



## Managing body pain caused by fibromyalgia

## Department of Rheumatology

Information for Patients

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## What is fibromyalgia?

Fibromyalgia causes pain and tenderness all over the body. It is a condition that it not really understood, despite lots of research looking into it. In a few people we do find a definite cause for their symptoms, but in most people it appears to come on gradually.

A vicious cycle of events can occur:

- You may have a poor un-refreshing sleep pattern as your pain gets worse. We know
  from research that if people are unable to get into the deep refreshing stage of sleep,
  they cannot then relax their muscles properly, and their involuntary resting muscle
  tension is raised.
- This leads to aching all over which can then stop you from sleeping properly the next night. This then causes further problems with your muscles.
- This also leads to further periods of tiredness despite taking long intervals of rest. You may start to nap during the day which can then prevent your body from getting into the deep stage of sleep the next night, making the problem worse.
- This becomes a vicious cycle which can get worse and can become very difficult to get out of.

We also know from research that patients with fibromyalgia sometimes have low levels of certain chemicals within the brain, which affects how they perceive a sensation of pain.

For example a light touch and movements that would not normally cause problems, can cause a real feeling of pain or numbness in someone with fibromyalgia, with symptoms such as pins and needles. But there is no physical problem to explain it that we can fix.

# Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

## Symptoms of fibromyalgia

#### The main symptoms of fibromyalgia are:

- pain you may feel as though you've got pain that spreads throughout your entire body, with certain parts such as your neck and back feeling particularly painful. See the diagram of trigger/ tender points on page 4. You may also notice clicking in your joints.
- tiredness (fatigue) and generally feeling like you have no energy.
- sleeping badly and waking up feeling like you have not head any rest.
- aching and stiffness which often feels worse during or after you've been active.

It is common for your condition to flare-up, making your symptoms suddenly worse.

#### Fibromyalgia can also cause:

- forgetfulness or poor concentration.
- stress, worry or low mood.
- tingling, numbness or swelling of your hands and feet.
- headaches.
- restless legs syndrome a tingling, uncomfortable feeling in your legs, especially at night.
- irritability, or feeling low or weepy.
- feeling like you urgently need to pee, especially at night.
- painful menstrual periods.
- diarrhoea, constipation and stomach pain sometimes separately diagnosed as irritable bowel syndrome (IBS).
- increased sensitivity to things like cold, sound, knocks and bumps.
- tender or overly sensitive joints and muscles.

The pain can feel like it's affecting your whole body, or it may be particularly bad in just a few areas. For some people, the pain gets worse in extreme temperatures when it is very hot or cold, or in damp weather.

Besides the pain, fatigue can also be the worst part of fibromyalgia for some people. This can lead to a difficulty to think clearly or remember things properly, which is sometimes called fibro fog or brain fog.

## Treatment options / managing your symptoms

Different painkillers can be tried but these may not fully work.

Sometimes low doses of medication such as nortriptyline, amitriptyline, pregabalin, gabapentin, duloxetine and fluoxetine may help in certain circumstances. These medications may also be used for treatment of depression, in this case we may use them to also help with pain in fibromyalgia. These drugs have an effect on some of the chemical's in your brain (neuro-transmitters) which can help to significantly reduce pain. It is important to be realistic about their possible benefits, and stop them if there is no significant improvement. Many patients still describe their pain score as 10 out of 10, despite being on 4 medications for pain, which can have harmful side effects.

The best approach is to stay fit and active as much as your condition allows. If you don't do enough exercise the condition usually gets worse. Aerobic exercise can help to get a more refreshing sleep pattern. Physiotherapy can be of benefit to get a regulated and sustainable exercise regime. An exercise programme using the principles of tai chi, pilates and yoga can also be beneficial.

Studies have shown that mindfulness/ mind-body therapy has also been found to be useful.

It is important that patients suffering from fibromyalgia pace themselves in any activity that they try. This means taking periods of rest after a period of activity, to get a balance. Do not over do it or push yourself beyond your limits. If you do not pace yourself, it could slow down your progress in the long term.

Another treatment approach is a psychological technique called cognitive behavioural therapy (CBT). If you would like to look at this option you will need to discuss this with your GP.

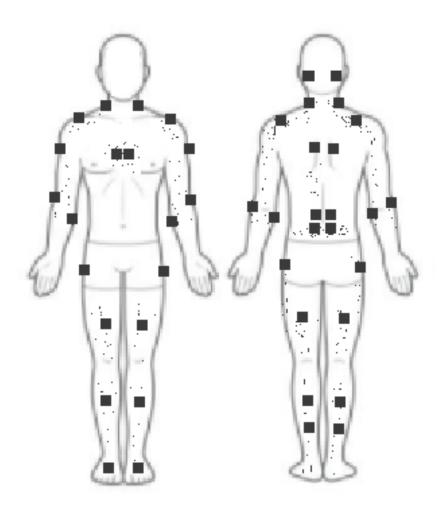
#### **Further information**

The sources below provide a useful understanding of the condition and how best to manage it to improve your health:

- https://www.bbc.co.uk/news/av/stories-45369402/fibromyalgia-like-red-hot-lava-radiatingthrough-my-body
- https://www.versusarthritis.org/media/1251/fibromyalgia-information-booklet.pdf
- <a href="https://fibroguide.med.umich.edu/">https://fibroguide.med.umich.edu/</a> developed by a team at University of Michigan and led by a world expert in fibromyalgia.
- www.bodyreprogramming.org/ this is a new intervention provided by colleagues in Plymouth and it continues to be developed with help from patients.
- www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/ developed by Torbay and South Devon NHS trust to help fibromyalgia patients get back a good quality of life.

## Trigger/ tender points

People with fibromyalgia can have widespread pain and tenderness around the body in specific trigger points, as shown in the diagram below. When you press on these spots they feel sore.



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