

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 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-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, akin 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 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



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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 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).

healthwatch
Calderdale

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 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 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