POLYMYALGIA RHEUMATICA

Information about polymyalgia rheumatica, what your diagnosis means, and the treatments that are involved

WHAT IS POLYMYALGIA RHEUMATICA?

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

WHAT ARE THE SYMPTOMS?

The main symptom is symmetrical aching stiffness in the shoulder and hip girdle regions in the morning that lasts longer than 45 minutes.

Other symptoms may include:

- Extreme tiredness
- Loss of appetite
- Weight loss
- Depression
- Difficulty sleeping due to discomfort

WHAT CAUSES PMR AND HOW IS IT DIAGNOSED?

It is not fully understood what causes PMR, but it is thought to be a combination of genetic and environmental factors.

PMR is a disease that almost exclusively affects those aged 65 or older, with women over 65 being the most common group.

PMR is diagnosed by a combination of your symptoms, and a blood test that looks at your levels of inflammation.

HOW IS PMR TREATED?

PMR is most often treated with long-term Prednisolone; a steroid medication. This reduces inflammation in the body and rapidly improves the symptoms of PMR.

Many people are able to stop taking steroids after 1-2 years. In some people, the symptoms can return and they may need the steroids for a longer period of time to keep symptoms controlled.

WHAT ARE THE RISKS OF PMR?

PMR does not generally tend to cause long term problems.

However, 1 in 5 people with PMR develop a more serious condition called Giant Cell Arteritis (GCA) also known as Temporal Arteritis. This is where the arteries in the head and neck become inflamed and cause symptoms such as:

- A headache, and you may have a tender scalp
- Problems with sight, such as double vision or loss of vision in one or both eyes
- Cramping pain in your jaw muscles or tongue when talking or eating

If you think you may have any of these symptoms, **call your GPs urgently or call 111**.

GCA requires immediate treatment, as it can lead to problems such as **stroke** or **blindness** if not treated quickly.

WHAT ARE RISKS OF STEROIDS?

Like all medications, steroids come with risks that are increased with long term use, such as:

- Indigestion or heartburn (this can be helped by taking your steroids with or after meals)
- Increased appetite
- Mood changes
- Problems sleeping (this can be helped by taking your steroids in the morning)
- Eye problems such as glaucoma
- High blood pressure
- Weakening of the bones (osteoporosis)

It is thought that liquorice can raise the amount of prednisolone in the body, and also increases the risk of low potassium.

HOW WILL MY STEROID DOSE CHANGE OVER TIME?

To reduce the risk of side effects, your doctor will ensure you only take steroids for as long as you need them. As such, most people follow a reducing regime of:

- Starting dose of 15mg/day until symptoms fully controlled (usually 3 weeks)
- Then reduce to 12.5mg/day for 3 weeks
- Then reduce to 10mg a day for 4-6 weeks
- Then reduce by 1mg every 4-6 weeks until treatment is stopped.

If you experience any flare up of symptoms during this time, speak to your doctor.
This reduction time is a guide, and will be tailored to your individual needs if required.
It is important you do not stop taking steroids suddenly as this can make you unwell.

WHAT SUPPORT WILL I RECEIVE FROM MY GP PRACTICE?

While you are taking steroids, to start with you will receive blood tests every 3 months to monitor your levels of inflammation.
You will receive a phone call with a GP or pharmacist after your first few dose reductions to see how you are getting on.
After this time, no appointments will be pre-booked but you are welcome to call and make an appointment if you notice symptoms returning.

What other medications might my doctor consider?

BONE PROTECTION

Some people may be at an increased risk of bone fractures, and this risk can be increased by long term use of steroids.
If your GP thinks you are at an increased risk, you may be offered a medication called a **bisphosphonate** to protect your bones.

IF YOU HAVE BEEN STARTED ON A BISPHOSPHONATE

Rarely, bisphosphonates can cause damage to your jaw or hip bone.
It is recommended that you ensure to have yearly dental check ups to monitor if there have been any changes. Your GP may recommend that you have a dental check-up before you start bisphosphonates.
If you have any new unexplained jaw or hip pain since starting the medication, please call your GP.

CALCIUM AND VITAMIN D

It is important to ensure you have a good amount of calcium in your diet to help keep your bones strong. Good sources of calcium are:

- Milk, cheese and other dairy
- Leafy green veg such as curly kale or okra
- Fortified non dairy milks
- Bread or anything made with fortified flour

Your doctor may give you a calcium and/or vitamin D supplement to take if they think you need it.
Vitamin D helps the absorption of calcium.

PROTON PUMP INHIBITORS

These are medications such as Omeprazole or Lansoprazole. They reduce the amount of acid your stomach produces and may be prescribed to help protect your stomach lining whilst taking steroids.

FEELING OVERWHELMED?

PMR&GCA Scotland have a website and helpline that can be called for advice, information about support groups, or even just for someone to chat to

Call: 0300 777 5090

9am-9pm
7 days a week

You can also find links to more information on the Greyfriars website