



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

Spotlight on the Macular Society

The Macular Society is the charity determined to beat the fear and isolation of macular disease with world-class research, and the best advice and support.

With the help of its members and supporters, it:

- Funds new research into a cure so that future generations won't suffer from sight loss caused by macular disease
- Helps people of all ages adapt to life with sight loss, by supporting them to regain confidence and independence so they can take back control of their lives.

Macular disease is the biggest cause of blindness in the UK. Nearly 1.5 million people are currently affected and many more are at risk. The disease can have a devastating effect on people's lives, leaving them unable to drive, read or see faces. Many people affected describe losing their sight as being similar to bereavement. There is still no cure and most types of the disease are not treatable. Age-related macular degeneration (AMD) is the most common form of macular disease, affecting more than 600,000 people, usually over the age of 50.

In West Sussex, the Macular Society runs 11 macular support groups to help increase the confidence and independence of people affected by macular disease across the region. Organised by the Society in partnership with local people, the groups offer information, encouragement and friendship to people with macular conditions, their friends and families.

For more information about macular support groups, and the Macular Society's work in West Sussex, please contact Stella Black, Macular Society regional manager, on 01306 644 908 / 07494 467 980, or email stella.black@macularsociety.org

The key topics people chose to speak to Healthwatch about were:

- Difficulties in accessing own GP appointments
- Unclear communication and lack of communication between health care professionals
- Loss of local and hospital transport and problems this is causing
- Cost of NHS medication for eye conditions.

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 can feed 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).

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.

healthwatch
West Sussex

You can also follow our social media channels:

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

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

For more information about macular disease, contact the Macular Society on:

Macular Society
Beating Macular Disease

Telephone: Advice and Information Service - **0300 30 30 111**.

Email: help@macularsociety.org Website: www.macularsociety.org

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, Community Partnership Co-ordinator, email: cheryl.berry@healthwatchwestsussex.co.uk