

Polymyalgia Rheumatica & Giant Cell Arteritis

Introduction

This brochure is for people with polymyalgia rheumatica (pah-lee-my-al-ja roo-ma-tih-kah), or PMR, and giant cell arteritis. It has been written for persons who have been diagnosed with these disorders and their family and friends. It is hoped that this information will help you to better understand your disorder and its treatment. This material is not intended to replace specific recommendations your doctor makes. Every effort has been made to provide general information that applies to most people with these disorders. In some ways, your condition and its treatment may differ from the information provided here. This often is because there is a unique feature about you and your condition that your doctor is taking into consideration. If you have questions about the material presented here or topics that were not covered, be sure to write them down so that you can discuss them with your doctor.

What is Polymyalgia Rheumatica?

Polymyalgia rheumatica is a disorder that causes stiffness and aching that begins in the neck, shoulder, and hip areas. It is not known whether it is a disease of the joints, muscles or arteries. However it is thought that inflammation in these areas leads to pain and stiffness.

Who gets PMR?

PMR almost always occurs in people over 50 years of age. The average age is about 70 years. It occurs twice as often in women as in men.

What causes PMR?

The cause of PMR is unknown. Since it occurs in older people. It may be related to the aging process. In a few cases it has occurred in several members of the same family. This may mean that it can be inherited. Still, the odds of someone else in your family getting this disorder are quite small. So far there is no evidence that MR is caused by an infection. There is no evidence that your family or friends can catch PMR from you.

What happens in PMR?

PMR causes stiffness and aching of the muscles about the neck, shoulders and hips. Most people with PMR have symptoms in at least two of these three areas. The shoulder region includes the muscles of the upper arm. The hip region includes the muscles of the lower back and thighs. In most cases, the symptoms start very suddenly. People with PMR may be perfectly well one day and then feel the full effects of this disease the next day. Sometimes the symptoms come more slowly.

Stiffness is a major feature in PMR. It often is worse first thing in the morning. When it is severe, you may have difficulty getting out of bed. Pain may wake you at night and turning over in bed may be difficult. The stiffness may be worse during periods of inactivity such as after a long car ride.

PMR also may cause other symptoms. These include fatigue, weight loss and a slight fever. Some people may experience depression in their attempt to cope with

of the body may ache as well. Sometimes joints in
ingling in the fingers (carpal tunnel syndrome) also

Most persons with this disease have been in very good health before their first symptoms. People often do not understand why they feel so terrible when the disease begins. These symptoms usually make them feel very different than before and can be quite overwhelming because of their effects on everyday life.

PMR usually is not associated with any other disease. However a person with PMR also may develop other forms of arthritis. Some people with PMR may also have a condition called giant cell arteritis.

How is PMR diagnosed?

PMR is a syndrome. A syndrome is a collection of symptoms. There is no single test that can be used to make the diagnosis in all people. This can make the diagnosis of PMR difficult. To make the diagnosis your doctor will consider your symptoms along with results of your physical examination and laboratory tests. Other rheumatic disease infections and cancer can cause symptoms similar to PMR. It can take a while to finally make the diagnosis of PMR. It is quite possible that a rheumatologist will be involved in your diagnosis. A rheumatologist is a physician with special training in diseases that involve joints, muscles and connective tissue. A rheumatologist can help diagnose your condition, provide treatment and follow your condition over time to make any necessary adjustments to your treatment.

To find out if you have PMR your doctor will:

- Ask about your symptoms and recent changes in your health
- Perform a physical examination
- Obtain certain blood tests

These blood tests will be used to check for diseases that cause symptoms similar to PMR. A blood test called the Erythrocyte Sedimentation Rate (or ESR) will likely be included. The ESR rate can measure the amount of inflammation present. As inflammation responds to medication the ESR usually goes down. In almost all persons with PMR the ESR is higher than normal. However the ESR is higher than normal in other diseases besides PMR. As a result the diagnosis of PMR cannot be made by blood test alone because the blood test cannot distinguish PMR from other conditions such as infection or other forms of arthritis.

Other special tests may be necessary. This additional testing will depend on your symptoms as well as what your doctor finds.

How is PMR treated?

The goal in treating PMR is to help relieve pain, stiffness and achiness. Treatment includes medications to help reduce inflammation as well as proper exercise and rest for some people in order to maintain joint flexibility, muscle strength and function.

Most often to treat PMR are corticosteroids, and non-steroidal anti-inflammatory drugs.

Corticosteroid drugs are strong medications that help reduce inflammation. They also help relieve stiffness and aches. They act quickly in PMR. Most people feel better within a few days or sometimes even the next day. There are many forms of corticosteroids. For example Prednisolone is a medication often used in PMR.

If your doctor places you on corticosteroid you should follow instructions carefully. It is best that you take the entire dose in the morning. You probably will feel better very soon after starting this medicine. It is important to keep taking the medicine even though you are feeling better. PMR can return if you stop this medicine too quickly.

You may need to take corticosteroids as briefly as six months or as long as one or two years. Some people may need to be treated even longer. As you improve while on this medicine, it is likely that the dose will slowly be decreased. Follow your doctor's instructions on how often to take your medicine. **Do not try to cut back the dose on your own or suddenly stop taking your medication**, since your symptoms can worsen.

Over a long time, corticosteroids may cause such side effects as:

- Weight gain
- Thinning of the bones (osteoporosis)
- Depression and mood swings
- Increased risk of infection
- Cataracts
- Glaucoma
- Worsening of diabetes or new diabetes in someone who has never had it
- Thinning of the skin and easy bruising
- Rounding of the face
- Difficulty sleeping
- High blood pressure (hypertension)

These medications affect everyone differently. You may have some of these side effects or none at all. If they do occur most of these side effects will go away when the medication is stopped or decreased. Your doctor can give you some helpful tips about diet and exercise to help with some of the side effects. If you are placed on this medication it is because your doctor feels that your symptoms are serious enough to need this medication. Be sure to discuss any concerns that you have about this medicine with your doctor.

Also let your doctor know about any side effects that you may be experiencing. For more information about corticosteroids contact your local Arthritis Foundation and request their brochure entitled Corticosteroids.

steroids

many of the medications you may have taken in produces small amounts of hormones that are forms of corticosteroids. When you take corticosteroids for more than a few days, your body may stop producing some of these hormones. This is not permanent. Your body gradually will start making the hormones again as the dose of your medication is lowered.

Your body depends on corticosteroids for many daily functions. These hormones are important during times of stress. Your body does not care whether it receives corticosteroids from natural hormones or from medication. However if you suddenly stop taking this medication your body may not make enough hormones on its own on short notice. This can make you seriously ill. Also your body's need for this medicine is greatest in the morning. That is one reason why most people should take their medication in the morning. Some important rules about corticosteroids are as follows:

- Do not stop this medication without discussing it with your doctor. Do not try to decrease this medication on your own. You and your doctor will need to work together to gradually wean you off this medicine.
- Tell your other doctors and other health professionals that you are taking this medicine. In some cases they may want to delay certain types of treatments if you are taking corticosteroids. Your medication may need to be increased for short periods of time if your body is under a lot of stress . for example, if you are recovering from surgery or a serious illness. Even after you have been off corticosteroids for as long as one year you should tell your doctor that you used to take them.
- Wear medical identification to let people know that you take these medications in case a medical emergency occurs. Should you be involved in an accident or become seriously ill it is very important that this information be known. Also tell your family that you are taking corticosteroids so they can tell others in an emergency.
- If you become ill and are unable to take this medication because of vomiting let your doctor know right away. You may need to increase your usual dose for several days when you are sick.

Many of the side effects of corticosteroids are directly related to the dose given. The therapeutic goal is to always find the lowest effective dose that will avoid as many of the side effects as possible. You probably will not need large doses of corticosteroid unless your PMR is accompanied by giant cell arteritis (see next section). Serious side effects are much less common with the low doses of corticosteroids usually used in PMR, but it is still wise to follow these safety rules.

Special Instructions for NSAID's

- Always take NSAID's with food, since they can upset your stomach and cause ulcers and bleeding.
- Call your doctor if an NSAID causes indigestion (upset stomach)

more than your doctor prescribes.
over-the-counter medications that contain aspirin or
prescribed NSAIDs.

Exercise and Rest

Both exercise and rest play an important role in your treatment. Exercise helps you maintain or regain your energy and muscle strength. Exercise also helps you fight the weight gain and osteoporosis (bone thinning) that can be side effects of taking corticosteroids.

It is important to use common sense when exercising and to not overdo it. If you are overactive your symptoms may worsen. Gradually increase the amount of exercise that you do. Good forms of exercise include walking, riding an exercise bike, and exercising in a pool. Ask your doctor or physical therapist for specific suggestions about the type of exercise that would be best for you. It also is important to get an adequate amount of rest. You need enough rest to give your body time to recover.

Treatment Goals

You will need to see your doctor regularly once you start taking medication. Tell your doctor how the medicine has affected your symptoms. Report any side effects that you may have developed such as weight gain or depression. Your doctor may use various tests like the ESR rate to adjust your medication. Even though you may feel well it is important to see your doctor regularly so you can be checked for any signs of relapse.

Once you have responded to corticosteroids the goal is to slowly reduce the dose to the lowest level necessary to control symptoms and prevent a relapse. This goal requires that both you and your doctor communicate honestly and completely about your treatment and its effects. Effective treatment allows most people with PMR to lead active and productive lives.

What is Giant Cell Arteritis and who gets it?

Giant cell arteritis or GCA is a condition in which certain arteries (blood vessels) in the body become inflamed. It can develop in some people with PMR. These two diseases often occur together. About 10-15% of people with PMR also have GCA. Almost 40% of people with GCA also have PMR. However, GCA can occur on its own without PMR. Like PMR, the cause of GCA is unknown.

What happens in GCA?

Giant cell arteritis usually affects areas near the temples on the upper front sides of the head. It also involves other arteries in the head, neck, arms and occasionally will affect other arteries in the body. Inflammation causes the artery to become narrow or blocked. Inflammation can cause problems because too little blood is getting through the blood vessels. The symptoms include:

- Pain in the jaw muscles when eating or talking
- Severe headaches
- Loss of vision, blurry vision or double vision . the vision loss often is described as having a curtain pulled partly over one eye
- Tenderness to the scalp or temples

Giant cell arteritis may be an especially difficult condition to diagnose in some people who never get head or neck symptoms. These people just have fever, fatigue, weight loss or anemia. Loss of vision can be temporary or permanent. It may improve or cause blindness. If you have PMR and start having vision problems, call your doctor immediately. Also tell your doctor if you develop any of the other symptoms. It is important to diagnose and treat giant cell arteritis early to prevent blindness.

How is GCA diagnosed?

Your doctor may need to remove a small piece of an artery above and in front of your ear to determine if you have giant cell arteritis. Often the artery will be taken from the temple through a small incision. You will not need to be put to sleep to do this, but you will receive medicine to numb the area. The piece of the artery then will be examined under a microscope. The artery will be inflamed if you have giant cell arteritis. An ESR read also can help determine the diagnosis because as in the case of PMR, the ESR rate is almost always higher than normal.

How is GCA treated?

Corticosteroid drugs are used to treat giant cell arteritis. Higher doses are required to treat giant cell arteritis than to treat PMR. Other medications are valuable if side effects from the corticosteroids become a problem. You can expect to stay on this treatment for many months to several years, but the dose will be lowered over time once symptoms are controlled.

The Future

Both PMR and giant cell arteritis usually will last one to two years. How long these conditions will stay in an individual case can vary quite a bit. Sometimes these diseases recur even if you have been doing well for some time.

Treatment allows most people with these diseases to lead active and productive lives. Most people are able to take lower doses of the medication after they have been treated for a while. Many people eventually are able to stop taking the medication after one or two years but the threat of relapse requires close communication between you and your doctor.

Resources

Contact your local Arthritis Foundation for more information about polymyalgia rheumatica or giant cell arteritis.