr Norman Sterling-Baxter who volunteered to help with this project and has been of great support especially in terms of his expertise in data analysis. We would also like to thank EDS UK, HMSA and PoTS UK for helping us reach adults with hypermobility syndromes across Yorkshire and the Humber through their networks.

Abbreviations

CFS	Chronic fatigue syndrome
EDS	Ehlers Danlos syndrome
EDS UK	Ehlers-Danlos support UK (national charity)
GP	General practitioner
HMSA	Hypermobility Syndromes Association (national charity)
TMJ	Temporomandibular joint
IBS	Irritable bowel syndrome
MCAS	Mast cell activation syndrome
ME	Myalgic encephalomyelitis
PoTS	Postural orthostatic tachycardia syndrome
PoTS UK	Postural Tachycardia Syndrome UK (national charity)

References

Websites:

Types of EDS, 2017, Ehlers-Danlos Support UK, viewed 6 February 2019

<https://www.ehlers-danlos.org/what-is-eds/information-on-eds/types-of-eds/>

The HMSA Kent Model, Hypermobility Syndromes Association, 2017, viewed 6 February 2019

http://hypermobility.org/professionals-section/hypermobility-syndromes-association-the-hmsa-kent-model/

Assessing joint hypermobility, 22 June 2019

https://www.ehlers-danlos.com/assessing-joint-hypermobility/

Brighton criteria for Ehlers-Danlos syndrome, 22 June 2019

http://strengthflexibilityhealtheds.com/brighton-criteria-for-ehlers-danlos-syndrome/

Appendix 1: Survey

You are being invited to take part in a project looking at the health and social care experiences of adults with hypermobility syndromes living in Yorkshire and the Humber. This survey will be open until 31st October 2018

You can find background information as to why we are carrying out this project, how we will maintain your confidentiality and what Healthwatch is on the Healthwatch Calderdale Website.

If you indicate that you wish to be kept informed about the project's progress and/or would be willing for local Healthwatch to contact you to so that you can tell us your story, there is an opportunity for you to provide your personal details at the end of survey. The information you supply will only be used for the purposes you specify.

Section A Clinical Background

* 1. Consent

I give my consent for local Healthwatch across Yorkshire and the Humber and Healthwatch England to use my data anonymously and to share the project's findings with other organisations.

- Yes
- No

* 2. Consent

I give my consent for local Healthwatch across Yorkshire and the Humber and Healthwatch England to use my data anonymously and to share the project's findings with other organisations.

- Yes
- No

Please answer all questions that are relevant to you

Your Symptoms

3. Please tell us how old you were when you first had symptoms of hypermobility. If you can't remember the exact age, please give a rough estimate.

4. What were your earliest symptoms? Tick all that apply.

- [ ] Fatigue
- [ ] Digestive problems
- [ ] Dislocations or partial dislocations (subluxations)
- [ ] Cardiac problems
- [ ] Joint/muscle/back pain

Other/s (please specify)

* 5. Have your symptoms changed since they first began? If you answer 'No' please go to question 6

- ( ) Yes
- ( ) No

6. What are your current symptoms? Tick all that apply and indicate whether symptoms are currently better, unchanged or worse than they were when they first began.

Fatigue	
Dislocations or partial dislocations (subluxations)	
Joint/muscle/back pain	
Digestive problems	
Cardiac problems	

Other/s (please specify each symptom and whether it is better, unchanged or worse)

7. Which health professionals did you consult about your symptoms before you were diagnosed with a hypermobility syndrome? If you do not yet have a diagnosis, please still answer this question. Tick all that apply.

- [ ] General practioner (GP)
- [ ] Physiotherapist
- [ ] Rheumatologist
- [ ] Cardiologist
- [ ] Clinical geneticist
- [ ] Gastroenterologist
- [ ] Neurologist
- [ ] Other/s (please specify)

8. Please tell us how the health professionals you encountered on your journey to diagnosis reacted or responded to you and your symptoms? For example, were they supportive, dismissive. What did they say about your symptoms? If you do not yet have a diagnosis, please still answer this question.

Your Diagnosis

* 9. Which of these best describes you. If your answer is *'I have a hypermobility syndrome but no formal diagnosis'* then go to section B

- I have been diagnosed with a hypermobility syndrome
- I have a hypermobility syndrome but no formal diagnosis

10. Please tell us how old you were when you were given your diagnosis of a hypermobility syndrome. If you can't remember the exact age, please give a rough estimate.

11. What diagnosis or diagnoses were you given in relation to your hypermobility? Tick all that apply.

- Joint Hypermobility Syndrome
- Ehlers Danlos Syndrome (EDS). Please state type under "other"
- Hypermobility Spectrum Disorder
- Marfan Syndrome
- Stickler Syndrome
- Osteogenesis Imperfecta

Other/s (please specify)

12. Which health professionals were involved in giving you your diagnosis? Tick all that apply. For example, if your General Practitioner (GP) sent you to a cardiologist who suspected you had a hypermobility syndrome and in turn referred you to a rheumatologist who diagnosed your condition, please tick GP, cardiologist and rheumatologist.

- [ ] General practitioner (GP)
- [ ] Cardiologist
- [ ] Clinical Geneticist
- [ ] Physiotherapist
- [ ] Neurologist
- [ ] Gastroenterologist
- [ ] Rheumatologist
- [ ] Other/s (please specify)

13. In addition, have you been diagnosed with any of the following conditions linked to hypermobility? If so, indicate which health professional made the diagnosis.
fill in all that apply

Postural Tachycardia Syndrome (PoTS)	
Digestive disorder	
Mast Cell Activation Syndrome	
Autonomic dysfunction	
Other/s? Please state condition/s and indicate which health professional/s made each diagnosis	

Section B Your experience of getting a diagnosis

We would like to know more about your experience of obtaining a diagnosis of a hypermobility syndrome. If you are still on your journey to diagnosis, please still answer the questions in this section.

14. Please indicate how difficult or easy it is/was to obtain a diagnosis using the examples to assist you (these are not the only possibilities).

- **Very easy**
  Professional recognised condition and made diagnosis. Professional examining one of my symptoms asked about others and made a referral leading to diagnosis.
- **Easy**
  One or two referrals before diagnosis; health professionals recognised the condition before I did.
- **Neither easy nor difficult**
  Involved several referrals; took a while but health professionals were trying to understand my situation and difficulties.
- **Difficult**
  Listened to but needed to keep pushing for referrals; many referrals required until difficulties understood. Took a long period of time.
- **Very difficult**
  Involved many referrals and consultations; took longer than seems necessary; challenging and difficult responses and reactions from health professionals.

Please explain the reason for your rating

15. How does/did the journey to getting your hypermobility diagnosis make you feel?

16. Please tell us about the diagnostic process. For example does it or did it involve many or few tests/scans/x-rays, a focus on family history?

17. Please tell us about your views on the health professionals involved in the diagnostic process. You may want to include your thoughts about the overall approach of the professionals or their level of awareness regarding your symptoms. If you have a particular experience (positive or negative) of any professionals, you may want to talk about these.

Section C Your NHS Care

18. To what extent do you agree with the following statement?

	Strongly Agree	Agree	Neither Agree nor disagree	Disagree	Strongly disagree
"The NHS care I receive is adequate to manage my hypermobility syndrome"					

19. Please tell us about your NHS care.

20. Please tell us about the ways in which your NHS experience has impacted your life. It may have affected you positively and/or negatively. Your experience may also have resulted in you receiving appropriate or inappropriate care.

Section D Your Social Care Experience

Some people have also had social care involved in their care and support of a hypermobility syndrome. We would like to know about your experience of these services as well.

21. Have you had a social care assessment? If your answer is "No", please go to section E

- Yes
- No

22. Please tell us about any support you have received following your social care assessment.

23. Please indicate how you feel about the support you have received by ticking the appropriate box using the examples given to assist you. These are not the only possibilities:

- ☐ **Very satisfied**
  Received more care than I thought was available; very quick response once assessed.
- ☐ **Satisfied**
  Get the care I need and have control over it; quick response once assessed
- ☐ **Neither satisfied nor dissatisfied**
  Acceptable level of care. Took a little while to get the care arranged and started.
- ☐ **Dissatisfied**
  Care provided not really suitable but don't want to lose possibilities of future care. Lengthy process and only addressed part of my needs.
- ☐ **Very dissatisfied**
  No care received after lengthy assessment process; felt like a waste of everybody's time.

Please explain the reason for your rating

24. Please comment on your social care experience.
You might for example want to let us know about how positive or negative it was, how it compared to NHS services, which services were helpful, which were less helpful or how you may feel about having further involvement with social care.

Section E What worked well/What would have made your experience better?

25. **What worked well in your NHS/social care journey ?**

26. **What would make the health and/or social care experience better?**

27. **Finally**

Is there anything else, positive or negative, that you feel is important to mention with regard to your experience of NHS care and/or social services?

Some Information about You

28. Which age group are you in?

- ☐ Up to 18
- ☐ 19-25
- ☐ 26-35
- ☐ 36-45
- ☐ 46-55
- ☐ 56-64
- ☐ 65+

29. Please indicate your gender

- ☐ Male
- ☐ Female
- ☐ Other (please specify)
- ☐ Transgender
- ☐ Prefer not to say

30. What is your ethnic group?

- ☐ Asian or Asian British: Indian
- ☐ Asian or Asian British: Pakistani
- ☐ Asian or Asian British: Bangladeshi
- ☐ Asian or Asian British: Chinese
- ☐ Black or Black British: Caribbean
- ☐ Black or Black British: African
- ☐ Mixed or multiple ethnic groups: White and Black Caribbean
- ☐ Mixed or multiple ethnic groups: White and Black African
- ☐ Mixed or multiple ethnic groups: White and Asian
- ☐ White: English, Welsh, Scottish, Northern Irish, British
- ☐ White: Irish
- ☐ White: Gypsy or Irish Traveller
- ☐ White: Other
- ☐ Other ethnic groups: Arab
- ☐ Any other ethnic group
- ☐ Prefer not to say

31. What is the first part of your postcode (e.g. HX3; WF12)?

32. Which local authority do you live in? [Select from a drop down menu]

33. Do you wish to be kept informed about the project?

- [ ] Yes. Please fill in this contact form.
- [ ] No

* 34. We would like to collect real life stories to show how hypermobility syndromes affect people's lives. Please indicate if you would be willing to provide your story at a later date.

- [ ] Yes. Please fill in this contact form.
- [ ] No

Appendix 2: Articles

Healthwatch Hypermobility Syndromes Project

YORKSHIRE AND THE HUMBER

Background

My name is Karen Huntley. I have hypermobile Ehlers-Danlos syndrome (hEDS), Mast Cell Activation syndrome as well as orthostatic intolerance. It took me over 20 years to obtain my diagnoses and during this time I became very unwell and sought the help of many doctors; none of whom identified a connective tissue disorder as the cause of my systemic ill-health. Last year, having sought help privately for Mast Cell Activation syndrome, the doctor suggested that I might also have Ehlers-Danlos syndrome (EDS). I subsequently made an appointment with a specialist consultant, who confirmed that I did indeed have hEDS. A diagnosis of orthostatic intolerance followed soon afterwards. It was a relief to finally understand the cause of my health problems.

In October 2017 I attended the Management and Wellbeing conference in 2017 run by the Hypermobility Syndromes Association (HMSA) and Ehlers Danlos Support UK (EDS UK). I learnt a great deal at the conference. I also noticed that there were many people at this conference who were reporting challenges and difficult experiences with regard to their National Health Service (NHS) and social care. I heard people recall that medical professionals often lacked knowledge about hypermobility, stories of delayed diagnoses and of lack of access to appropriate treatments. I later went to the Northern Patient Day run by postural tachycardia syndrome UK (PoTS UK) and EDS UK, attended by about ninety people, where I made similar observations. Again when I attended my local EDS support group, I heard comparable accounts, akin to the health care experience I had had myself.

'Find out more about our project and contribute this summer by telling us about your health and social care experiences.'

What is Healthwatch

I work on a part-time basis for Healthwatch Calderdale in West Yorkshire; a charity, which is independent of the NHS. Healthwatch is the consumer champion for health and social care. It operates at a local level through its network organisations as well as a national level (Healthwatch England). There is a local Healthwatch for every local authority area. These form a network of 153 organisations.

The role of Healthwatch is to obtain the views of local people regarding their experiences of local health and social care services, for example how local people feel services could be improved and how local people feel about planned changes to local services etc. The idea is that each local Healthwatch organisation shares the information it collects with local commissioners, where appropriate making recommendations to local health commissioners about how services should be improved or altered to better meet the needs of local people. Local Healthwatch organisations are also encouraged to share information with Healthwatch England so that it can identify issues affecting people across the country and inform changes to services.

The Healthwatch Hypermobility Project

My observations at hypermobility events locally and nationally have led to me lead a project across Yorkshire and the Humber on the health and social care experiences of adults with hypermobility syndromes (e.g. hypermobility spectrum disorder (HSD), the Ehlers-Danlos syndromes, Marfan syndrome, Osteogenesis imperfecta, Stickler syndrome and Pseudoxanthoma elasticum).

The aim of this project is to:

- Gather feedback from adults with hypermobility syndromes in Yorkshire and the Humber

'My observations at hypermobility events locally and nationally have led to me lead a project across Yorkshire and the Humber on the health and social care experiences of adults with hypermobility syndromes...'

regarding their experiences of health and social care services

By doing this we intend:

- To develop an understanding of health and social care experiences of adults with hypermobility syndromes in Yorkshire and the Humber
- To report on the health and social care experiences of adults with hypermobility syndromes, sharing our understanding with commissioners and service providers so that they have a clearer picture of health care experiences for this group of people
- To interact with commissioners and service providers to work towards addressing the service issues identified
- To share the information with Healthwatch England, along with appropriate existing secondary data on the health and social care experiences of people with hypermobility syndromes

At this stage, we do not know exactly what the impact of our project will be. We are keen however to ensure the collective voices of adults with hypermobility syndromes are heard with regard to their health and social care experiences.

Our work so far

To date, we have held focus groups in York, Leeds and Sheffield to establish the main issues that people with hypermobility syndromes face with regard to their health and social care. These themes are currently being used to formulate the next step of our project, which is a survey.

We need your help

This summer between July and September 2018, we will be asking adults with hypermobility syndromes across Yorkshire and the Humber to help us by providing more detailed information via a survey about their health and social care experiences. The survey will be available online over this three-month period. Feedback can also be given via telephone if filling in an online survey is difficult for you. Access to the survey from July 2018 onwards will be via links which will be posted via HMSA, EDS UK as well as on the following Healthwatch websites:

Healthwatch Calderdale
Healthwatch Barnsley
Healthwatch Bradford
Healthwatch Doncaster
Healthwatch East Riding of Yorkshire
Healthwatch Kingston upon Hull
Healthwatch Kirklees
Healthwatch Leeds
Healthwatch North Lincolnshire
Healthwatch North East Lincolnshire
Healthwatch North Yorkshire
Healthwatch Rotherham
Healthwatch Sheffield
Healthwatch Wakefield
Healthwatch York

More specific details as to how to access the survey will be provided in the HMSA e-news next month. All the information collected from the survey about you for this project will be kept strictly confidential. What you say will be reported anonymously with identifying personal data removed to ensure your confidentiality. If you have any questions about the project, please contact Karen Huntley via email at:karen.huntley@healthwatchcalderdale.co.uk

The views and opinions of any authors expressed in 'Have Your Say' articles, do not necessarily state or reflect those of the HMSA or its Medical Advisors.

Healthwatch hypermobility syndromes project

Yorkshire and the Humber

Find out more about our project and contribute this summer by telling us about your health and social care experiences

Background

My name is Karen Huntley. I have hypermobile Ehlers-Danlos syndrome (hEDS), mast cell activation syndrome (MCAS) as well as orthostatic intolerance. It took me over 20 years to obtain my diagnosis and during this time I became very unwell and sought the help of many doctors; none of whom identified a connective tissue disorder as the cause of my systemic ill health. Last year, having sought help privately for MCAS, the doctor suggested that I might also have Ehlers- Danlos syndrome (EDS). I subsequently made an appointment with a specialist consultant, who confirmed that I did indeed have hEDS. A diagnosis of orthostatic intolerance followed soon afterwards. It was a relief to finally understand the cause of my health problems.

In October 2017 I attended the Management and Wellbeing conference run by Ehlers Danlos Support UK (EDS UK) and the Hypermobility Syndromes Association (HMSA). I learnt a great deal at the conference. I also noticed that there were many people at this conference who were reporting difficulties and difficult experiences with regard to their National Health Service (NHS) and social care. I heard people recall that medical professionals often lacked knowledge about hypermobility related conditions, stories of delayed diagnoses and of lack of access to appropriate treatments. I later went to the Northern Patient Day run by Postural Tachycardia Syndrome UK (PoTS UK) and EDS UK, attended by about ninety people, where I made similar observations. Again when I attended my local EDS support group, I heard comparable accounts, even to the health care experience I had had myself.

What is Healthwatch?

I work on a part time basis for Healthwatch Calderdale in West Yorkshire, a charity which is independent of the NHS. Healthwatch is the consumer champion for health and social care. It operates at a local level through its network organisations as well as at a national level (Healthwatch England). There is a local Healthwatch for every local authority area; these form a network of 152 organisations.

The role of Healthwatch is to obtain the views of local people regarding their experiences of local health and social care services, for example how local people feel services could be improved and how local people feel about planned changes

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to local services etc. The idea is that each local Healthwatch organisation shares the information it collects with local commissioners, where appropriate making recommendations to local health commissioners about how services should be improved or altered to better meet the needs of local people. Local Healthwatch organisations are also encouraged share information with Healthwatch England so that it can identify issues affecting people across the country and inform changes to services.

The Healthwatch Hypermobility Project

My observations at hypermobility events locally and nationally have led to me leading a project across Yorkshire and the Humber on the health and social care experiences of adults with hypermobility syndromes (e.g. hypermobility spectrum disorder (HSD), the classical Ehlers-Danlos syndromes, Marfan syndrome, osteogenesis imperfecta, Stickler syndrome and pseudoxanthoma elasticum).

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The aim of this project is to:

- Gather feedback from adults with hypermobility syndromes in Yorkshire and the Humber regarding their experiences of health and social care services

By doing this we intend to:

- To develop an understanding of health and social care experiences of adults with hypermobility syndromes in Yorkshire and the Humber
- To report on the health and social care experiences of adults with hypermobility syndromes, sharing our understanding with commissioners and service providers so that they have a clearer picture of health care experiences for this group of people
- To interact with commissioners and service providers to work towards addressing the service issues identified
- To share the information with Healthwatch England, along with appropriate existing secondary data on the health and social care experiences of people with hypermobility syndromes

At this stage, we do not know exactly what the impact of our project will be. We are keen however to ensure the collective voices of adults with hypermobility syndromes are heard with regard to their health and social care experiences.

Our work so far

To date, we have held focus groups in York, Leeds and Sheffield to establish the main issues that people with hypermobility syndromes face with regard to their health and social care. These themes are currently being used to formulate the next step of our project, which is a survey.

We need your help

This summer (between July and September 2018), we will be asking people with hypermobility syndromes across Yorkshire and the Humber to help us by providing more detailed information via a survey about their health and social care experiences. The survey will be available online over this three month period. Feedback can also be given via telephone if filling in an online survey is difficult for you. Access to the survey from July 2018 onwards will be via links which will be posted via EDS UK, HMSA as well as on the following Healthwatch websites:

Healthwatch **Calderdale**

Healthwatch **Barnsley**

Healthwatch **Bradford**

Healthwatch **Doncaster**

Healthwatch **East Riding of Yorkshire**

Healthwatch **Kingston upon Hull**

Healthwatch **Kirklees**

Healthwatch **Leeds**

Healthwatch **North Lincolnshire**

Healthwatch **North East Lincolnshire**

Healthwatch **North Yorkshire**

Healthwatch **Rotherham**

Healthwatch **Sheffield**

Healthwatch **Wakefield**

Healthwatch **York**

More specific details as to how to access the survey will be provided in the EDS UK e-newsletter in the coming weeks. All the information collected from the survey about you for this project will be kept strictly confidential. What you say will be reported anonymously with identifying personal data removed to ensure your confidentiality.

If you have any questions about the project, please contact Karen Huntley via email at **karen.huntley@healthwatchcalderdale.co.uk**

Appendix 3: Demographic data

The age range of participants was as follows (from 236 surveys):

Age range	Up to 18	19-25	26-35	36-45	46-55	56-64	65+
Number of respondents	8	29	37	47	26	8	4
%	5.03%	18.24	23.27%	29.56%	16.35%	5.03%	2.52%

Table 4: Age ranges of participants (from 236 surveys)

The majority of people surveyed identified as female (93.83%), with a further 4.94% stating they were male. A total of 0.62% of respondents identified as transgender, 0.62% indicated that they preferred not to answer this question.

Gender	Male	Female	Transgender	Prefer not to say
Number of respondents	8	152	1	1
%	4.94%	93.83%	0.62%	0.62%

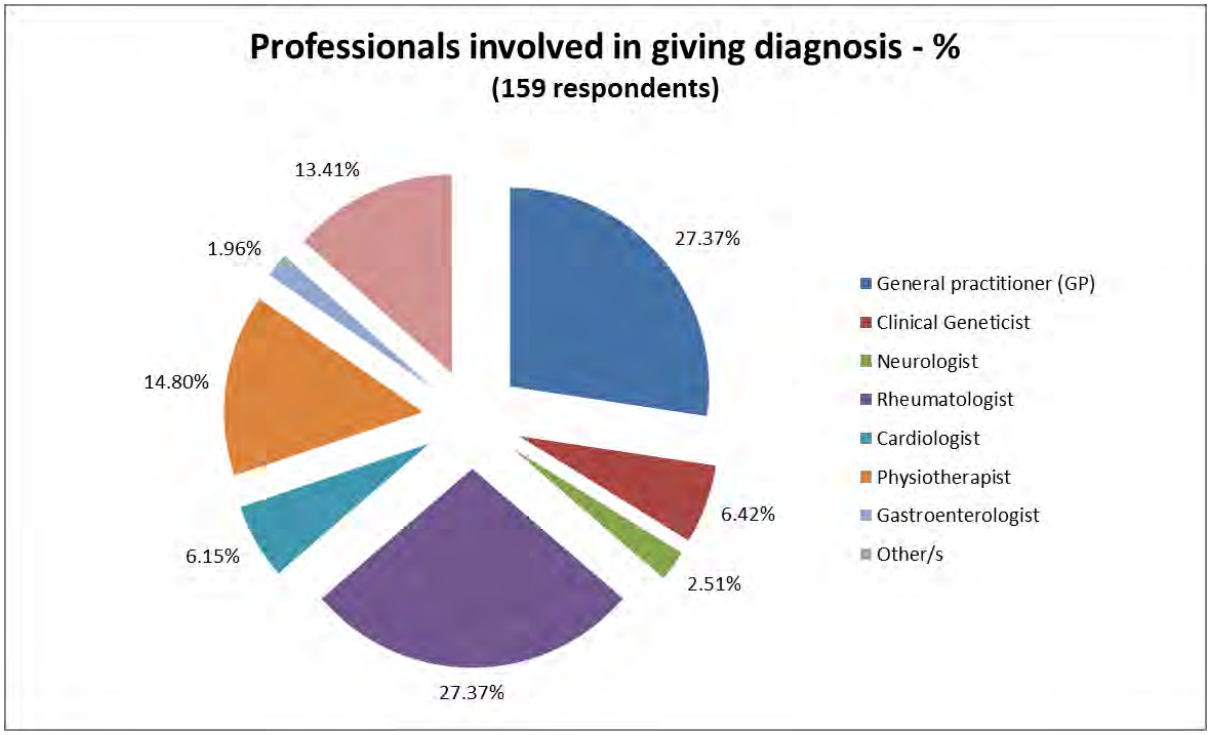
Table 5: Gender of participants from 236 surveys

By far the most represented ethnic group was White: English, Welsh, Scottish, Northern Irish, British, which constituted 89.63% of respondents. White Irish accounted for 1.22% of participants. A further 3.66% of respondents stated their ethnic group to be white other. A total of 1.83% stated that they belonged to the mixed multiple ethnic groups (see table below for details). 2.44% of people stated that they prefer not to answer this question.

Ethnic group	Number of respondents	%
Mixed or multiple ethnic groups:		
White and Black Caribbean	2	1.22%
White and Asian	1	0.61%
White:		
English, Welsh, Scottish, Northern Irish, British	147	89.63%
White:		
Irish	2	1.22%
Other	6	3.66%
Any other ethnic group	2	1.22%
Prefer not to say	4	2.44%

Table 6: Respondents by ethnic group

Appendix 4: Health professionals involved in diagnostic process



Other health professionals mentioned as being involved in the diagnostic process were:

- Gynaecologist/obstetrician
- Dermatologist
- Orthopaedic Consultant
- Podiatrist
- Pain Specialist
- Acute Medicine Specialist
- Occupational Health
- Immunologist

Appendix 5: Other additional diagnoses

Condition	Times mentioned by participants
Fibromyalgia	13
Myalgic encephalomyelitis/chronic fatigue syndrome	7
Raynaud syndrome	7
Temporomandibular joint (TMJ) disorders	7

Arthritis/osteoarthritis	6
Anxiety	4
Depression	4
Asthma	3
Bursitis	3
Chiari malformation	3
Cranial cervical instability	3
Irritable bowel syndrome (IBS)	3
Migraines	3
Hearing loss/presbycusis	3
Swallowing disorders	3
Abdominal neuralgia	1
Aneurysm	1
Astigmatism	1
Atlantoaxial instability	1
Atypical narcolepsy	1
Atrioventricular nodal re-entry tachycardia	1
Benign paroxysmal positional vertigo	1
Borderline personality disorder	1
Bowel prolapse	1
Cervical kyphosis	1
Charcot Marie tooth	1
Coeliac disease	1
Cognitive dysfunction/brain fog	1
Degenerative disc disease	1
Ehlers-Danlos syndrome related airway collapse	1
Endometriosis	1
Gastroparesis	1
Histamine intolerance	1
IgA deficiency	1
Impingement syndrome	1
Inflammatory bowel disease	1
Interstitial cystitis	1
Jejunal diverticulosis	1
Lupus	1
Marfanoid habitus	1
Mast cell mediated bladder disorder	1
Menorrhagia	1
Myopia	1
Osgood-Schlatter disease	1
Pain	1
Plantar fasciitis	1
Prolapsed cervical discs	1
Prolapsed discs in spine	1

Prolapsed womb	1
Rectocele and cystocele	1
Restless leg syndrome	1
Scleritis	1
Scoliosis kyphosis	1
Scheuermann's Disease	1
Silent reflux	1
Sjogren's syndrome	1
Slow motility	1
Symphysis pubis dysfunction	1
Syringomyelia	1
Underactive thyroid	1
Urticaria	1
Vitamin B deficiency	1

Appendix 6: Case Studies

Hypermobility:

The past...

The hardest bit for me was not having a diagnosis and repeatedly being made to feel like I was making things up, or being dramatic.

Misdiagnosed, missed opportunities, wasted resources and unnecessary pain and frustration for all involved.

I knew I was a bit different... I felt like I was old before my time.

Until I found the HMSA in the late 90's I didn't know anyone else with the same condition and sometimes I felt like a hypochondriac

I think there's a feeling (among doctors) that 'there's nothing that can be done and so why are you being sent to me?'

Social services really struggled with the unpredictability of my EDS and it's symptoms.

On accessing support at work: **I've found the process often quite disappointing, embarrassing and humiliating.**

The present...

There isn't a clear referral pathway.

Living with hypermobility now is frustrating, I don't know where to turn half the time.

Most injuries I self-treat.

Do your own research, diagnose your own condition, find out where the expert specialists are and battle like hell to get to see them.

It is extremely frustrating to be told that it's just how my body is and I have to live with it.

Being better informed means I don't panic so much when a new symptom comes along.

Having a diagnosis was very validating and helped me to describe to others what was going on in my body. Whilst a diagnosis doesn't change symptoms, it gives you an anchor and a compass.

The future...

There definitely needs to be a better pathway to a diagnosis.

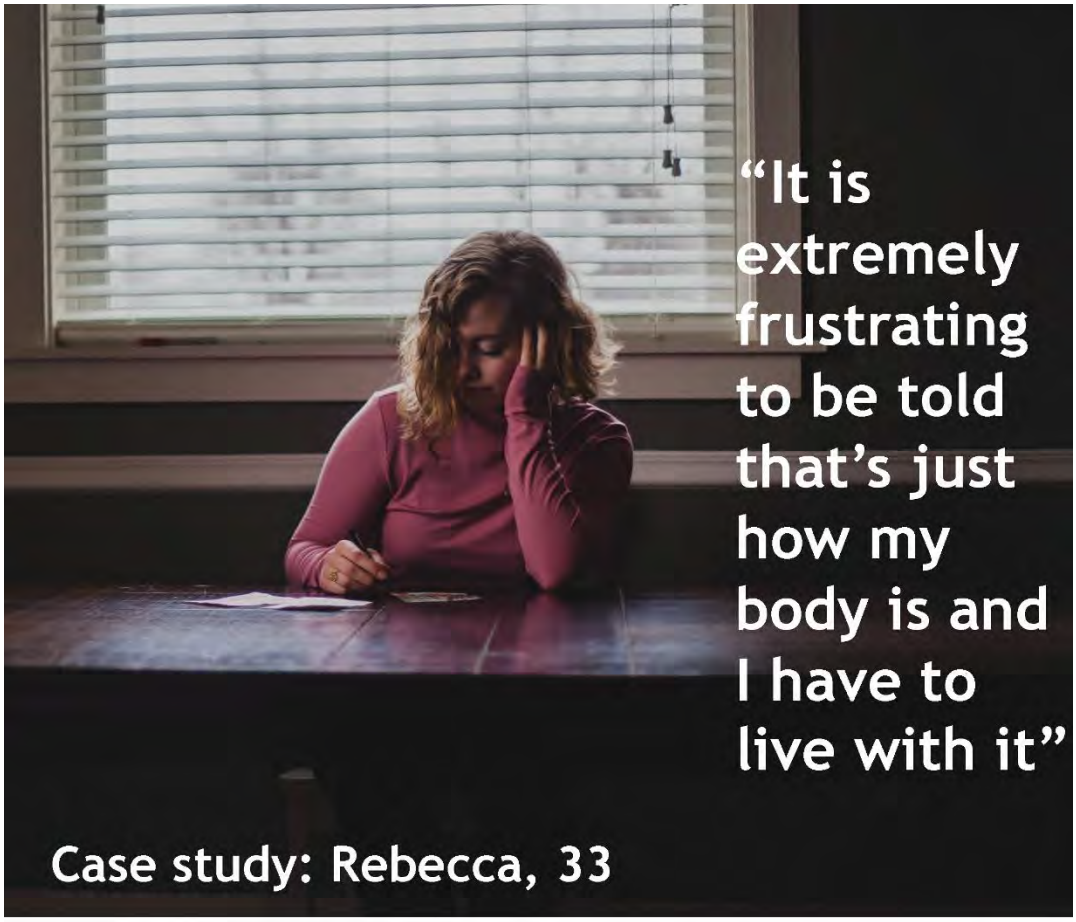
We need a team we can go to for support as our condition can fluctuate it would be nice to have that open door.

One thing that would really help me would be quick access to physios... a phone call or Skype.

Have a dedicated clinic for people with a hypermobility syndrome in the same way as there are diabetes clinics.

Assess children more thoroughly from a younger age/review as they develop.

I hope that the increased awareness will eventually translate into increased research.



I grew up in the 1990's and my family thought I could do amusing party tricks with my hypermobile joints, but I felt from an early age not enough was done to understand why and how it may affect my life in years to come.

It took a long time for me to be properly assessed and diagnosed. Often I was just sent for physio and rehabilitation by General Practitioners (GPs) who saw my injuries as single occurrences rather than viewing my body holistically and recognising symptoms of a wider syndrome or dysfunction.

I was diagnosed with postural orthostatic tachycardia syndrome (PoTS) at age 24 and I was I referred to a hypermobility clinic.

The clinic (genetic specialists) was really based in a children's hospital. I was seen and assessed once - told I had mild type 3 'hypermobility syndrome' (Ehlers Danlos syndrome; this is now known as hypermobile Ehlers Danlos Syndrome) and that I wouldn't need to be seen again.

I have been experiencing severe neck, shoulder and back pain for nearly 7 years.

Now I'm 33 and it is extremely frustrating to be told that's just how my body is and I have to live with it.

'It's times like that when I feel resentment for not having been recognised early on in life and something could have been done to support me so I don't result in these recurring pains and injuries.'

I think it would be better to assess children with hypermobility more thoroughly from a younger age and review them as they develop and help families to understand the importance of things which support a child in their development if they are hypermobile.

For example, ensuring a child has the correct footwear and encouraging choices in physical activity that support joint protection to help assist the child to develop good habits.

Children need to develop into confident young people who know their body, its limits and feel confident and positive but this will only come from those around them supporting this ethos.

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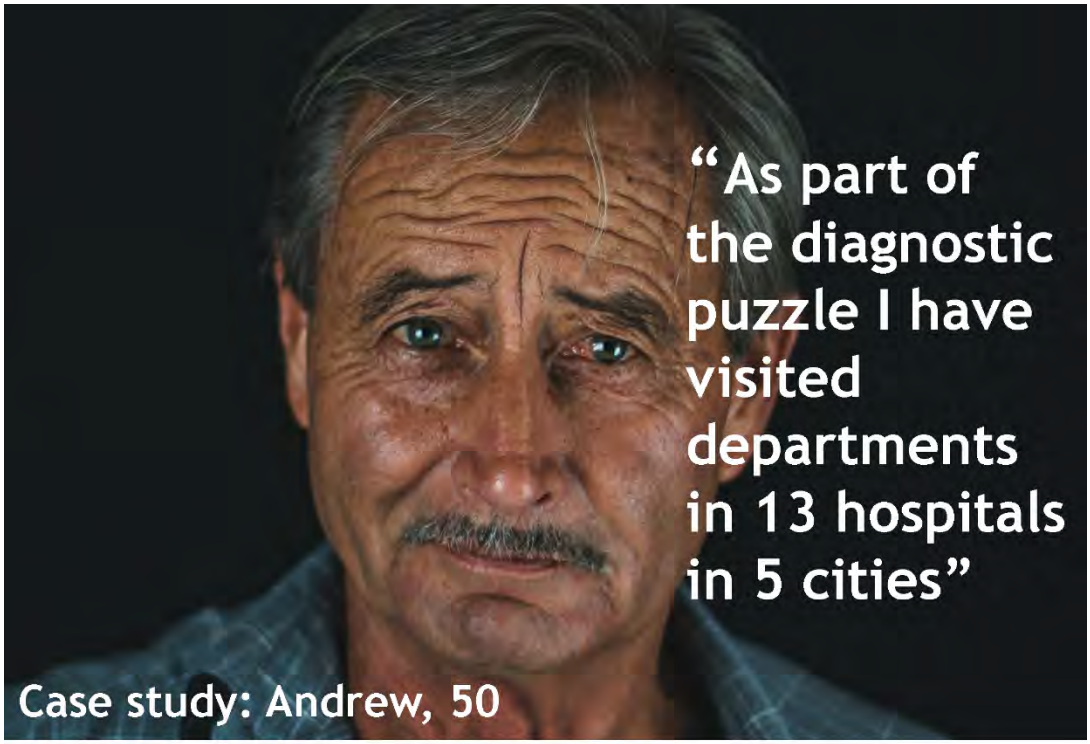

Life with a hypermobility syndrome can be summed up as misdiagnosed, missed opportunities, wasted resources and unnecessary pain and frustration.

I have been living with hypermobility spectrum disorder (HSD) all my life, for much of it I just didn't know that is what was causing my problems.

I started out with congenital foot deformities, which can be associated with weak connective tissue. These required surgical correction. I always had sprained ankles and wrists, lots of muscle and joint aches and pains, plus problems with lower back pain and my knees.

"It's just growing pains", "your over sensitive", "tests are normal, there is nothing wrong", "you'll have to live with it" was the never-ending refrain.

I lived with it, managed through school and college and then at work. I had periods of absence from my education and work during bad times up until 1990 when my health really started to go downhill following a bad viral infection. I was eventually labelled with Chronic Fatigue Syndrome (CFS).

As various new symptoms began to appear, I slowly diverged away from a CFS diagnosis but continued to have unsatisfactory encounters with various medical professionals but with nothing was found.

It all changed when, I brought an action for disability discrimination relating to a benefits assessment I had had.

This led to the most thorough examination by a leading CFS specialist who asked if I'd been assessed for heritable diseases of the connective tissue.

Since then, as part of the diagnostic puzzle, I have visited multiple departments in 13 different hospitals in 5 cities. I have collected diagnoses of HSD, benign familial hypermobility syndrome with Marfanoid features, postural orthostatic tachycardia syndrome (PoTS), a spinal cerebrospinal fluid (CSF) leak, and hereditary alpha tryptasemia syndrome. I can say with absolute certainty that I know far more about my condition than the professionals do due its rarity. My General Practitioner (GP) will not prescribe some of my medication without the consultant's permission.

For under-recognised conditions where there are no specifically commissioned NHS services or referral/management pathways, your NHS care is down to chance - whether or not your GP knows a consultant in the area who is up to date and knowledgeable.

"You have to be able to do your own research, diagnose your own condition, find the expert specialists and battle like hell to get to see them".

I think there needs to be a specialist clinic where patients are seen and mostly supported by a small team of nurse specialists who can refer on as necessary.

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