## **Partnerships**





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

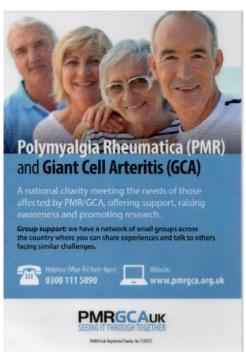
## Spotlight on the Polymyalgia Rheumatica and Giant Cell Arteritis Support Group

PMRGCAuk - The Polymyalgia Rheumatica and Giant Cell Arteritis UK registered charity was set up to meet the needs of people with these debilitating conditions, along with their friends, family and professionals. They offer information and support at all stages - from diagnosis through to recovery. Above all, they offer hope.

Polymyalgia Rheumatica (PMR) and Giant Cell Arteritis (GCA) are linked rheumatic conditions, little known by the public and poorly understood in medicine. Causing severe pain and discomfort, the standard treatment is long term use of corticosteroids. Undiagnosed and untreated, GCA can lead to catastrophic sight loss - but this can easily be prevented if caught in time.

Polymyalgia rheumatica (PMR) is a condition that causes pain, stiffness and inflammation in the muscles around the shoulder, neck and hips.

Giant cell arteritis (GCA), or temporal arteritis, is an inflammatory disease affecting the large blood vessels of the scalp, neck and arms. Inflammation causes a narrowing or blockage of the blood vessels, which interrupts blood flow. The disease is commonly associated with polymyalgia rheumatica.



The PMRGCAuk has a network of Support Groups across the country where people can share experiences and talk with others facing similar challenges. One such Support Group meets each month at Pagham Small Hall.

The insight from those who attended the PMRGCAuk Support Group in Pagham was collated and anonymised and forms part of the insight and evidence that Healthwatch West Sussex gather to identify common themes around what works and doesn't work for people living with these health issues.

## Healthwatch West Sussex use this insight to influence service development and 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 <a href="mailto:helpdesk@healthwatchwestsussex.co.uk">helpdesk@healthwatchwestsussex.co.uk</a>, Website <a href="https://www.healthwatchwestsussex.co.uk">www.healthwatchwestsussex.co.uk</a>,



You can also follow our social media channels: Facebook <u>@healthwatchwestsussex</u>
Twitter <u>@healthwatchws</u>

For more information about the PMRGCAuk Support Group in Pagham

Contact: Patricia Dawson, Telephone number: 01243 263866

www.pmrgca.org.uk Helpline: 0300 111 5090

email: helpline@pmrgca.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, Community Partnership Co-ordinator, email: <a href="mailto:cheryl.berry@healthwatchwestsussex.co.uk">cheryl.berry@healthwatchwestsussex.co.uk</a>