‘Polymyalgia Rheumatica & Giant Cell Arteritis: A Survival Guide – Second edition’

To help you through your PMR and GCA journey

Author, Kate Gilbert, PhD, has distilled what she has learned from the experience of having PMR (and recovering!), and from years of working alongside those living with PMR/GCA, rheumatologists and researchers, during her years as a trustee of PMRGCAuk. The book has chapters of factual information on PMR and GCA, on living with these illnesses and maintaining quality of life, on managing steroids and other medication, and on finding support.

“I have tried to write the book that I would have liked to read when I had PMR, not only when I was first diagnosed, but also a few months in, when I realised that it wasn’t going to be as straightforward as they had led me to believe.”

Kate Gilbert

Further Information

Information on PMR and GCA and how the charity can support you can be found on our website: **www.pmrgca.org.uk**

A free digital or hard copy information pack is available from the website, including:

- British Society for Rheumatolgy Guidelines for the Management of PMR and GCA.
- Information on all the support groups in the UK.
- A copy of our most recent NewsWire, the charity’s magazine, with information on medical advances.
- Membership information.
- Versus Arthritis booklets on PMR and GCA.

Support Groups

Our network of support groups around the country is growing! Scotland is an independent organisation, but it is affiliated to PMRGCAuk. If you don’t have a group near you and would like to help us start one, please contact us.

Find a group near you at: **www.pmrgca.org.uk/get-support/groups/** or call us on **0300 999 5090**

PMRGCAuk Helpline

Our volunteers are available during the day, Monday–Friday, 9am–5pm, and if they are unable to speak to you immediately, will return your call as soon as possible.

Helpline: **0300 111 5090**
Email: **helpline@pmrgca.org.uk**

Please remember we are unable to give medical advice.

Online Forum

Join our lively online forum for support and to share your experiences of living with PMR/GCA.

https://healthunlocked.com/pmrgcauk

General contact details

Website: www.pmrgca.org.uk
Facebook: facebook.com/pmrgcauk
Twitter: @pmrgcauk
Office: 0300 999 5090

Registered Charity: No 1128723

PMR GCA UK

Polymyalgia Rheumatica & Giant Cell Arteritis UK

Symptoms

PMRGCAuk is the national charity supporting people in the UK affected by polymyalgia rheumatica (PMR) and giant cell arteritis (GCA)

Polymyalgia rheumatica (PMR)

Polymyalgia rheumatica (PMR) is an inflammatory condition of unknown cause. It is recognised as an autoimmune illness. It causes pain, tenderness and stiffness in the large muscles around the shoulders, hips and back. It uniquely affects people over the age of 50 with the peak being in people in their 70s and 80s. It tends to affect women more than men.

What are the symptoms?

- Stiffness, pain, aching, and tenderness in the muscles around the shoulders, pelvis, and neck
- Symptoms that are worse early in the morning but ease during the day
- Difficulty turning over in bed, getting out of bed, reaching and rising
- Fatigue and/or depression
- Night sweats and/or fever
- Loss of appetite and/or weight loss.

What tests are needed?

Symptoms can be similar to some other conditions. Blood tests are helpful to confirm whether there are signs of inflammation in the body. However this can also be seen in many other medical conditions, so interpretation by a doctor is essential.

What is the treatment?

Prednisolone (glucocorticoid or "steroid") is the usual treatment. It reduces inflammation and quickly eases symptoms.

A starting dose of about 15mg per day is gradually reduced (tapered) over many months, sometimes years, to a smaller dose. Many patients are able to stop treatment eventually but can vary quite considerably, from two years for a straightforward case to several years for other cases.

Are there any complications?

About 1 in 20 people on treatment for PMR develop giant cell (or temporal) arteritis (GCA), a related condition causing inflammation of arteries.

Giant cell arteritis (GCA) (or temporal arteritis)

GCA is a disease know as 'giant cell' because of the presence of very large inflammatory cells in the wall of the arteries, causing them to swell and sometimes become occluded.

The condition affects large arteries in the head, neck, upper limbs and main artery of the body, the aorta. Historically, the condition was sometimes called 'temporal arteritis' because the temporal arteries were seen to be visibly swollen and the involvement of the deeper blood vessels was not recognised.

GCA afflicts people over the age of 50, though the peak age is in those between the ages of 60 and 80. It typically affects women more than men and those of northern european descent.

What are the symptoms?

If you have these symptoms, especially if you have a history of PMR, contact your doctor immediately:

- Headaches – the exact form that can take can vary, but the pain of GCA is a new headache, of the kind that the person hasn't had before
- Pain in the head
- Tenderness of the scalp, eg when you comb your hair
- Blood vessels at the temples may look or feel prominent
- Sudden loss of vision
- Double vision

People may also experience:

- Tiredness
- Low mood
- Night sweats
- Fever
- Loss of appetite
- Weight loss

What tests are needed?

Blood tests have to be done to look for the level of inflammation in the body. Abnormal tests do not confirm the diagnosis, but normal tests do make it less likely to make a diagnosis of GCA.

Your doctor will refer you to hospital on suspicion of diagnosis. The best way to diagnose the condition is with either an ultrasound scan, a biopsy of the temporal artery or (though this is more rare) a specialised scan called a PET scan.

What is the treatment?

Suspected GCA is usually treated immediately with a high dose of prednisolone (steroid) to reduce the risk of complications and relieve the headaches and other symptoms. Starting treatment immediately is important but your doctor must ensure that your blood tests are done prior to starting the treatments.

A typical starting dose of 40–60mg is gradually reduced over many months or years to a smaller dose. Some patients are able to stop their medication entirely after about two years, under medical supervision, but other people may need treatment for much longer.

Doctors may also prescribe additional medicines alongside prednisolone.

Are there any complications?

GCA left untreated could lead to the following possible complications:

- Loss of vision in one or both eyes
- Double vision
- Rarely: stroke or other consequences of a blocked artery.

Once treatment has been started, all of these complications are very rare.

Up to 50% of people with GCA also have symptoms of PMR at some time. This tends to respond very well to the same prednisolone treatment.