

You are not alone

Polymyalgia Rheumatica and Giant Cell Arteritis

Newsletter Spring/Summer 2013

5 things to look for in a Rheumatologist

A common piece of advice to those who have just been diagnosed with rheumatoid arthritis (RA) is to 'find a good rheumatologist,' but what makes a specialist 'good'? Do they give frequent flyer points at every appointment that you can redeem for gift certificates to the store of your choice? Do they wave magic wands that reduce your symptoms? If you're new to the medical world and already feeling overwhelmed by your diagnosis, it can be hard to know what to look for in a doctor. Here are a few suggestions:



Makes Time for You

All doctors tend to be busy, but once you're in the office, good doctors will take their time. Making time for you means that they focus on you, making eye contact instead of having their nose buried in your chart. It means that your doctor will have good listening skills, helping you tell your story in a way that isn't rushed and without making you feel as if you're wasting their valuable time. Making time for you is one of the cornerstones of what's called 'a good bedside manner' and creates an environment of trust, which is an essential component of a patient-doctor relationship.



Is on Your Team

Living with a chronic illness means changing the way you interact with doctors, subtly shifting the decision-making role to you. After all, you are the one who has to live with this disease every day and you know better than anyone how your body reacts to different treatments. A good rheumatologist will respect that you're the leader of your medical team and will provide you with the information you need to make the decision that's best for you. They will support you in doing your own research, encourage you to ask questions and explain the pros and cons of various treatments so you can make a fully informed choice. A good doctor will know

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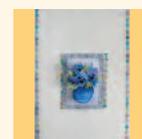
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Need help?

Want to join?

Please get in touch:

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www.pmr-gca-northeast.org.uk

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how to offer their opinion with the appropriate weight, ie they will know when to back off and when they, as your expert consultant, should strongly recommend a specific treatment. When you have a relationship based on respect and trust, you, as a patient, will also know when to insist on your way and when to follow the advice of your rheumatologist.



Is Available

You will likely have regular appointments with your rheumatologist every three to four months or so and once your disease responds to treatment and stabilises, you will probably not need to speak to your doctor more than that. However, if you start flaring, develop a weird side effect or for another reason need to speak to your doctor in between your regular appointments, good rheumatologists will be available, either to return a phone call or to squeeze you into their appointment schedule.

Cultivate your doctor's secretary – although your doctor sets the tone in the office, the secretary is in charge of the appointment book and therefore is the person with the real power. Nurturing a positive relationship with her (*they are most often women*) by taking time to have a chat and a laugh when you're in the office will increase your chances of getting a quick appointment in a full schedule.



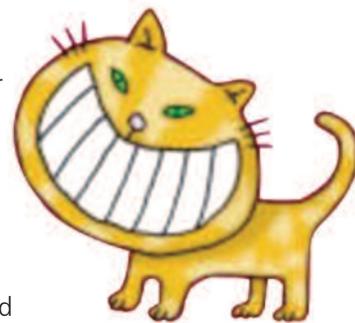
Will Be Compassionate and Resourceful

Having a chronic illness can be difficult and having a chronic illness that's unpredictable and painful can be a real drain on your emotional well-being and may create problems in personal relationships, employment, etc. A good

doctor will understand this and will, by showing warmth and concern, create an environment in which you feel comfortable enough to talk about your fears and frustrations and safe enough to cry when things are really bad. And when you do, a good doctor will offer helpful tips and referrals, eg to a counsellor, occupational therapist etc, if practical help will solve your problems, or comfort and reassurance if that's what you need.

Has a Sense of Humour

Developing a sense of humour about your illness its impact on your life and the reactions of other people can be one of the most effective ways of dealing with a chronic illness. Finding a doctor who is relaxed and human enough to bring humour into the consulting room (*when appropriate*) can go a long way towards creating an effective and trusting relationship between doctor and patient. Having an appointment where your doctor has listened to you, given you information, shown you respect and had a laugh with you, will help you feel as if you and your doctor are on top of your disease, give you hope and help you remember that at the end of the day, there is still joy to be found.



If your first doctor doesn't meet your expectations of what a 'good rheumatologist' should be, don't be afraid of getting a second opinion. If possible, interview a few alternatives.

As in all relationships, it takes time and effort from both parties to build a good connection, but you should be able to tell fairly early on if she or he has potential. If you live in an area where your options to see another rheumatologist are limited, don't give up – it's possible to 'train' a doctor over time. Through good communication, subtle guidance and firm, but respectful sticking to your guns, almost any doctor can be taught.

Editor note: This article applies to any chronic illness.

You can read more of Lene Andersen's writing on *The Seated View*. Toronto Canada.

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PMR&GCA UK North East Support Donations & Gift Aid

We wish to thank all the people who have donated monies to us over the past few months. We also wish to thank those taxpayers who filled in **Gift Aid** forms.

Gift Aid enables us to claim 25p for every £1 donated from HMRC. Once you fill in a **Gift Aid form** we can claim without you ever having to fill in another form.

Further information on our website:
www.pmr-gca-northeast.org.uk

Shared care

A better way to **diagnose and treat PMR?**



Difficulty in diagnosing PMR:

The symptoms of polymyalgia rheumatic (PMR) can be devastating, as many readers will understand from personal experience, but the fact is that PMR is not easy to diagnose.

PMR is a common rheumatological condition and affects 1 person in 100 over the age of 60 years – but how often do you think a general practitioner sees a new case of PMR? If a GP looks after 2,500 people; about 800 will be over 60; of these about 8 will develop PMR over the next 25 year. So that's about one new case every 3 years. There is little chance of someone becoming an expert in something they see so infrequently. On top of that, the symptoms of PMR can also be caused by all sorts of other conditions, some of which are very common. It is no wonder that sometimes GPs get the diagnosis wrong, and to me it is more surprising when they get it right!

So how can we make it easier for patients to be seen by rheumatology specialists who have developed the expertise needed to make an accurate diagnosis without adding to the delay and frustration that many have to endure? In our rheumatology service we have achieved this by establishing a 'Rapid Access PMR Clinic'.

The Rapid Access PMR Clinic: It usually takes about 8–10 weeks for us to see an ordinary new patient after the GP has made a referral, but not for PMR. We reserve some clinic places just for patients who the GP suspects may have PMR and these are available at 2-3 weeks' notice. To qualify, a patient must have our specific 'referral criteria', which include pain and stiffness in and around the shoulders and a raised blood test for inflammation. In addition, we request that GPs should not start their patient on glucocorticoid (steroid) treatment. This is because taking glucocorticoids clouds the picture and can prevent us using our diagnostic system properly. It is true that this means some patients have their treatment delayed for a few weeks and we have set it up as 'rapid access' to keep this to a minimum. But on the other hand, it means we can make a clear and definite diagnosis right from the start, and avoid lots of confusion later.

Making the diagnosis and starting treatment:

About half the patients referred to the clinic turn out to have PMR and our clinic system does seem to work, because we can distinguish PMR from other conditions on either the first or second visit in the vast majority of cases. The rest of the rapid access patients turn out to have all sorts of other problems, including different types of arthritis,

chronic pain problems, cervical spondylosis, frozen shoulders and other medical conditions. We pass them over to the routine clinic for full diagnosis and treatment.

Once we have the diagnosis we can start treatment with prednisolone, which is a glucocorticoid or type of steroid. We have a standardised treatment package based on the idea that we would like to make the symptoms go away quickly and stay away. Unless there are any special circumstances, we give patients 15mg daily for 6 weeks, then 12.5 mg daily for 6 weeks, then 10 mg daily for 1 year, then reduce by 1 mg daily each month and eventually stop.

Back to the GP: Nearly all our patients get better on this treatment with no recurrence of symptoms and only very mild or no side effects. We do not need to see them again in the clinic, and we send them back to their GP to make sure everything runs smoothly for the 2 years of treatment and when the treatment stops.

However, nothing is perfect, and some of our patients (only 2 in 10) find that at some stage along the way, usually between 6 and 18 months after treatment was started, their symptoms begin to creep back. This is not always due to the PMR returning – sometimes they have developed a completely new problem. Sometimes a few patients are particularly sensitive to the side effects of glucocorticoids and so the GP might wonder if they can be reduced more quickly than usual. For all these patients, we are ready to see them again within a few weeks and advise on treatment changes or other investigations. When these are sorted out, the patient continues their treatment through the GP surgery.

GP and hospital sharing care: So this is how I see the best way to share the care of patients with PMR: Using their skills and knowledge of general health problems GPs get suspicious and refer to our Rapid Access Clinic. We see the patient quickly, and using our extensive experience of dealing with hundreds of patients, we make a secure diagnosis and start on a standard treatment package – and send the patient back to their GP. If anything goes wrong – recurrence of symptoms or important side effects – the GP sends the patients back to us to clarify the treatment. In this way we use the skills and expertise of GPs and hospitals to best effect, sharing the care of our PMR patients – and together giving them the best treatment we can.

John R Kirwan BSc, MD, FRCP

Consultant Rheumatologist, Bristol

Professor of Rheumatic Diseases, University of Bristol



With membership just short of 200 and an online forum with over 600 members worldwide, we are kept very busy 'up North'. A surge in interest in our cause has also kept us on our toes in the past few months.



Dr Helen Twohig (second left).

One of our aims is 'to facilitate and contribute to research into PMR and GCA' so when we were approached by Amy Horton 4th Year Medical student from Newcastle University and Dr Helen Twohig from Sheffield University to help with their research we grasped the opportunity to do so. Amy and Dr Helen attended Middlesbrough January meeting/lunch and Amy also attended Gateshead January meeting/buffet to talk to our members and distribute questionnaires etc. We involved all our members and forum participants and Amy and Dr Helen are both overwhelmed with the response. We look forward to continuing to support them and seeing the results of their work.



Amy Horton (standing).

Dates for your Diary

Gateshead next meeting

Monday 24 June 2pm
Central Library, Gateshead.

Guest: Sue Saunders: The Benefits of Tai-Chi, Relaxation and Gentle Exercise

Middlesbrough next meeting

Wednesday 26 June 1.30pm
Marton Country Club. Short AGM

Guests: Kay West, Physiotherapist, James Cook Hospital and Ruth Boyes, PAT (Pets in Therapy Dogs) and dogs Charlie and Stella



Angela Moody and Jackie Grayson are Rheumatology Nurses at James Cooke University Hospital, Middlesbrough. They both attended the March meeting and will attend future meetings. They will be a great asset to our meetings in Middlesbrough.

Jacqui says: I have been a Rheumatology Nurse Specialist at the Queen Elizabeth Hospital Gateshead for almost 18 busy and rewarding years. The management of many of our diseases over this time has changed dramatically, improving patient outcomes and experiences. It is a real honour to be asked to be a patron of PMR&GCA UK North East Support and I look forward to supporting and becoming involved in the group.



We are hoping very soon to be able to issue all our members with a new Medication Booklet and Card with area to record steroid dosages and other items. The Blue steroid card, created in 1964, is now outdated, hard to obtain and not fit for purpose.

Secretary Pam Hildreth has been invited by Professor Dasgupta to attend PMR guidelines working group in London in March. Pam attended this meeting and prior to that meeting worked closely with Jennifer Knott (East Anglia Support Group) issuing questionnaires and gathering information on both the NE forum and healthunlocked. Pam will keep us informed of progress.



Our 5th Anniversary came and went in March and to celebrate Ann Sadler kindly baked cupcakes (to a Mary Berry recipe, no less), which were iced by Carol Suffell and Pam.

A celebration cake was cut by Enid Mitchell, the very first member to join the Gateshead Group. Since that date, Enid has run our raffle raising funds over the years. Phil Corr runs the raffle in Middlesbrough and also raises a substantial sum. Our thanks to both Phil and Enid.



PMR-GCA Scotland

On 16 April PMR-GCA Scotland, a Scottish Registered Charity, held their AGM and a Seminar in the Queen's Hotel, Dundee.

Scotland, as some of you may be aware, runs their own National Health Service and while it is similar to the NHS which operates in England (Wales also has its own variation), it does have a different organisation and system which is why it is registered as a Charity in Scotland. PMR-GCA Scotland is affiliated to the PMRGCAuk, just as we are in the North East, independent, but affiliated and we keep in close contact.

We had been extended an invitation to attend from the Chair, Mrs Bea Nicholson, and as I had already planned to be in Scotland that day, I accepted the kind invitation.

The meeting was well attended with over 50 people and the Guest Speakers were Professor Bhaskar Dasgupta; Dr Jane Gibson, Consultant Rheumatologist at Whyteman's Brae Hospital in Kirkcaldy; and Dr K Gilbert, Chair of PMRGCAuk.

Professor Dasgupta talked about GCA, its history and the progress that has been made in the last five years with both more research being undertaken and the 'Fast Track' trials that are currently taking place.

Dr Gibson gave a talk on PMR, its history and the difficulty of diagnosis and that a Rapid Access (within 24 hours) GCA clinic is being implemented.

Dr Gilbert spoke on the need for support groups, helplines, information and also the need to raise the profile of both PMR & GCA and to assist in research.

A lovely buffet lunch was provided and it was well worth attending the meeting and to meet up with old friends and make new ones.

Mavis R Smith



Can you help please?

Professor Bhaskar Dasgupta and author/journalist Eric Clark, a GCA/PMR sufferer, are putting together a book, provisionally titled **PMR and GCA At Your Fingertips**, for publication next year. Meant primarily for patients

and their families, it should also appeal to healthcare workers, including GPs, because of the unrivalled knowledge and expertise of Professor Dasgupta. The book will consist of about 500 key questions and answers.

Here is the plea for help: If anyone has a question they would like to be included would they send it to ericclark@clarkwrite.com. The book should provide real practical help and information to sufferers. Everyone who submits a question (or questions) will be offered a discount when the book is published.

Update Eric and Bhaskar are grateful for the questions that continue to arrive and they will welcome more.

If anyone has a question they would like to put forward and don't have access to the Internet, you can send them to us by post and we will forward.

Eric Clark is an acclaimed investigative journalist and author who has PMR and GCA.

80 miles for PMR&GCA UK North East Support

My Nordic walking experience



L to R the team are: Richard, Lindsay, Geraint (Bo) and Jim Aitkenhead.

Well, we did it! It was 80 miles, not 70, after we had taken a few wrong turnings... and it rained, and rained, and rained... But what a walk. We, that is to say Jim, Rich, Bo and Lindsay, started here in Ulverston and the first day was sunny and warm. We headed out over beautiful farmland in the south lakes, in the company of seven or eight other walkers. The path climbed to a tarn on a high boggy moor where we ate lunch, and then wound our way back down into the next valley, to walk alongside the lake to Coniston.

The next day there was a severe weather warning as we headed up into the hills. The rain wasn't too bad to start off with, but as the wind got stronger the rain got heavier and heavier. We found a great cafe along the way and discovered 'cake power', that is to say you eat a huge slab of cake and then walk very quickly indeed through the pouring rain to the next stopover point, which was Great Langdale.

It carried on raining all night and well into the next day. We walked up Langdale in a downpour, but first we climbed the wrong hill and had to climb back down when the path ahead was blocked by a raging torrent and we realised the bridge we needed was miles below. Hmm, rubbish map reading on Lindsay's part but it warmed her legs up well. So, every puddle became a pond, every path had a river running down it and the actual rivers were in full spate.

We climbed out of Langdale over Stake Pass and along the very wet, slippery and unpleasant valley the other side of the hill. It took nearly all day to walk four miles, and there were still 12 to go, though the last bit was easier. We arrived in Keswick after dark.

Day four was much better – sun and showers, and for much of the day it was raining everywhere else but not on us. The path went round the back of Skiddaw and was high and beautiful. The peak we climbed at the end gave fantastic views of Scotland, Eden Valley and the North Pennines, as well as the Lake District hills that were now behind us.

On the final day we paddled and skidded our way through endless miles of sticky red mud into Carlisle. What a walk!

Jim Aitkenhead

BA(Hons) Econ, FCII, APFS, ACSI

In November 2012, AGE UK began a Nordic walking class in Redcar as part of its 'Fit as a Fiddle' programme. "Meet at Stray Café Redcar seafront at 10.30am – finish 11.30am – no need to book, turn up pay £3, poles and tuition provided."

I was slightly worried that as a PMR sufferer I would be very slow in comparison to a non-sufferer but the as everyone was over the age of 50, it only lasted one hour and as Redcar Stray is very flat walking either beach or grass I decided to give it a go. And anyway there was always the café to escape to!

We start and finish each session with some gentle warm-up exercises, then we are taught how to hold the poles (never call them sticks!) Then we walk. Dave, our instructor, says that Nordic walking exercises muscles, many in the chest, that never get exercised in any other sport or gym class. Must say, I always feel that my posture is more upright when we've finished.

Although I am often at the back of the group, being slightly slower than the others, I do enjoy the experience, fresh air and company. Not to mention a nice coffee, cake, and chin-wag in the café afterwards!

Pam on the right. Redcar Beach December 2012.



Healthy breakfast foods

by Caroline Cassidy

It's the most important meal of the day and yet a recent survey by PAGB, the trade association for over-the-counter medicines and food supplements, revealed that 22 per cent of Brits are skipping breakfast.

As the first meal of the day, breakfast sets us up with the nutrients and energy we need to get going, and is essential if we are to avoid the temptation to resort to unhealthy snacks come mid-morning.



Swift smoothie

If a lack of time is the reason you're skipping breakfast, consider a smoothie to start the day. Not only will it provide you with a calcium-packed dairy hit, but the addition of your favourite fresh fruits means you're not missing out on essential vitamins.



Cereal starter

The traditional bowl of cereal can be both filling and healthy, and an excellent source of fibre – but what kind of cereal you buy is key. Many contain high levels of salt, sugar and saturated fat, so pay attention to the label and opt for a wholegrain variety fortified with vitamins and minerals.



Eggcellent

Scrambled, poached or soft-boiled, there is no denying the humble egg's nutritional qualities. Packed with protein and low in saturated fat along with vitamins A and D, they're a great way to fill yourself up and keep you going until lunchtime. Enjoy with some wholegrain toast for added satisfaction.



Say yes to yoghurt

Fabulous for those who regularly run late, all that's required is a spoon to take advantage of this calcium and protein-filled option. Friendly bacteria will keep your gut in good shape, studies have shown that yoghurt can lower cholesterol and boost immunity. Add fresh fruit or eat it with muesli for even greater benefits.



Winter warmer

To send you out with a cosy glow, it really doesn't come much better than porridge. The oats are an excellent source of fibre, which can help to reduce cholesterol, and they release energy slowly to help stave off that mid-morning slump. Choose semi-skimmed milk and dried fruit to get one of your five-a-day.

Weekend treat



←No

Yes→



The odd bacon sandwich is irresistible to most, but if you fancy something altogether healthier as you peruse the Sunday papers, try grilled mushrooms and tomatoes on wholegrain toast. Not only are you getting the energy and fibre from the whole grains, but you'll have two of your five-a-day done before lunch.

Tips and Tricks for PMR



Don't waste that lemon peel. Learn its Secret.

Warning: Unwaxed lemons only – unless you steep all your fruit for 10 minutes in vinegar: this takes off the wax, pesticides and other things put on to keep them fresh.

Many professionals in restaurants and eateries are using or consuming the entire lemon and nothing is wasted.

How can you use the whole lemon without waste? Simple – place the lemon in the freezer and when frozen, get out your grater and shred the whole lemon, no need to peel it, then sprinkle it on top of your food.

Sprinkle it into your whisky, wine, vegetable salad, ice cream, soup, noodles, spaghetti, sauce, rice, sushi, and fish dishes. All foods will unexpectedly have a wonderful

taste, something that you may have never tasted before. Most likely, you only think of lemon juice and vitamin C. Not any more. Now that you have learned this lemon secret, you can use lemon even in instant cup noodles.

The major advantage of using the whole lemon, other than preventing waste and adding new taste to your dishes?

Well, you see lemon peel contains as much as 5 to 10 times more vitamins than the lemon juice itself. Yes, that is what you have been wasting. From now on you can consume all of those nutrients and get even healthier.

Lemon peel also helps in eradicating toxic elements in the body. So place your lemon in your freezer, grate it on your meal every day.

That is the Lemon Secret!

As one door closes...

My name is Margaret Stanley, I'm 60 and live in South Wales with my partner Dennis and our two large 'rescue' dogs. I had the grumblings of PMR in my mid 50s, stiffness in the mornings, nothing too serious and, of course, I was too young for PMR! I took early retirement in March 2011, aged 58, planning to do the all the things that I had never had time for before and whilst I was still 'fit and well'. I had worked in the voluntary sector for many years and I had been offered a position with Hope Rescue, managing the many volunteers dotted around the country.

December 2011 and the proverbial 10-ton truck hit me and within days, I was completely immobile, could not get out of bed unaided and PMR was diagnosed. I had to give up the work with the dog rescue and a lot of other things too. I've not had a very easy ride with PMR; too many flares, too many side effects and complications, and I have not been able to reduce my steroids. All in all, I was not a 'happy bunny'. A close friend suggested I start making 'decoupage' greetings cards for Hope Rescue; *'it would help raise much-needed funds for the dogs and would also help take your mind off your illness'*. My 'edited' reply being, *'You cannot be serious; boring, haven't got the patience and I am most definitely not arty/crafty.'* But she was determined and found something easy for me to start



with and showed me how to do it. Nobody could have been more surprised than me when they turned out rather well, so I tried some a bit harder next time. The rest is history, now I can make personal cards from people's photographs, birthday cards with children's favourite characters on etc. I've raised over £400 for Hope Rescue and I'm not ashamed to admit, my friend was right. When I am making cards, I am not

thinking about my aches and pains and when will this horrible illness finally go away.

As well as doing something for Hope Rescue, I also wanted to be able to do something for the PMR&GCA NE Support Group. The support I have had, especially with my many trials and tribulations, cannot be measured. My journey would have been even harder without the forum. The idea of making cards with pansies came along, as the pansy is the emblem of the charity. These sell like hot cakes too!

PMR continues to stop me doing many of the things we just take for granted. It serves me no purpose to dwell upon what I cannot do now but to focus on what I can do and the sense of pride gained in doing something different. It's an old saying, 'But as one door closes, another opens'. It might take time to find the right door (or you need a good friend to drag you there), but it has helped me no end and raised a fair bit of money too.

If anyone wants to order cards direct, email meggies@sky.com

Morning



One lonely, dark and starless night
I thought I saw a soul in flight
A dear departed, lost and gone –
How I wished I'd been the one
To leave this life so full of pain
lost dreams and hopes: to live again
Where freedom rules and dreams come true

But something said 'not you, not you'

And as I watched, appeared a star
A tiny light – it seemed so far
It shone and glimmered, grew and grew

And someone said 'not you, not you'

'It's dreams and hopes you've lost tonight
Not life itself; why, that's still bright'
When dreams and hopes are dead and gone
Wait for the dawn – the morning sun
brings others; shiny, bright and new
And with them, just a tear or two
for something gone – but, no, not you.
Quietly shifting, life just changing gear
But not life lost – see, I'm still here.

Catie Pickersgill, July 2009

A member and a Support Group Organiser
who has PMR & GCA.

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