PMR GCA UK
Polymyalgia Rheumatica & Giant Cell Arteritis UK

£4.50 Free to members

NEWSWIRE

WINTER 2025
ISSUE 47

Read reports of our Members' Day speakers:

Professor Bhaskar Dasgupta MBE

Dr Claire Owen

READ KATH'S STORY OF NUTRITION TO HELP WITH PMR WEIGHT GAIN

Christmas Tips

DR SARAH MACKIE TALKS ABOUT SICK DAY RULES

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Welcome

A warm welcome from me in my first edition as Chair of PMRGCAuk.

There is a theme of change and new beginnings throughout these pages with the stepping down of my predecessor, Professor Humphrey Hodgson, and founding trustee, Wendy Morrison. Both of them played a huge part in making the charity what it is today and I'm looking forward to working with my fellow trustees, volunteers and staff, to carry on the baton they have passed to us.

A huge thank you to everyone who took part in Marathon in a Month. We're already planning ahead for next year, and Will Gregory, who helped us to launch the first campaign, is back with tips to get us walking through the winter months. Kath's story might be the inspiration needed to make some healthier nutrition choices going forwards. While it might be difficult to make changes during the festive season, the New Year often feels like a good time for a fresh start.

We are very grateful to our Members' Day speakers. Professor Dasgupta MBE and Dr Claire Owen gave their time and considerable knowledge to help further our understanding of the conditions we live with. Do read the reports for an overview of their presentations.

With my own experience of talking with people on the helpline and helping run the Brighton support group, I know that all our volunteers make an extraordinary difference to people with PMR and GCA. Various studies show that volunteering gives benefits to the volunteers, with one finding that 77% of volunteers improved their own mental health and wellbeing, and 90% benefited socially through meeting new people. The feedback we received from our support group organisers backs this up. Do find out a bit more about our support groups, how enjoyable they are to run and easy they are to set up. It would be lovely to see more of them in 2026.

Happy Christmas

Fiona Johnson
Chair of Trustees

CHRISTMAS OPENING HOURS

HELPLINE: The helpline will be "closed" on December 25th and 26th and also, on January 1st, 2025, as well as over the weekends. Calls to the helpline will go to the "out of hours" voicemail where messages can be left. These messages will be monitored and only calls deemed to be urgent will be returned. All other calls will receive a call back on the next working day.

OFFICE: The office will close at 5pm on 23rd December and reopen on 5th January 2026.

All information in this magazine is for informational purposes only and is not a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your doctor or other qualified healthcare provider regarding your own medical condition or treatment. Never delay in seeking medical treatment because of something you may have read in this magazine.

CHARITY NEWS

Welcome to our new Chair of Trustees

Fiona Johnson joined the charity in 2018 and initially became involved with the PMRGCAuk telephone helpline, which she now co-ordinates, as well as providing assistance to the Brighton Support Group. She became a trustee in 2023. Recently, Fiona has been nominated by PMRGCAuk to act as a 'patient expert' on the NICE Committee that is appraising Upadacitinib – a new potential medication for GCA. Fiona is also an 'Expert by Experience' member of the new Guideline Working Group for the update to the GCA clinical guidelines.

With a career in social work, Fiona brings a wealth of skills to her new role of Chair. She also has significant experience of working with medical staff to get appropriate treatments for her daughter who has a rare genetic condition. This helped when accessing health care for her own GCA.

On becoming Chair of Trustees, Fiona said: "I hope to ensure the charity is able to progress and strengthen its three main aims: supporting patients; fostering research; and educating professionals and the public about PMR and GCA. In recent years supporting patients has been a predominant concern of the charity and I want to sustain those functions, while increasing and expanding our input in campaigning for greater research into causes of, and better treatments for, PMR/GCA, whilst enabling fuller and better education of professionals and the public about both conditions.

In her spare time, Fiona is a keen gardener, cook, singer and cat-lover.

Professor Dasgupta receives his MBE

As reported earlier in the year, Prof Dasgupta was awarded an MBE for services to people with PMR and GCA.

He received his medal from Her Royal Highness The Princess Royal in July.

Farewell to...

Professor Humphrey Hodgson

Humphrey became Chair of Trustees in 2018. He steered the charity through the difficulties of Covid-19 and grew its standing in the world of research.

He set up constructive dialogues with the Department of Health (DoH), including with the then medical director of NHS England, to persuade them to put education of GCA further up the priority list. Using the Freedom of Information Act, he was also able to obtain information from the DoH to reveal which NHS trusts had, and importantly which did not, have ultrasound for fast-track GCA diagnosis.

During his tenure, the charity became an essential partner in any research application for work on PMR/GCA, including becoming a partner organisation with NIHR (National Institute for Health and Care Research). This involved setting up a peer review process that enables us to be recognised for involvement for grant giving and stands us in good stead for any similar projects in the future.

Under Humphrey's watch, the charity began to grow its fundraising capability to help ensure its long-term stability. He also encouraged Kate Gilbert to write the third edition of her very popular book on PMR & GCA which we are looking forward to next year.

We are very grateful to Humphrey for his considerable contributions and wish him all the best for the future.

Wendy Morrison

We also said farewell to trustee, Wendy Morrison who was one of the original founders of PMRGCAuk. We will pay tribute to Wendy's commitment to the charity and her work in the next edition of NewsWire.

OUR FIRST BIG GIVE CAMPAIGN!

We will have completed our first matched funding campaign with The Big Give at midday on 9th December*. Thank you to everyone who has supported this with donations, to our supporters who made pledges of funds totalling £1,500 and to our champion funder, Reed Foundation, who pledged £1,000. We hope we will raise sufficient donations to access all these pledges to help raise awareness of GCA.

(*If you're reading this before the deadline, it's still possible to make a donation at **www.donate.biggive.org/campaign/a05WS000006g2pyYAA**)

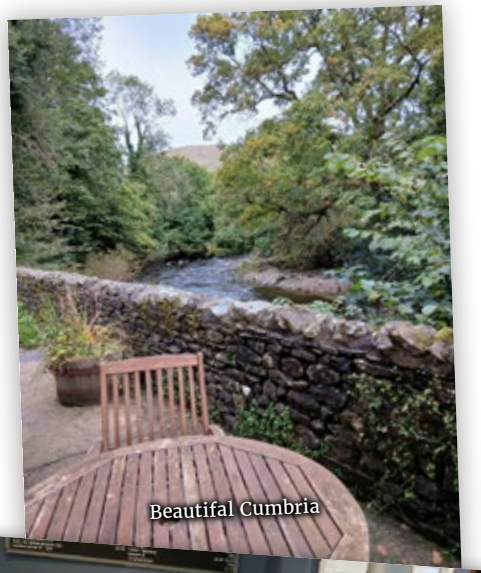
Groups around the country

Pat and Jude Wetters, organisers of North West & Cheshire group

Barnet group met in October and plan to meet again in December. They are expecting six new enquiries to attend as well as some regular attendees.

Brighton group now has 16 members and may need to look for an alternative venue. People appreciate the support and the fact they can ask anything with a high probability that someone will be able to answer the question. The group collectively raised over £1,000 for Marathon in a Month

Cumbria group focuses on friendly chat in a cafe providing mutual support and sharing information and experiences. Their next meetings will be in Sedbergh on Wednesday 14th January & Wednesday 4th March 2026


Beautifal Cumbria

Cumbria Cakes!

East Dorset group meets in a local garden centre cafe every month for tea/coffee/lunch and a chat.

Consultant Rheumatologist Dr Kurshid regularly attends the group to answer queries. They have a Christmas lunch planned and are hoping to book speakers for future meetings.

Great Yarmouth and Lowestoft group, established this year, meets quarterly. They have 25 members, with people hearing by word of mouth and through flyers they put up on local GP notice boards with details of upcoming meeting dates.

They have the support of a rheumatology consultant, and they have a meeting with him to talk about how they can better help patients' experiences regarding steroid tapering and consultant referrals.

They are holding a Christmas Raffle at their December meeting.

Havant Group continues to grow via referrals from their local rheumatology department and word of mouth. They have various speakers and sessions planned for 2026. One of their members has written a welcome booklet for new joiners which includes details about their meetings and useful resources.

Luton & St Albans group meet every two months at Stockwood Park Discovery Centre Cafe. They now have 10 members. At their last meeting they welcomed two new members and circulated information on the STERLING – PMR study.

Maidstone group continues to be well supported and recently welcomed two new members, along with their partners. In July, one member undertook the Marathon in a Month challenge, raising an impressive figure. In August, the focus was on osteoporosis. Dr Vanessa Quick's NewsWire article (Summer 2025) on steroids and the adrenal glands was relevant for many members and provoked much discussion.

In October, members welcomed a speaker from the Kent & Medway Recovery and Wellbeing College.

North West & Cheshire group alternates meetings between in-person and online via Zoom. In July, they were delighted to improve on last year's Marathon in a Month and raised an amazing £1,881!

They have distributed posters and leaflets to local GP practices. Co-organiser Pat has also presented to the PPG at her GP practice to raise awareness of where PMR/GCA patients can go for help and support. Another member has been accepted onto the GCA guidelines working group as an expert by experience, headed by Dr Sarah Mackie.

Previous co-organiser Gail Booth has become Deputy Chair of PMRGCAuk, and Jude Wetters has become new co-organiser alongside Pat. They are planning a Christmas special meet up in December.

North West & Cheshire Meeting

Orpington Group walkers

Orpington group continues to meet monthly on Wednesday afternoons and is always very welcoming of new members. The group took part in the Walk a Marathon in a Month in July and raised over £700 including gift aid.

The rejuvenated **Oxford group** hopes to meet three times a year. They met at Yarnton Nurseries in October, sharing experiences and discussing plans for future meetings. They welcome any new members.

Eight members of **Pinner and Ruislip group** joined forces to complete 'Walk a Marathon in a Month'. They completed 196 miles and raised a mighty £1363 (not including Gift Aid).

They held their first summer lunch in a local pub which was well attended.

Pinner & Ruislip MIAM

Pinner & Ruislip Summer Lunch

Plymouth group took a short break over the summer, meeting in late September at the Discovery Cafe in Plymouth for an informal chat.

They are holding a Christmas Lunch in early December.

Sevenoaks, Tonbridge & Tunbridge Wells group has continued to meet on a two-monthly basis and have found the Hand and Sceptre in Southborough a welcoming meeting place.

Sevenoaks, Tonbridge & Tunbridge Wells group

Southend and Chelmsford group's September meeting had a talk on the subject of osteoarthritis, which affects 3.8 million people in the UK, followed by Q&A.

Truro Group has moved to a new venue at Kea Community Centre, just outside Truro. They have their own room with audiovisual facilities, use of a well-equipped kitchen and free parking.

Four members of the group raised the fabulous sum of £1,000 whilst taking part in Marathon in a Month!

In May they had a talk from local charity iSight Cornwall who offer practical advice and support for sight loss.

Two new members attended the Whitstable group meeting in July, one of whom was a newly-diagnosed man from London on holiday in the area!

The group is meeting for Christmas lunch in early December.

WedPM Zoom group meets on the fourth Wednesday of the month and has helpful and interesting discussions relating to PMR and GCA.

West Dorset Group meets every two months at the PIP Poundbury café meeting room. They also support members from Somerset. In July, members were invited to join with East Dorset Group for a joint meeting with Poole based consultant Dr Khurshid. Posters have been distributed to local surgeries to promote the support available.

Three members of **Worthing group** participated in Marathon in a Month. They each completed the 26.2 miles through all weathers, and raised an astonishing £1,345 from friends, family and fellow support group members.

The group has 23 active members. They held their annual tea party in July and may hold another Christmas Party at the end of the month.

Yorkshire group held four in-person meetings across the county during the summer.

Their Zoom meetings, on the third Thursday of the month, are open to anyone regardless of postcode.

They have recently attracted four new members, one of whom had PMR when she was 60, and after a period of remission now has GCA at the age of 90.

Several members from the group took part in Marathon in a Month, helping to raise much-needed funds for the charity.

If you would like to attend any future meetings or contact a group, please refer to the back page for contact details.

THANK YOU!

Thank you to the following for volunteering as new group organisers: Jude at North West and Cheshire, Maureen and Sue at Oxford, Dorothy at Camden and Sylvie at East Dorset.

MAKE A DIFFERENCE WHERE YOU LIVE: START A SUPPORT GROUP

When we asked our support group organisers what they get out of running a group, their answers had a common thread: friendship, fulfilment and purpose.

They told us how much satisfaction they get from helping others, how members often become friends, and how running a group keeps them active and their understanding of PMR and GCA growing. It's clear that volunteering as a group organiser is deeply rewarding and often life-enhancing.

Be extraordinary.
Be a volunteer.

Ordinary People Doing Extraordinary Things

Our organisers are people just like you. Most have or have had PMR or GCA and wanted to both give and receive support. Some started groups from scratch; others stepped in to help an existing organiser or took over when someone stepped down.

Every group is unique. Some are small and cosy chats in a café; others host speakers or work closely with their local rheumatology departments. Some groups also run online meetings, so those who can't attend in person – due to health, distance or work – can still take part. Whatever the format, they all offer a space to talk, share worries and tips, and be reassured. Most importantly, the groups work in the way that the organiser is most comfortable.

You Don't Have to Do It Alone

Running a group can be a team effort. Many organisers share the role with someone or delegate small tasks like making the tea, booking speakers or managing a WhatsApp group to stay in touch.

PMRGCAuk provides plenty of help along the way. We can set you up with a charity email address, promote your group on our website, social media and in NewsWire, and supply leaflets and posters for local surgeries and community spaces. You'll also be invited to our regular Zoom sessions for organisers, which are "always worth logging in for".

As one organiser put it, "It was such a relief, when I first came to a group, to find people who understood what living with PMR is like. Now, when new members arrive and I see that same relief on their faces, it makes it all worthwhile."

Be Extraordinary – Be a Volunteer

You don't need special expertise, just time, empathy and a willingness to get involved. With many areas of the UK still without a local support group, we'd love to help more people connect.

If you'd like to find out how we can help you start a group, or to chat with an organiser about what's involved, please email **charon@pmrgca.org.uk**.

We'd love to hear from you.

AGM AND MEMBERS' DAY REPORT

The AGM was well attended by more than 100 members and another 250 requests for access to recordings to catch up later.

After the business of the AGM, **Dr Vanessa Quick** hosted the Members' Day and welcomed our first speaker, **Professor Bhaskar Dasgupta MBE**.

Dr Vanessa Quick, host of the Members' Day

The role of imaging in GCA diagnosis and monitoring

Prof Dasgupta started his talk by reflecting on his career-long interest in PMR and GCA. He particularly highlighted the discovery of Interleuken-6 (IL-6) as a key inflammatory marker in PMR and GCA, noting that this finding was pivotal in the development of IL-6 inhibitors such as tocilizumab and sarilumab, which are now established treatments for these conditions. He reflected that over the past 30 years, progress has been made in the understanding, diagnosis and treatment of PMR and GCA but acknowledged that more work was needed.

He discussed the evolving view of PMR and GCA, not as distinct diseases, but as different phenotypes of a common spectrum of inflammation, what he and colleagues propose to call "GPSD" (GCA-PMR Spectrum Disorder). He discussed his recent Delphi study and the key propositions that it explored. This was a structured way of gathering opinions from patients and doctors through several rounds of questionnaires to reach a shared agreement on a complex issue. The propositions included whether PMR and GCA belong to a common spectrum and the role of imaging in defining phenotypes (subgroups). The study further examined whether doctors should routinely consider GCA when assessing for PMR (and vice versa), and whether defining these subgroups within the spectrum might guide more targeted treatment strategies.

Prof Dasgupta then discussed the role of ultrasound imaging in GCA and PMR.

The EULAR (European) guidelines recommend ultrasound as the first-line investigation for GCA. In patients with GCA, ultrasound may show something called a halo sign. The halo is produced by the thickened walls of inflamed arteries.

In people who lose their sight, the walls of the blood vessels to the eye become so thickened that they completely obstruct the blood flow, causing ischaemia (lack of oxygen and nutrients) to the affected eye. This thickening known as the halo is visible on ultrasound. The larger the halo, the greater the chance of ischaemia. Prof Dasgupta shared images to demonstrate this effect during his presentation.

Ultrasound can also tell us whether the condition is limited or extensive: whether it's "cranial disease" (limited to arteries around the head, typically causing headaches, scalp tenderness, and jaw pain), whether it's large vessel disease (affecting the bigger arteries in the upper chest, neck and arms), or whether it's both. The reported ultrasound is an 8-vessel scan which looks at the two common temporal arteries, their frontal and parietal branches, and the axillary arteries under the armpits. The greater the number of vessels showing a halo sign, the higher the "halo count" or "halo score," which strengthens the doctor's confidence in a GCA diagnosis and gives an indication of how active the disease is. Additional arteries can also be assessed, such as vertebral,

"Thank you for such an informative webinar - as a very new member, I am so reassured that joining was the best decision possible and I look forward to a future with much more hope than I have had for many years."

Slide from Dr Claire Owen's talk

carotid, and subclavian arteries, allowing clinicians to assess most of the blood vessels commonly affected in GCA.

Ultrasound can also be useful in PMR, but fewer PMR patients have access to ultrasound as the majority are treated in primary care and do not get referred to rheumatology. On scans though, you may be able to see features of PMR by looking at the bursae, the sacs of fluid around the shoulders. You can see tenosynovitis, inflammation of the tendon sheath of a tendon, particularly the biceps tendon. If bursal fluid is present bilaterally, then PMR is more likely. He expressed his view that in the future there should be PMR fast-track pathways like those developed for GCA so that clinicians will be able to diagnose PMR with ultrasound as well.

Prof Dasgupta shared images throughout his presentation to illustrate what can be seen in ultrasound in both GCA and PMR. He emphasised that imaging does more than confirm diagnosis; it underpins stratification, dividing patients into subgroups according to disease severity and phenotype. Each subgroup has different risks and may need distinct therapies. Importantly, ultrasound can also track treatment response. Baseline imaging, followed by scans at follow-up, can monitor resolution or persistence of inflammation. Follow-up is particularly important in large-vessel GCA, where relapses are common and steroids often insufficient.

Prof Dasgupta concluded that access to imaging remains uneven. Few PMR patients receive ultrasound, and GCA services are not universally available. He described three main barriers: entrenched reliance on steroids ("steroid obsession"), insufficient ultrasound training, and resource constraints. He called for expanding ultrasound training for rheumatology trainees, providing machines in district hospitals, and campaigning for awareness among clinicians and patients alike. He also advocated shifting PMR care from general practice to specialist-led services. He argued that by embedding PMR within the GPSD framework and adopting "fast-track GPSD pathways," patient outcomes might be significantly improved.

The role of imaging in revealing the cause of PMR symptoms

Our second talk was from **Dr. Claire Owen**, a clinician-scientist rheumatologist whose PhD on PMR had a specific focus on CT-PET imaging. A PET scan is a type of medical imaging that shows how actively inflamed different parts of the body are by tracking a small amount of radioactive sugar injected into the bloodstream.

Dr Owen started by talking about how PMR has long been misunderstood due to the limitations of early biopsy and scanning technology, as well as a historical focus on the joints. While some inflammation can occur within the joints, it is far less compared to rheumatoid arthritis, and in many PMR patients is absent altogether.

Further early research documented the presence of subacromial bursitis (inflammation of the bursa - little bags of fluid that help the tendons slide in and out of the shoulder) which can cause quite significant pain when you lift your shoulder. On MRI, subacromial bursitis was seen in almost all patients with PMR in the study. As MRIs improved, inflammation in PMR patients was identified as sitting around (rather than within) the joints and this was described as "extracapsular" (found outside the joint capsule). This can now be seen on ultrasound, and it has been incorporated into some diagnostic algorithms for PMR.

Early PET scans identified inflammation at the shoulders, hips, and in between the vertebrae in the spine as well, referred to as interspinous uptake.

PET scans are now combined with CT imaging, which adds anatomical detail, such as the position of bones and organs, helping doctors see exactly where the areas of abnormal inflammatory activity are located.

Dr Owen explained that almost all PMR patients experience inflammation around the ischial tuberosities (the bones we sit on at the bottom of the pelvis) as well as significant inflammation around the knee joints, hamstring muscles, connective tissues and structures surrounding the

shoulders, hips and knees as well as a few other places.

On a CT-PET scan of a healthy person, one would only expect the brain and internal organs to light up. Dr Owen shared a scan from a PMR patient, which clearly showed heat in the shoulders and hips on both sides and in the pelvis. Looking more closely at the shoulders, she pointed out bursitis, inflammation of the biceps tendon, and some milder involvement of the joint. PMR may be differentiated from other conditions based on the distribution of the inflammatory activity seen on the CT-PET scan.

She showed us similar intense uptake at the hips which corresponded to the trochanteric bursa (fluid-filled bags), the hamstring coming off the ischial tuberosities in the buttock area, and the hip capsule too.

Challenging the view that PMR only affects the shoulders and hips, she argued that it's a whole-body condition, something that CT-PET scans can clearly demonstrate in PMR patients.

For example, CT-PET can show bursitis in the neck and the lumbar spine vertebra, providing a good explanation for why 80% of patients with PMR often experience significant neck pain, often radiating into the head and lower back pain as well. The area around the hamstring muscles is often the 'hottest' area seen on a CT-PET scan, corresponding to soreness in the buttock regions. Inflammation identified behind the knee corresponds to the ligaments within the knee and a degree of joint capsulitis.

Based on her research group's CT-PET data, hand and wrist involvement is probably present in about 50% of patients. Again, like the hips and shoulders, it's not just isolated to the joint. They see significant involvement of the tendons in the hands which often leads to a glove-like swelling of the hands in the early days of the presentation. They see this in about a third of their patient scans.

Dr Owens recognised that it's not all about pain and stiffness in PMR, and discussed additional studies on fatigue, sleep disturbance and depression, as well as physical tests of PMR patients. This part of her talk is reported by Richard Cuthbert, Chair of PMRGCA Scotland (see p.15).

Dr Owen concluded by saying that imaging has made a big difference by making the 'invisible' manifestations, known only to the patient, visible on the scans as well. She acknowledged the other symptoms such as fatigue, depression, and deterioration in physical function are important too and that they need to harness this knowledge to improve diagnosis and management.

We would like to thank both our speakers for their excellent talks and recommend anyone who hasn't watched the recordings to do so for greater detail than we can cover here and also for the Q&A. If you'd like the link, please contact **charon@pmrgca.org.uk**.

Reported by Fran Benson, Janette Mannell and Dr Vanessa Quick

Marathon in a Month 2026 is coming!

Look out for more details in the next edition.

"I walked 97 miles in total and raised over £500. I'm so pleased and proud and I'll definitely repeat it next year."

Participant,
Marathon in a Month 2025

MEMBER'S STORY:

MANAGING WEIGHT AND PAIN DURING PMR

Kath (52) from West Yorkshire shares her story

I first noticed backache and hip pain in September 2019 when I was just 46 years old. Over four weeks, the hip pain got worse, and my neck and shoulders seized up. I also felt persistently unwell.

Because of my age, I had to visit the GP three times before they took my symptoms seriously. Initially, I was referred to MSK because the GP thought I'd injured myself while running. The appointment was refused, but finally a nurse practitioner took bloods to help confirm there was a problem, and I was eventually diagnosed in February 2020 (just before lockdown) after a PET-CT scan.

Before PMR, I was a runner and very active. PMR changed my life. It was difficult managing it against the backdrop of Covid-19 and being in the shielding group. Working has also been challenging at times due to tiredness. PMR is not well understood by work colleagues or workplace occupational health clinicians. I had to learn to pace myself.

I haven't had to deal with flares, but tapering has been difficult and slow, particularly in the early years. It felt like it took a long time to get to 10mg. I tried methotrexate and leflunomide, both unsuccessfully.

Over time, I was able to slowly decrease with the support from my consultant, slowing down around the 7mg mark due to fatigue. Not rushing at this stage was crucial and I had great support to continue with my slow taper.

I started on 20mg prednisolone in early 2020 and I finally took my last dose five years later.

I put on five stone while I was taking steroids, and this added to my problems. I developed mild to moderate sleep apnoea, (stopping breathing around 15 times an hour). I was also edging into pre-diabetic ranges for my blood sugar. I felt awful a lot of the time with persistent fatigue, aches, pains and brain fog. It wasn't the PMR causing this, although the steroids certainly contributed.

I realised I had to do something about my weight. I was due to go on an amazing holiday to Singapore and wanted to feel well for the trip. I had noticed early on in my journey, that my pain was worse for a day or so after I drank alcohol or had too much refined sugar.

When I was at 5mg of prednisolone, I signed up with the nutritionist Dominique Ludwig* who I found on Instagram. She seemed to have a very sensible approach to losing weight, focussing on good nutrition with lots of fibre and minimally processed foods, backed up with information and science which enabled me to learn the principles of eating well. The first week was hard, but it quickly became much easier. I lost four stone, and my blood sugar returned to the normal range and the sleep apnoea disappeared. I began waking up feeling far more refreshed.

Very early on in the weight loss, my pain levels reduced which meant I could successfully taper with more confidence. I'm now off steroids and in remission from PMR.

I've been supported by the Yorkshire support group. The charity helpline was invaluable in the early days when navigating my unhelpful GP.

These are the key principles I learnt and implemented following Dominique Ludwig's advice:

Are you able to share your story to help other people with PMR or GCA?
Please contact **fran@pmrgca.org.uk** or call 0300 999 5090 if you can help.

- Focused on three filling meals a day
- Stopped snacking (this helps manage blood sugar)
- Focused on protein and whole vegetables, and limited simple carbs
- Ate my evening meal at least two hours before bed and then fasted 12–14 hours until breakfast
- Threw away my breakfast cereals and made my breakfast protein-based. This was probably the most important thing I did.
- If I did eat something sweet (refined carbohydrates or sugar based) I did it after a meal to limit the blood sugar spike.
- Made sure to include healthy oil and fats e.g. olive oil, avocado, salmon.
- Cut out refined/ultra processed foods

I found the first week of changing my diet, cutting back on sugars and simple carbohydrates, was really hard but it got easier very quickly and I reaped the benefits quickly too. It really helped me to think about the importance of fuelling my body with quality foods – after all, I wouldn't put the wrong fuel in my car and expect it to work well.

* Dominique Ludwig is on Instagram at dominiqueludwignutrition and regularly shares healthy, high-fibre, high-protein and healthy fat recipes as well as tips and advice.

THANK YOU for your support!

Marathon in a Month 2025

Our flagship fundraiser raised a staggering £14,000! It was brilliant to see so many people join in, either individually or as part of a team, sharing the miles between them. Support groups took on a starring role, with many of them participating, so a special thank you to the group organisers who promoted them and/or joined in. You can see how some of them did on the groups page (p.4)

As well as raising awareness and vital funds for the charity, it has been wonderful to hear stories of how rewarding taking part has been, of friendships made and health improved.

"Marathon in a Month motivated me to start walking again after months of fatigue – and I did a mile every day in July."

"I live in an apartment block & because of this campaign, discovered that another resident had PMR & a third person had GCA! We joined forces, completed the marathon and have carried on walking since."

Remember A Charity Week

In our second year of participating in Remember a Charity Week, we shared videos and stories on social media. Thank you to everyone who shared or commented on our posts or got in touch to let us know they would be leaving a gift to the charity in their will.

"Finding the charity two years into my PMR was an absolute lifeline for me and also made me realise that my late mum had PMR but had never been diagnosed. It gave me the knowledge to manage my condition and therefore improve my quality of life. So, in our memory and for the incredible support I've had, I will be leaving a gift in my will to PMRGCAuk to help others in the future. I am proud to be a trustee of this small but brilliant charity, and I know that all donations, large or small, make a huge difference."

The Cheltenham Half Marathon

Thank you to **Mike Kember** who ran a half marathon and raised over £700 for PMRGCAuk.

A Rheumatologist Explains...

What are the sick day rules?

Dr Sarah Mackie
Consultant Rheumatologist

A member asked: "I've got flu-like symptoms with a high temperature and a nasty cough. The [steroid] sick day rules in the HealthUnlocked FAQ section recommends increasing the steroid dose during illness. I'm feeling pretty rough from the infection, but my PMR itself seems fine. Do I still need to increase my steroids?"

This question reminds me of the dark days of the Covid lockdowns, when so many of my patients were "shielding" at home while taking long-term prednisolone[1]. This prompted us to do a survey: **"Variability in counselling for adrenal insufficiency in COVID-19 and beyond: a survey of rheumatology practice"**. Given that we weren't certain what patients had been told, how could we get the correct message out to our patients about what they should do if they were to become unwell with Covid? So we made a leaflet that could be sent in the post, containing this text:

*"If you have been taking corticosteroid (prednisolone) tablets for over a month, then it is possible that you have developed **adrenal insufficiency**. The adrenal gland makes **steroids**, which are important for the body to work properly. If your body needs an extra **"boost"** in situations like **major injury** or **serious infection**, it usually makes some extra steroid for a few days to help you through.*

*Prednisolone is very similar to **cortisol**, one of those essential steroids [made in the adrenal gland]. If you take long-term prednisolone tablets, the adrenal gland can become "lazy" at making cortisol. This is **adrenal insufficiency**. This is not normally a problem, as you will get your steroids from your tablets.*

*Adrenal insufficiency is usually only a problem if you have an **unexpected major illness** and your "lazy" adrenal gland doesn't make that steroid boost the body needs. If you take long-term prednisolone and you get sick, you may need to take extra tablets (**"sick day rules"**).*

*If you have been taking **5mg or more of prednisolone, for 4 weeks or longer,** then it is possible that you have developed **adrenal insufficiency**. Adrenal insufficiency can last for some time. So, if you are taking **less than 5mg now**, but you used to take a **bigger dose**, you could still have adrenal insufficiency now.*

If you take long-term steroid tablets, adrenal insufficiency will only give you a problem if:

- *You stop taking steroids abruptly.*
- *You are reducing your prednisolone dose below 5mg, and you try to reduce it too fast.*
- *You have another illness, e.g. Covid-19 or major surgery: if you usually take less than 20mg prednisolone daily, you might need some extra steroids for a few days."*

The leaflet went on to suggest various options for increasing steroid dose, but in writing it, we realised there were many "ifs and buts". After much discussion, we decided to err on the side of caution, reasoning that during lockdown, it was probably better to take a few extra mg for a few days if in doubt. These days, though, I'd strongly advise you to ask your own doctor or phone NHS 111 if you aren't sure whether the sick-day rules apply to you – definitely don't rely on internet forums or ChatGPT!

So, in summary, to return to your original question, "steroid sick day rules" are for anyone taking long-term prednisolone for any reason, not just PMR. During a serious upset like severe flu, following the sick-day rules for a few days might help your body's systems cope with the upset a little better. But please, do talk to your doctor! There are too many "ifs and buts" to give a one-size-fits-all on this.

Sarah Mackie

Dr Sarah Mackie
Consultant Rheumatologist

1. Prednisolone is a member of a class of drugs called "corticosteroid" or more precisely "glucocorticoid" although often we just call it "steroid" for short. "Steroid" is a name for a broad class of molecules with a four-ring chemical structure. Some drugs (synthetic ster-oids) are designed to mimic steroids made naturally by the body. Prednisolone, a corticosteroid, mimics the glucocorticoid hormone, cortisol, that's made in the adrenal gland. Do not confuse prednisolone with anabolic steroids, which mimic the androgen hormone, testosterone, that's mostly made in the testes. Anabolic steroids are widely discussed on some parts of the internet, as they may be misused by people who want big muscles. Anabolic steroids have no place in the treatment of PMR.

If you have a question for Dr Sarah Mackie, please email **letters@pmrgca.org.uk**. For ethical reasons, Sarah can't give medical advice or discuss individual cases.

Top tips for surviving Christmas

Share this list to remind family and friends that you need support

The thought of Christmas and its extra demands while dealing with fatigue and other effects of steroids and PMR/GCA can be overwhelming.

We've compiled tips from people with PMR/GCA to help manage the busy season.

1. If you have your clinician's approval to manage your taper schedule, don't drop your dose just before a busy/stressful period.
2. It's okay to do things differently: if your family comes to you, suggest they come for less time or someone else hosts instead. Or cancel Christmas and do something simple!
3. Use online shopping to get food and presents delivered (even better if you've signed up to Give as you Live!)
4. Be honest about what you can cope with and your need to pace yourself. You'll enjoy yourself more if you're well rested and not overloaded.
5. Don't be afraid to say you can't do something on the day – you might look well but that doesn't mean you are well.
6. Delegate! From shopping, to wrapping, to cleaning, prepping, baking and cooking – spread the load.
7. Write your cards over a week or two (or consider using e-cards instead) and print address labels.
8. Use your freezer to store cooked meals or vegetables that can be reheated when needed.

Finally, remember that for most people, these diseases do not last forever so if you're not feeling particularly festive this year, don't feel too downhearted, because next year may well be different.

Thank you to contributors on HealthUnlocked and Facebook who shared their tips.

GIVE AS YOU LIVE THIS CHRISTMAS (and beyond!)

Did you know you can raise money for the charity without making a donation? If you use the Give as You Live (GAYL) shopping platform while you're shopping online, many retailers are signed up to give a percentage of your shop to us as a donation.

Whether it's Christmas shopping, food shopping, purchases on Ebay, booking tickets on Trainline or something from one of the 6,000 online shops that offer GAYL donations, you can fundraise for the charity.

It's easy to set up and use and it's nice to know that your everyday shopping is supporting people with PMR and GCA.

To set it up, go to **www.giveasyoulive.com** and complete a few details to create an account.

Choose which charity you'd like to support by typing PMRGCA into the search box.

Make sure to also click on the Donation Reminder on the GAYL home screen and follow the instructions which will then raise a prompt whenever you're on a site that offers to give a donation to us. If using your phone, you can download the donation reminder to your device. Alternatively, download the Give as you Live Online App from the Apple Store or on Google Play.

After that, everything else is taken care of by links in the background. You will be able to check how much your shopping has raised for us by logging into your GAYL account.

MAKE WALKING A HABIT

We know that there are many benefits to movement and exercise, and that regular walking that becomes a habit is a good way to improve your health. Whether you want to take part in an activity such as (Walk a) Marathon in a Month or simply to feel better, it can be difficult to get started, or if you have started, to keep going during the winter months.

At this time of year, remember you don't need to walk in every type of weather. You might find opportunities to increase your steps indoors – perhaps at the supermarket or a shopping centre. On days when walking with others is possible, make the most of it, and allow yourself a rest when company isn't available or when the weather/outdoor conditions are less favourable.

Top tips for walking

1. Download or request our Maintaining Movement. Activity and Exercise with PMR booklet (which is also appropriate for those with GCA) Request or view the booklet at **www.pmrgca.org.uk/information-and-advice/resources/**
2. Watch the accompanying video for the booklet: **www.pmrgca.org.uk/exercise-webinar-video/**
3. If you're new to exercise – start small and build slowly
4. Increase your activity/steps or minutes by just 2-5% per week
5. Stretch before or after your walk, paying particular attention to your calf muscle – to stretch these, place your hands against a wall or work surface and push one heel back behind you. Hold the stretch for around 20 seconds and then repeat with the other leg.

Thank you to Consultant Physiotherapist Will Gregory for his advice with this article.

NEWS, RESEARCH AND DEVELOPMENTS

Work begins on updating the BSR GCA guideline

The British Society for Rheumatology (BSR), the professional association for British rheumatologists, published its latest GCA guideline in 2020. This covered significant recent advances in clinical practice, including ultrasound for diagnosis and tocilizumab for treatment. The time has now come to update that guideline. This typically takes some years, as it has to follow a rigorous multi-step process (**www.rheumatology.org.uk/guidelines**).

The group will be chaired by Dr Sarah Mackie who is very keen to ensure the guidance takes full account of the patient experience.

PMRGCAuk members have generously volunteered to join the Guideline Working Group as experts by experience. This includes PMRGCAuk Chair, Fiona Johnson and Treasurer, Geoff Holroyd.

Geoff said, "We are excited to be able to give the patient's perspective and make sure those views are taken into account in the way the guidelines are drafted."

Participants will be giving their time to attend meetings and review information in this important process. The first meeting, involving around 40 people (including seven patients), took place in October and the overall project is planned to continue throughout 2026 and into 2027.

Published articles

Two articles have been published recently which demonstrate some of the important discussions that are going on to help improve treatment for PMR patients.

Professor Bhaskar Dasgupta MBE has published an editorial piece in the BSR Rheumatology exploring whether patients with PMR should be referred to rheumatology. You can read his article here **www.academic.oup.com/rheumatology/advance-article/doi/10.1093/rheumatology/keaf467/8251478**

Dr Max Yates has also published an editorial piece in The Lancet Rheumatology exploring the need for more scrutiny of the benefits of universal ultrasound screening for PMR patients when there is a greater need to address misdiagnosis and other factors that affect patients. The article is not directly accessible to patients but may be available to professional members at **www.sciencedirect.com/science/article/abs/pii/S2665991325000311?via%3Dihub**

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Pmr Gca SCOTLAND

Notes from the Chair – Richard Cuthbert

October 2025

I enjoyed the UK charity's AGM in September (a full report of proceedings appears on pages 7–9). I found Dr Claire Owen's talk extremely interesting where she explained how our knowledge about PMR grew as the science of imaging techniques developed. However, the section that I found most interesting was at the end when she talked about some research by colleagues in Melbourne led by Dr Jessica Leung. The findings themselves would not come as any great surprise to a PMR patient, but there is satisfaction in having your gut feelings confirmed in a scientific way. The researchers worked with a group of 36 PMR patients and a control group of 32 volunteers who were broadly matched in respect of age and gender.

The first study looked at fatigue and sleep quality using medically recognised tests performed three months after PMR diagnosis and then repeated 18 months later. The PMR patients were classified with severe fatigue in 36% of cases initially and 35% at follow-up, whereas the control group were 3% at both points. Poor sleep quality was recorded for 77% of the patient group rising to 84% at follow-up, compared to 56% at both points for the control. It is mildly reassuring to learn that we are not suffering alone and to get confirmation that there can be a measurable shortfall between what we are experiencing and what is normal.

The second study looked at a measure for any depression being experienced by the participants. The initial finding from one test (HADS) was of 22% incidence in the patient group against 3% in the control. After 18 months, the patient group had dropped to 15% compared with 9% in the control. A second test which they used showed a similar trend over the period. This shows an encouraging improvement in that aspect of health for the patients, but still there is a significant presence which the researchers found to be strongly associated with poor physical function. Interestingly, she mentioned that a colleague had pointed out that the presence of IL-6 (a key factor in PMR) is thought to have a significant impact on mood.

Which leads to the third study which looked at some physical aspects. A range of tests measured walking speed, muscle mass and strength, and balance. The results for the patient group were consistently poorer than the control and tended to get worse at the 18-month follow-up. Worryingly, the deterioration appeared to be significantly more pronounced in the female participants.

As I said earlier, these are not very surprising results overall – we all encounter aspects of these problems at some stage. The important thing is whether the medics acknowledge the problems that we report to them and can come up with ways to close at least some of the gaps found above.

Something that is trying to move forward on the treatment front is a drug looking to be authorised and available for use in the treatment of GCA. About seven years ago, tocilizumab (an existing drug for rheumatoid arthritis) went through approval processes to be authorised for use in treating GCA, and it has proved to be extremely good in some cases. In the UK, we now have another existing drug (again initially produced for rheumatoid arthritis and now licenced in the US and Europe in connection with GCA) going through the approval processes in England (NICE) and Scotland (SMC). We await the outcomes with great interest because these drugs work in two distinctly different ways, and what could be better than if we find ourselves with a greater range of options for GCA treatment.

Our network of groups around the country is growing!

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