

# The pain puzzle

Developing many painful muscles is no laughing matter. **Charmaine Dymond** weighs up the facts about polymyalgia rheumatica – the condition also known as PMR – and finds out what treatment can make a real difference, fast

**O**nce you get the hang of pronouncing it, polymyalgia rheumatica starts to roll off the tongue, but that still doesn't make it a household name. Despite the fact that it is one of the commonest inflammatory diseases affecting older people, most of us have never heard of it.

So what is polymyalgia rheumatica (or PMR)? The short answer? It is a condition which causes many (hence the poly) painful muscles (the myalgia). The main identifying symptom of PMR is shoulder pain, and people will often also experience pain in their neck, hips, thighs and back, inflammation of joints, mild fever, low mood and fatigue. Very little is known about why particular muscles become inflamed.

Typically symptoms develop over a few days or a week. Many may write it off at first as the aches and pains of old age – even though it can affect people as young as 50 – or think it is the flu. But the pain of PMR doesn't respond to everyday painkillers and can be debilitating.

Pat Smith, 57, suddenly

developed PMR two years ago: 'I had been fine, but I woke up in the middle of the night and I couldn't move. I couldn't move my head, shoulders, arms or my neck. It was really scary. I couldn't even hold the phone. I didn't know what was happening.'

Philip Wilson, 65, first noticed something was wrong when he had trouble lifting a bowling ball at his local league. 'Within a week I couldn't walk – it attacked me that quick,' he says.

People with PMR will often find their pain is worse in the morning, or after short periods of rest. Philip found this out the hard way, when he thought he'd have a bath to warm everything up. 'But I couldn't get out of the bath. In the end, we put some pillows under my backside and lifted me up on them, and then my wife lifted me up.'

Without treatment, the inflamed muscles can affect your mobility in all sorts of ways. 'My son had to take me to the doctors because I couldn't drive,' says Philip. 'I couldn't operate the clutch with my leg.'

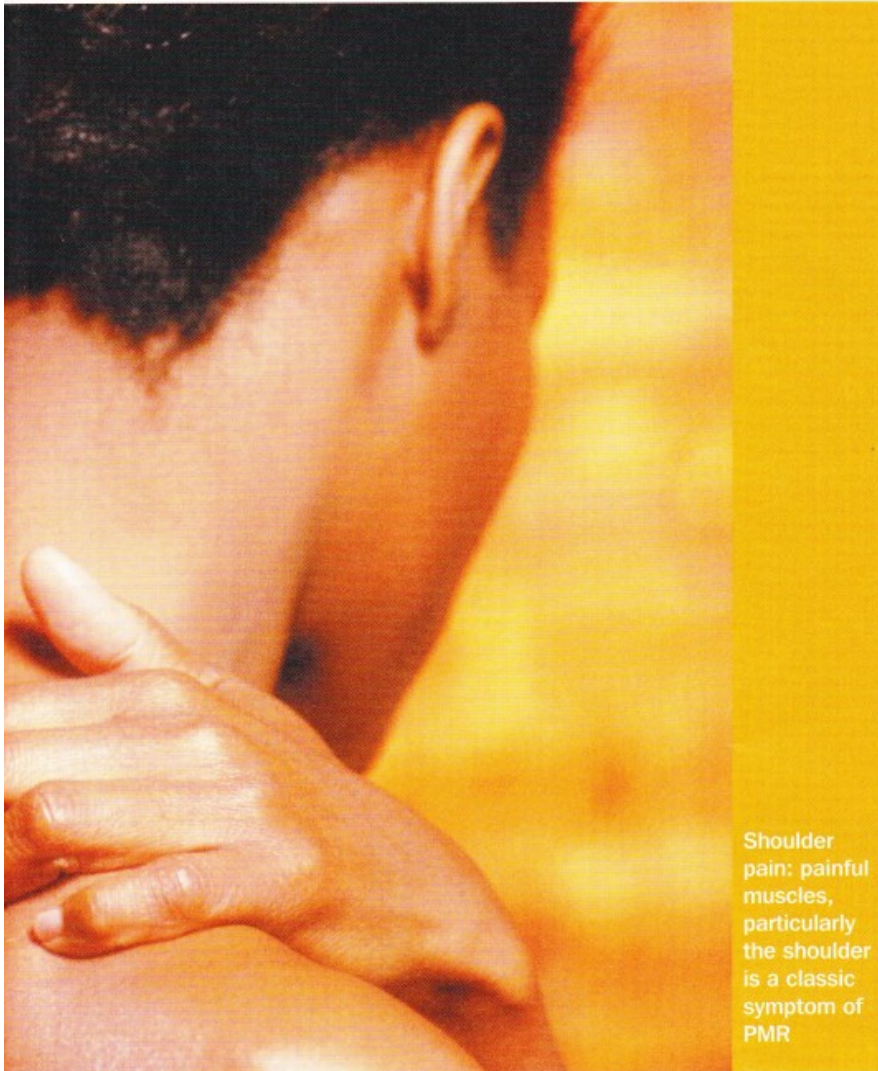


## Diagnosis

Because the symptoms of PMR can easily be mistaken for something else, it can make for a difficult diagnosis. Dr Bhaskar Dasgupta, consultant rheumatologist at Southend Hospital, stresses the importance of looking for the classic symptoms of PMR – shoulder pain being a vital clue. Doctors should also consider whether the individual falls into one of the categories of people PMR is most likely to affect. PMR occurs two to three times more often in women than in men; white European people seem to be more likely to be affected; and it is most commonly found in people over the age of 60.

The results of an ESR (erythrocyte sedimentation rate)





Shoulder pain: painful muscles, particularly the shoulder is a classic symptom of PMR

blood test, which measures inflammation, should then be weighed up. But Dr Dasgupta warns: 'The blood tests that we do in PMR are suggestive of PMR, but [the inflammation] can be due to other causes.'

Often, it is the quick response to treatment – usually the oral steroid prednisolone – that confirms diagnosis. 'The characteristic response of PMR is that, with treatment, people improve within one week – at least 75-90 per cent improvement in the first week,' says Dr Dasgupta. And if they don't get better? 'Then the GP must think of a different diagnosis.'

Pat remembers how her doctor suspected PMR: 'He said, "I'm going to zap you with a very high dose of steroids and see what

## With treatment, people improve within one week

happens". When the next day came, I said, "Doctor, you're a miracle worker". He said he'd been proved right that it was PMR.'

### Getting the treatment right

Steroids help ease the pain of PMR by reducing inflammation. Doctors gradually reduce the dosage over time until a 'maintenance' dose is found: 'This is the lowest dose of steroids that keep the symptoms at bay,' says Dr Niel Amin, a GP from Enfield.

Pat has found this a frustrating experience: 'You slowly come down on the steroids and then it flares up

and you go back on the steroids and then you go down again – it's just a vicious circle.' But because of the long-term side effects of steroids (see below), it is important to reduce the strength treatment as much as possible. While the relief achieved by the steroids is usually very rapid, treatment usually lasts for two to three years, sometimes longer.

Philip has been on steroids for five years now: 'I've gradually got better and better but I'm at a stage where I'm as good as I can be now. It's been like this for the past five years. The first 12 months were the worst.

While treatment improves people's lives dramatically, its side effects are worth more than a casual mention. Using steroids is not without risk. This is why finding the right maintenance dose for an individual is so important.

'We are very careful with steroids because they do have a propensity for causing side effects,' comments Dr Amin. The higher the dosage, the more intense these side effects may be.

Weight gain, stretch marks, and thinning of the skin are all common side effects of steroids that can affect not just a person's physical appearance, but also their emotional wellbeing. Isabel Combe, a hairdresser by trade and self-confessed 'girlie-girl', found that her confidence plummeted: 'You think you're going to take a tablet and that'll be it. To go from clothes size 10 to 16 – it's definitely life-changing... My cheeks went quite large and my eyes went very small. It's starting to get better. But going out? I've really got to be in the perfect frame of mind to do it.' These more dramatic side effects rarely occur in people on the doses of steroids normally used in PMR.

Long-term use of oral steroids can also cause osteoporosis, or thinning of the bones. Doctors recommend a diet high in calcium and vitamin D to protect against this, as well as weight-bearing exercise such as walking. If you are particularly at risk of osteoporosis, your doctor may recommend medication to protect against it.

Steroids can also increase your chance of infection. Pat was unlucky enough to develop



continued from page 31

shingles and consequently had postherpetic neuralgia, pain which continues after the shingles rash has disappeared. 'It's not so much the condition, it's the side effects of the steroids that I really want to get rid of now,' she says.

Other side effects include an increase in blood pressure, high blood sugar and cataracts, and these are all things doctors will look out for. Though some of the side effects have the potential to be pretty nasty, people should seek treatment for their PMR as it can dramatically improve quality of life. 'It definitely was worth it,' says Shirley Borin, 71, who was diagnosed with PMR 10 years ago.

### Giant cell arteritis

Giant cell arteritis (GCA), also called temporal arteritis, affects about 1 in 20 people being treated for PMR. It is not known exactly how the two conditions are related: 'We think there's a link. We don't know if one causes the other. A lot of patients with giant cell arteritis will have PMR and some patients with PMR do develop giant cell arteritis,' says Dr Dasgupta.

With GCA, certain blood vessels, particularly around the temples, become inflamed. This can lead to the blood vessel being completely blocked, and means the surrounding tissue will not receive enough blood. Blindness and other serious eye problems can occur, therefore it is important to start treatment quickly for GCA. It usually requires a much higher dose of prednisolone than for PMR. Isabel considers herself lucky that her GP recognised her symptoms right away. 'I hadn't heard of GCA and the dangers. After I went to the GP, within an hour I was in the hospital.'

The most common symptoms of GCA include headache, tenderness on one side of the head, problems with vision and pain in the jaw. Isabel continues: 'My jaw was really really sore. I'm going to laugh about this now, but I wanted to go about with my mouth open – that was the most comfortable position for me.'

If treated as quickly as Isabel's was, GCA shouldn't cause any long-term problems.

### Coping day to day

Treatment eases the pain people experience with PMR significantly, but the extent of pain relief will vary from person to person. So how do people cope with the pain that may be left over after the initial flare up? 'Partly,' Isabel says, 'you become used to living with the pain and get on with things.' She continues: 'I have good days and I have bad days. I can sometimes go three or four weeks and not feel too much pain or too much discomfort and then all of a sudden it just seems to rush into the body again.'



Shirley Borin was diagnosed 10 years ago; Isabel Coombe (inset) developed giant cell arteritis



### It will get better. I'm not going to live like this forever

Knowing what you're capable of and knowing when to stop are also very important. 'Some days I'm not so bad and I can do all sorts. The next day I pay for it. It's a very funny condition,' says Pat.

Philip takes a very pragmatic approach and will have a go at doing something, but stops or asks for help if he has trouble: 'If I'm sweeping the back path to get rid of all the leaves I do what I can and when my arms ache I stop,' he says simply. Before PMR hit, he was very active in his local playing fields association as a volunteer groundsman, but now knows there is a limit to what he can do. 'I can start the lawn mower with two

hands and cut the grass because [the lawn mower] does it on its own – I don't have to push it.'

Others develop their own unique coping or distraction strategies. Shirley Borin was treated for two years. 'In the evening while watching television I would tightly squeeze the outer edge of my ear with my fingers,' she says. 'That was strange, but it helped. It was a very intense pain.'

Isabel believes that eating an organic diet has helped, but reflects: 'It might be mind over matter – it could be a load of rubbish. I just felt that I had to do it.' Pat finds that using cold therapy brings some relief. 'I used to sit with heat pads, but cold seems better,' she says. 'It takes the ache out for an hour or so.'

### For the future

There is no known cause of PMR, but it is suspected that infection can trigger it. Dr Dasgupta believes diagnosing PMR should be made easier. 'A lot of research needs to be done,' he says. 'Unfortunately, PMR has not been a big research priority.'

Pat, on the other hand, would prefer to see research into new treatments to avoid the use of steroids and their side effects: 'I'm desperate to get off them,' she says. Perhaps she will be glad to hear that the British Society of Rheumatology is publishing draft guidelines on how to safely manage PMR in May 2006. These aim to make for easier and safer diagnoses and to minimise the strength of treatment, which should in turn limit side effects.

Thankfully, there is a light at the end of the tunnel, as PMR does eventually burn itself out and most people make a full recovery. Shirley thinks she is doing pretty well, 10 years on from being diagnosed. 'I'm not in pain and can walk about all day, I tend to just ignore it.'

'I think that's what keeps me going,' says Isabel. 'I think, it's not as bad as some kinds of arthritis. I know it will get better. I'm not going to live like this forever.'

**an**  
For further information and support, please call the Arthritis Care helpline on 0800 800 4050 (10am-4pm weekdays)