



Supporting and working with community groups and clubs to promote a deeper understanding of local health and care needs and experiences

Spotlight on Multiple System Atrophy (MSA) Trust

The Multiple System Atrophy Trust www.msatrust.org.uk is the UK's leading charity supporting people affected by multiple system atrophy (MSA) - a rare neurological disease with no known cause or cure. The condition, which affects adult men and women, can result in problems with movement, balance and autonomic functions of the body such as bladder and blood pressure control.

The Trust's Vision is a world free of MSA. Their Mission is to find the cause and, ultimately, cure for MSA. Until that day, they do all they can to support people affected by MSA and strive to ensure that they are not alone on their individual journeys.

The Sussex Support Group covers both East and West Sussex and hold free meetings quarterly at Worthing Quaker Meeting House Worthing BN11 5DR.

You can find details of meeting times on the Trust's website (see Support Group bottom left of the home page). For more information about joining this group, please contact the Trust Office on support@msatrust.org.uk

The key topics people from the MSA support group chose to speak to Healthwatch about were:

- Understanding the MSA services
- Difficulties in accessing condition specific GP's and local Parkinson's Nurse Specialist
- Unclear communication by health care professionals
- Support for Carers

The insight from each person was collated and anonymised and forms part of the insight and evidence that Healthwatch gather to identify common themes around what works and doesn't work for local people.

This insight is used to influence services development and feeds into:

- West Sussex Health and Wellbeing Board
- HASC - Health and Adult Social Care Select Committee
- WSCC Joint Strategic Needs Assessment
- Safeguarding Adult Board
- NHS Sustainability Transformation Partnership workstreams (Sussex & East Surrey).

In this way, voices and experiences from the MSA Trust Support Group Worthing help to influence the ongoing development of Health and Social Care in our County.

Healthwatch West Sussex also share reports with the Care Quality Commission (who are responsible for the registration and inspection of services which deliver regulated activities) and to Healthwatch England to form part of the national picture used to influence national developments, such as the NHS70 10 year forward plan.



Not only do we collect the experiences of local people, but we can also provide free information and guidance just call: **0300 012 0122**.

Email helpdesk@healthwatchwestsussex.co.uk,
Website www.healthwatchwestsussex.co.uk.

You can also follow our social media channels:

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

Twitter [@healthwatchws](https://twitter.com/healthwatchws)

healthwatch
West Sussex

If you would like to learn more about attending the Worthing MSA Support Group contact the Trust Office on support@msatrust.org.uk

If you are setting up or would like to share news of a similar project we would be interested to hear from you. Please contact Cheryl Berry, Partnership Co-ordinator, email: cheryl.berry@healthwatchwestsussex.co.uk