

## Hypermobility: national feedback

### November, 2019 update

After Healthwatch Calderdale's work into hypermobility syndromes was raised locally, nationally via an adjournment debate in the House of Commons and on social media nationally, we have been contacted directly by people across the country sharing their own experiences of NHS care for hypermobility syndromes.

While we cannot represent people individually outside of the Calderdale area, we decided to collate the national feedback as an update to our work as it shows the themes we discovered in our work in Yorkshire and the Humber are being experienced in other parts of the country.

Geographical areas where people have contacted us from are: Warwickshire, Herefordshire, the North West, South West, Sunderland, Kent and London.

### Main themes from national contacts:

- Why are local Healthwatch organisations elsewhere unable to explore hypermobility?
- GP lack of knowledge of condition
- Difficulties obtaining referrals
- Misdiagnosis
- Poor access to care
- Negative impact on wider health
- Private assessments
- Impact on life
- Lack of joined-up support for children
- Ideas

### Local Healthwatch unable to explore hypermobility:

Warwickshire: One person contacting us asked her local Healthwatch in the Midlands to explore the issues around hypermobility. She was told staff did not have the resources to explore it, either independently or with other Healthwatch local to them.

She was told: *"...We do not think the work needs to be duplicated in (Healthwatch area) as Healthwatch Calderdale have 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."*

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 of condition:

North West: One woman told us that her GP talked about mental health when she first presented her symptoms. She struggled on for months experiencing much pain, before asking for a second opinion due to her experience the first time. On the second occasion, her mental health was once again explored ahead of her presenting symptoms.

Sunderland: *“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”.*

South 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”.*

#### Difficulties obtaining a referral:

South London: *“How long did it take to get a diagnosis? I started having symptoms in my teens which were put down as growing pains or just dismissed. I've been trying to find what was wrong with me for years and I have countless medical appointments and test 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 woman 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”* adding *“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 fought 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. She waited over 12 months to see the neurologist and was admitted to the Accident and Emergency Department prior to that due to her condition. Once she did see the neurologist her symptoms were taken seriously, but she felt the pathway to getting there was challenging. She was also “accidentally” discharged from neurology so had to be re-referred and wait another 9 months.

South 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 general practitioners (GPs) mentioned MCAS. I had never heard of EDS before, but reading it made instantly so much sense. So I went to see my GP and told him I wanted to be evaluated for EDS. He wasn't convinced at all, but he did test 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 area and the specialist service is a tertiary referral.”*

#### Misdiagnosis:

North West: *“One clinician logged an ailment on the system as the patient having “a funny turn”.*

North West: GP told one woman her magnetic resonance imaging (MRI) scan was normal, but having learnt about hypermobility & craniocervical instability 18 months later, the patient requested a copy of her MRI and saw it was abnormal in various ways, plus her brainstem was being compressed, which was missed.

#### Poor access to care:

South West: Getting care/treatment after a diagnosis wasn't straightforward for one woman, 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.”* She said the London-based specialist is overwhelmed with referrals so are unable to take on more patients.

North West: a woman “pleaded” for physiotherapy for her neck and shoulders to manage the pain and keep the muscle strength, but none was received.

Sunderland: *“I am constantly in pain, 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”.*

*“If I attempt to “push” through my symptoms, my immune system weakens causing me to catch viruses and infections, often multiple at one time, which exacerbates my other conditions and becomes very difficult to recover from. I feel as if I have exhausted every avenue for seeking help with my conditions, many of which have not been monitored at all since diagnosis.”*

South London: *“I have been on physiotherapy services which made me worse. I have gotten worse since my diagnosis but cannot access any physiotherapy nor specialist services as my GP feels I've had “too many”.*

#### Negative impact on wider health:

North East: One woman told us that even after her diagnosis, any other medical issue is then “assumed” to be linked to her hypermobility. The woman said: *“This is poor and shoddy care and further upsets the feelings of sufferers who frankly in*

*the majority rather than minority of cases have been fobbed off their entire lives and treated like hypochondriacs. This is a national scandal and absolutely needs to change.”*

Sunderland: Individual was told that because she was assumed to have Hypermobility EDS, a life-threatening condition, which she also has, is not being explored with genetic testing.

#### Private assessments:

North West: due to poor feedback about NHS care, one woman was told she would have to be seen out of area, which would unlikely to be funded, so she faces

#### Impact on life:

Sunderland: one woman has been unable to work and was told by a postural orthostatic tachycardia syndrome (POTS) 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 do not receive anything for the mobility component. She receives no other benefits.

North West: another individual, who sought advice outside of the NHS, was able to manage her pain to the extent she has less seizures and is able to 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.

paying privately for tests. She expects the initial cost to be £1,650.

#### 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 son. 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, who has hypermobility herself, found it hard to get a diagnosis and care for her children when they were displaying symptoms. She said they were “passed from pillar to post” adding *“Diagnosis needs to happen early to mitigate cumulative effects of the condition.”*

#### Ideas:

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 very useful, as it's very difficult at the moment to find a GP, especially one familiar with EDS, who remains at one practice for any length of time.”*

Another felt regional centres of excellence would be a useful idea.