



# Health and social care experiences of people with hypermobility spectrum disorder (HSD) and hypermobile Ehlers–Danlos syndrome (hEDS)

National feedback:  
late 2019–2020

**healthwatch**  
Calderdale

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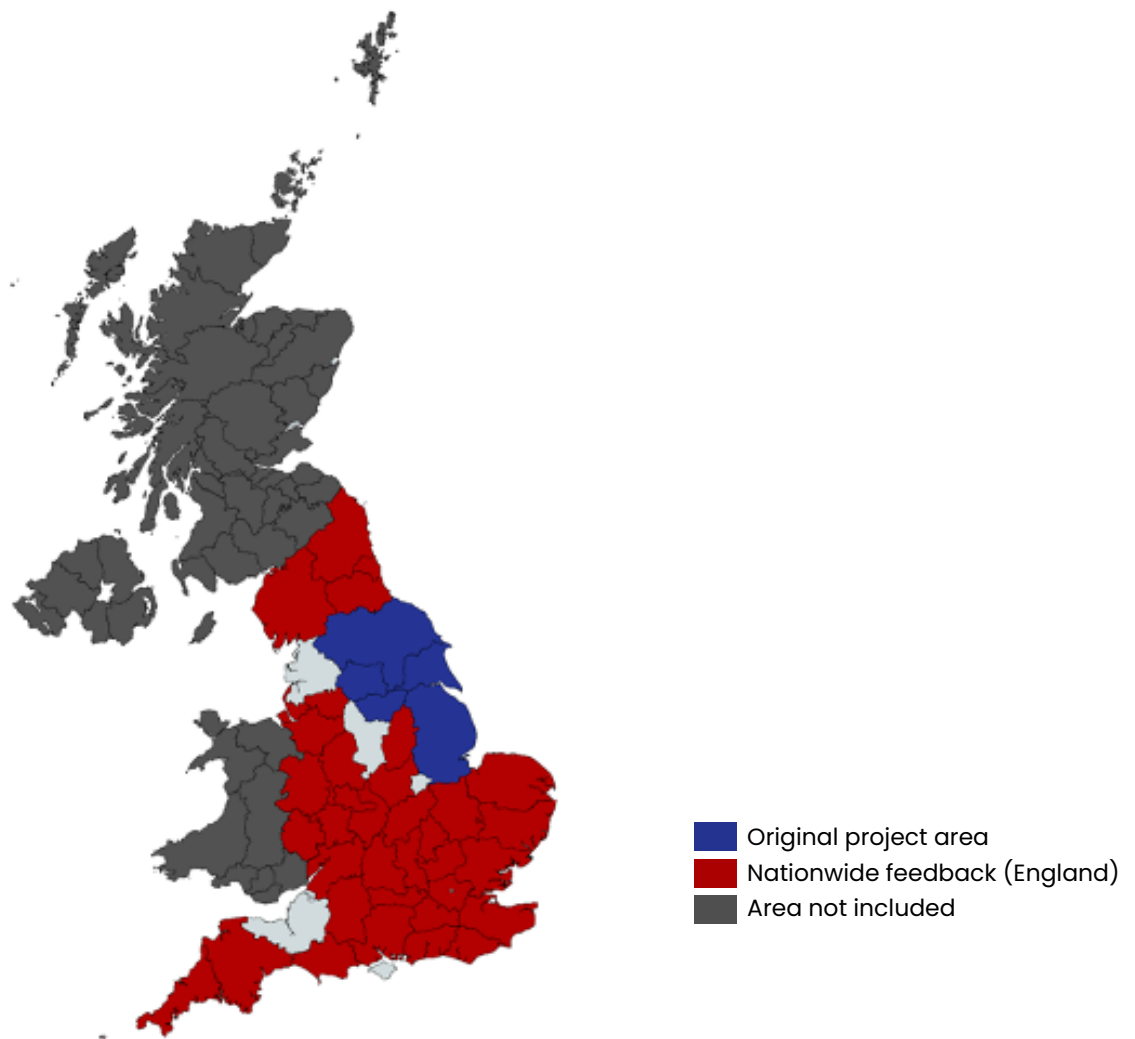
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# Introduction

Local Healthwatch across Yorkshire and the Humber published a report in 2019 on the health and social care experiences of people with hypermobility spectrum disorder (HSD) and hypermobile Ehlers-Danlos syndrome (hEDS). The issues were then raised locally by Healthwatch Calderdale, which led the work nationally via an adjournment debate in the House of Commons and on social media (2019). At this point, Healthwatch Calderdale started to receive feedback directly from people across the country sharing their own experiences of NHS care for these types of hypermobility syndromes.

While we are unable to support people outside of the Calderdale area, we decided to collate the national feedback as an update to our work as it shows the issues we discovered in our work in Yorkshire and the Humber are also being experienced in other parts of the country.

The detail in this report comes from feedback from people across all but a few areas of England (see red areas highlighted on the map)



# Main themes from national feedback

- Why local Healthwatch organisations elsewhere are unable to explore issues surrounding NHS care for these types of hypermobility syndromes
- Lack of General Practitioner (GP) knowledge of conditions
- Difficulties obtaining referrals
- Diagnosis issues
- Poor access to NHS care
- Private assessments
- Life Impact
- Lack of joined-up support for children
- How the situation could be improved

## Local Healthwatch unable to explore hypermobility

### West Midlands

One person contacting us asked their local Healthwatch to explore the issues around NHS care of these conditions. They were told that staff needed more resources to explore it independently or with other local Healthwatches.

**“We do not think the work needs to be duplicated in (Healthwatch area) as Healthwatch Calderdale has worked in partnership with 15 other Healthwatch and written a very informative report. With their permission we will use this report to influence commissioners in the West Midlands.”**

### South West

Another person from the South West told us.

**“I can say without a shadow of a doubt that your local findings are mirrored elsewhere in the country. The themes highlighted in your reports are ones I hear on a daily basis and have experienced myself.”**

# GPs lack of knowledge about the condition

People stated that their GPs did not know the condition or other conditions that are relatively common in people with hypermobility such as postural tachycardia syndrome (PoTs) and mast cell activation syndrome (MCAS).

**“Three GPs had not heard of it. Had tilt table test and confirmed I had PoTS. No treatment was offered. Specialist said ‘We don’t know much about it.’”**

**“Not one of several GPs or specialists believed in it or had heard of it. No treatment offered.” (referring to MCAS)**

## North West

One person told us that their GP talked about mental health when they first described their symptoms. This person struggled on for months experiencing much pain, before asking for a second opinion. On the second occasion, their mental health was once again explored.

## Tyne and Wear

**“I have had several different GPs who have left my GP practice and I currently do not have one who is familiar with my condition.”**

## London

**“There is an absolute lack of training and knowledge on this condition so unless the patient studies it they are unlikely to get diagnosed and even less likely to access proper treatment and service. I was dismissed several times by my GP for problems related to my hypermobility, and for some, I still have not been able to access treatment.”**

## East Sussex

**“GP had not heard of it. Persuaded him to refer me to the London EDS clinic.”**

## Teesside

**“I spent my whole life in and out of doctor’s offices. I’ve always been met with a lot of I stumped medical professionals and felt like I had to take control of the situation myself.”**

**“I was abnormal as a child and saw many, many, health professionals. Not one picked up on my hypermobility. I wish to live in a world where everyone understands pain, always in pain, and doctors not understanding why.”**

**“A common response is, ‘Oh, you’re a bit bendy, yeah?’. Which conveniently ignores the various other symptoms that have spanned the last 20 years and seen me ushered into various consultants, wards, doctors, surgeries, nurses, specialists, prescriptions, all while trying to alleviate a single symptom while my health declines further.”**

## **Difficulties obtaining a referral**

### **London**

**“I started having symptoms in my teens that were put down as growing pains or dismissed. I’ve been trying to find what was wrong with me for years and I have countless medical appointments and tests behind me. As it is often the case, I felt I had to become ‘my own doctor’, as I was constantly dismissed, not believed, told to get on, that it was just anxiety or all in my head/psychosomatic (as if by telling me that, magically, it would just disappear.”**

### **South West**

One person in the South West was in her 40s by the time she got a diagnosis which fitted her symptoms. She described her experience as:

**“40 years of completely incorrect treatment. Prior to diagnosis, I was treated as though I was a hypochondriac (even though I reported the same issues repeatedly – pain, dislocations, fatigue, gastro issues, etc.) and repeatedly fobbed off with ‘you must be stressed/depressed’.”**

### **North West**

One person had to really press for a referral to a neurologist, then later found the clinician had put on the referral: ‘Obvious self-harm scars on left arm’ – scars which were decades old. They waited over 12 months to see the neurologist. Once they did see the neurologist their symptoms were taken seriously, but the patient felt the pathway to getting there was challenging.

### **London**

**“What I wanted investigated was mast cell activation syndrome (MCAS), and I found out from Facebook that the Ehlers–Danlos syndrome (EDS) toolkit for GPs mentioned MCAS. I had never heard of EDS before, but reading it made instantly so much sense. I went to see my GP and told him I wanted to be evaluated for EDS. He wasn’t convinced but tested my hypermobility and agreed to refer me. He tried to refer me to University College London Hospitals (UCLH), but it was refused as I was out of the area and the specialist service is a tertiary referral.”**

# Diagnosis issues

## Teeside

One patient says a local gastroenterology doctor has forcibly sectioned some patients because they cannot eat due to gastroparesis, which often affects people with hypermobility. This doctor removed their feeding tubes and deemed them because t **“Why did it take 28 years for a health professional to recognise me? I can’t afford my kids or me to get a private diagnosis, which is devastating. Otherwise, I would’ve been diagnosed a very long time ago.”**

## Essex

**“At that hospital, they were adamant that my pain was simply an injury that had ‘healed’ and my pain was due to pain gates still being open, and my ‘fear’ of moving, I argued that this was not the case. I was right they were wrong but too blinkered to see what was staring them in the face. They only saw what they wanted to see. It was 25 years ago and it still angers me now.”**

# Poor access to NHS care

## South West

Getting care/treatment after a diagnosis wasn’t straightforward for one person, who said: **“There is no local specialist service and consequently because of the issues I was facing and negative outcomes from previous inappropriate treatment I was referred to London.”** This person reported that the London-based specialist is overwhelmed with referrals so unable to take on more patients.

## North West

A person “pleaded” for physiotherapy for her neck and shoulders to manage the pain and keep the muscle strength, but none was received.

## Tyne and Wear

**“I am constantly in pain and have digestive and neurological issues that have not been investigated, cannot stand without pronounced heart rate increases causing dizziness, vision blackouts and possible fainting, then overheating, flushing and sickness which can only be relieved by lying down, and severe fatigue.”**

**“I feel as if I have exhausted every avenue for seeking help with my conditions, many of which have not been monitored since diagnosis.”**

## **Teesside**

**“A proper care pathway is so desperately needed for sufferers of people with Ehlers-Danlos Syndromes and hypermobility spectrum disorders because right now it’s fragmented at best and quite frankly is terrible. Even things like counselling aren’t offered, and we have so much to deal with its overwhelming, to say the least. If we had a proper care pathway, people would be diagnosed earlier instead of being sent for individual problems to be dealt with such as a referral for a knee problem, a back problem and so on. When it’s fragmented like this, it’s not picked up on quickly, leading to us suffering more and for longer and this in turn, is a bigger burden on the NHS.”**

## **Essex**

**“I naively thought that once I got the EDS diagnosis, getting access to the correct treatment would be straightforward, but this has not been the case. Everything is a battle; most medical professionals are ignorant about EDS and hypermobility. There is no joined-up thinking. I have to get referred here, there and everywhere and wait months to see anyone in the hope that I will be lucky enough to see someone who knows something about this condition. My GP is sympathetic but does not know what best to do to help me, and I am becoming increasingly exhausted and jaded by it all.”**

# **Private assessments**

## **North West**

Due to poor feedback about NHS care, one woman was told she would have to be seen out of the area, which would unlikely be funded, so she faces paying privately for tests. She expects the initial cost to be £1,650.

## **Essex**

**“In spite of many years of what I can now see are typical hypermobile EDS symptoms, I was not diagnosed until I was in my 50s. It was only because of a chance meeting with someone with EDS and coincidentally a passing remark from a private pain management consultant when I was concerned about continuing symptoms in spite of treatment. “Well you are hypermobile after all” to which I replied, “Am I?” I consequently sought diagnosis through a private rheumatologist; fortunately, we had medical insurance.”**

**“I have been getting some help from an osteopath, not available from the NHS of course; I have to pay for it. The osteopath is positive I have scoliosis, but this again has not been picked up by any NHS doctors or physios. When I mentioned it to one of the junior NHS physios, he dismissed the idea, saying that he very much doubted it as it ‘would have been picked up by now’.”**



# Life impact

## Tyne and Wear

One individual has been unable to work and was told by a specialist physiotherapist to use a wheelchair at all times outside. She receives Personal Independence Payment (PIP) at the lower level of daily living allowance but does not receive anything for the mobility component. She receives no other benefits.

## North West

Another individual who sought advice outside of the NHS managed her pain to the extent that she has fewer seizures and can go outside daily, something she was unable to do prior. She can walk once a fortnight; prior to this, she hadn't walked in a year.

## Teesside

The dose and the volume of medications made one patient so unwell that it caused a bowel obstruction. The same patient had to give up studying halfway through their second year because of difficulties they were experiencing in managing their condition.

Another patient told us: **"I'm tired. I don't know how to fight the system anymore. My house is inaccessible to me. My wheelchair is inaccessible to me. I have no independence anymore. I have to rely on others, and I hate it."**



# Lack of joined-up support for children

## Warwickshire

One mother says she struggled to access joined-up healthcare and a clear referral pathway for her teenage child. She also says they struggled to access social care and mental health support, plus the Education, Health and Care Plan (EHCP) was not 'fit for purpose' and her child was missing education due to lack of support as a result of unsupported needs.

## South West

A mother with hypermobility found it hard to get a diagnosis and care for her children when they displayed symptoms. She said they were 'passed from pillar to post' adding **"Diagnosis needs to happen early to mitigate cumulative effects of the condition. My middle son is also showing many signs, and when I brought this up with his paediatrician, he has since been discharged because he didn't have a clue what it was."**





# Ideas for improvement

People called for

## **“A better treatment pathway within the NHS.”**

One person said: “As care and symptom management, ideally, calls for such a multidisciplinary approach, it seems to me that it is unclear to GPs and consultants who should be managing and collating this care. A better system of handover between GPs would also be useful, as it's difficult at the moment to find a GP, especially one familiar with EDS, who remains at one practice for any length of time.”

### **Essex**

“It has to change. We need multi-disciplinary EDS clinics to help us with our various problems. So many people are suffering like I am and the NHS is doing little to help us.”

Another felt regional centres of excellence would be a helpful idea: “It would be good to have a dedicated clinic for people with a hypermobility syndrome in the same way as there are diabetes clinics.”

### **Teeside**

“There should be a standardised pathway for all EDS/HSD patients. That way both medical professionals and patients know where they stand.”

“A proper care pathway is so desperately needed for sufferers of people with Ehlers-Danlos Syndromes and hypermobility spectrum disorders because right now it's fragmented at best and quite frankly is terrible. If we had a proper care pathway, people would be diagnosed earlier instead of being sent for individual problems to be dealt with such as a referral for knee problem, referral for back problem and so on. When it's fragmented like this, it's not picked up on quick enough leading to us suffering more and for longer and this in turn is a bigger burden on the NHS.”

This feedback will be passed to Health England, the charities Ehlers Danlos Support UK and the Hypermobility Syndromes Association and the Ehlers Danlos Society.


# healthwatch Calderdale

Healthwatch Calderdale  
The Elsie Whiteley Innovation Centre  
Hopwood Lane  
Halifax  
HX1 5ER

[www.healthwatchcalderdale.co.uk](http://www.healthwatchcalderdale.co.uk)

t: 01422 412141

e: [info@healthwatchcalderdale.co.uk](mailto:info@healthwatchcalderdale.co.uk)

 [Facebook.com/HealthwatchCalderdale](https://www.facebook.com/HealthwatchCalderdale)

 [@hwcalderdale](https://twitter.com/hwcalderdale)

*Instagram /hwkirklees/*