

# 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