

Fibromyalgia

Patient Information Leaflet

MSK Musculoskeletal Physiotherapy Service



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What is fibromyalgia?

Fibromyalgia is a long-term condition that causes widespread pain across the body, coupled with extreme tiredness (fatigue). People with fibromyalgia may also have other symptoms. These can differ from person to person and may change from day to day.

Fibromyalgia is thought to involve changes in the way the brain and nervous system processes pain signals. This means that the body becomes more sensitive to pain, which can feel more intense and widespread. This may additionally extend to greater sensitivity to light, sounds, temperature and touch.

Although fibromyalgia can be very painful and affect quality of life, it does not cause damage to muscles, joints or internal organs.

What are the main symptoms?

Everyone's symptoms can be different, but some of the most common symptoms are:

Pain

The type of pain people experience with fibromyalgia can vary. Typically, this pain is felt across multiple different

parts of the body and can vary day to day. Pain is often worse with stress, illness, poor sleep or doing too much.

Stiffness

People will often report their body and joints feeling harder to move first thing in the morning or after they have been sitting for a long time.

Increased pain sensitivity

People with fibromyalgia will often experience a heightened pain sensitivity. This means that things you may not have previously found painful are now very painful and this pain can often last a lot longer.

Cognitive problems

People often refer to this as 'brain fog'. Common symptoms include difficulty concentrating, memory issues, slow or confused speech (i.e. difficulties finding words or expressing thoughts clearly).

Fatigue

Fibromyalgia is often associated with extreme levels of tiredness that is not relieved with rest or sleep. This will often vary from day to day without a clear cause.

Sleep disturbance

Sleep can be affected in multiple ways. Often, people can find it difficult to get to sleep or be woken multiple times throughout the night. One of the most common things

that people will experience is non-refreshing sleep. So, no matter how many hours you have slept, you still wake up feeling tired.

People with fibromyalgia may also experience:

Headaches

Symptoms may include headaches and/or migraines

Irritable bowel

This can cause people to have stomach pain, bloating, constipation or diarrhoea. Sometimes people are diagnosed with irritable bowel syndrome (IBS).

Low mood

This can range from episodes of feeling sad and down to formal diagnoses of depression.

Anxiety

People with fibromyalgia may often feel more anxious, stressed or overwhelmed.

Strange sensations

Pins and needles, tingling, burning sensations, amongst other symptoms are commonly reported in hands and feet, but can affect anywhere on the body.

What causes fibromyalgia?

The exact cause of fibromyalgia is unknown, but it is thought that there are several different factors involved. These include:

Physical or mental trauma

A history of physical or mental trauma, as well as stress, can play a part. In some cases, people will develop symptoms following an illness, an injury or following a period of emotional stress. However, sometimes people cannot identify a particular trigger.

Changes in how the body processes pain

Pain is a protective output of the brain and nervous system, created after interpreting signals from all over the body along with psychological factors and what's going on around you.

In fibromyalgia, the nervous system may become much more sensitive to things that didn't previously affect you, including pain. Low levels of certain hormones in the brain (such as serotonin, noradrenaline and dopamine) are also believed to play a part.

Disturbed sleep patterns

Sleep problems are a common symptom but are also a contributing factor to developing fibromyalgia. Poor

sleep over a long period of time has links with the development of fibromyalgia.

Family history of fibromyalgia

Having a close relative with fibromyalgia is believed to be a potential contributing factor. Genetics are also thought to potentially play a part.

Despite these risk factors, often there is no single cause, and symptoms often develop slowly over time.

Diagnosis

Diagnosing fibromyalgia can be difficult as there is not one specific test to diagnose it.

A diagnosis is usually made by a healthcare professional based on:

- a history of widespread body pain that has been ongoing for more than 3 months
- associated symptoms such as fatigue, memory difficulties and waking up feeling not refreshed
- other symptoms such as pain or cramps in the abdomen, headaches and problems with mood.
- assessment to rule out other conditions that can cause similar symptoms

Health professionals will often use clinical tools and scoring systems to help build the picture around a diagnosis.

Management

Fibromyalgia does not cause lasting damage to the body's muscles, bones, joints or organs. Research suggests that it is not a progressive condition that will inevitably get worse. However, there is no quick fix with fibromyalgia and management involves multiple different things to successfully control and manage symptoms.

Exercise and physical activity

Regular exercise and physical activity are one of the most effective treatments. There is no single form of exercise that is better than another. The best exercise for you is one that you enjoy, can afford, fits into your daily routine and you are likely to keep up with.

Guidelines suggest:

- A minimum of 150 minutes of moderate intensity activity per week. This is something that raises your heart rate and gets you breathing more heavily.
- Strength exercises twice a week.

Exercise can help for many different reasons:

Pain relief – exercise stimulates our body to release hormones such as endorphins. These are our body's natural painkillers, so can help reduce pain.

Improves mental wellbeing – the release of hormones when we exercise can help reduce feelings of stress, anxiety and low mood.

Helps us feel more alert – release of hormones during exercise helps boost alertness.

Improves sleep – exercise helps improve sleep quality and duration. Exercising can make us feel more tired, therefore help with sleep, but avoid exercising too late into the evening as this can keep you awake.

Improving muscle strength – if we are inactive, our muscles can become weaker, and our joints become stiffer. Exercise will help your body become stronger and capable of doing more.

When starting a new exercise, don't push yourself too hard too soon as this can cause a significant increase in your pain. However, it is normal when you start a new activity to feel a bit achy. This is because your body is doing something that it isn't used to doing.

Starting small, and gradually building up over time will allow your body to slowly adapt and become stronger, without causing significant increases in pain.

Pacing activities

What is pacing?

Pacing is a way of managing your activity so that you can stay active, without making your pain worse. It means finding an amount of activity that you can do comfortably, and then slowly increasing it over time.

Many people with pain fall into a common pattern of doing too much on one day, which can cause more pain, then needing several days to recover.

This is often called a 'boom and bust cycle'.

Pacing helps you avoid this cycle.

Why does pacing matter?

When you have pain, your tissues and nervous system can become more sensitive. If you suddenly do a lot more activity, your pain may increase. People often call this a flare-up.

Keeping your activity levels steady and consistent gives your body a better chance to adapt and build tolerance.

Common mistakes:

Doing too much on 'good days' – if you wake with less pain, it is easy to try and do everything at once. This often leads to more pain the next day.

Resting completely on 'bad days' – many people stop all activity when pain increases because they worry about causing damage.

However, pain does not always mean harm. Staying gently active is usually helpful.

Increasing activity too quickly – it's tempting to make big jumps in activity when you feel motivated.

However, slow, steady progress works better and is more likely to last.

What do we recommend?

Start with an amount of activity you can manage most days of the week. Then increase it gradually, using small steps rather than big leaps.

Example:

If walking for 10 minutes causes a flare-up, try starting with 5 minutes instead. Do this regularly and then slowly build up as your body adapts.

Look after your mental wellbeing

Our experience of pain is closely linked to our mental wellbeing. Feelings of stress, anxiety, low mood, and other things that affect our mental health can directly influence and heighten the level of pain we experience. Looking after your mental wellbeing can have positive effects on the level of pain.

Strategies may include:

- relaxation techniques and exercises
- engaging in gentle exercise
- spending time doing things you enjoy
- speaking to family, friends or health professionals for support

For more specific guidance and support with managing your mental health, please visit:

<https://selfhelp.cntw.nhs.uk/organisation/leicestershire-partnership-nhs-trust>

Managing sleep

Sleep and pain are very closely linked. When you sleep, your body works hard to:

- repair and restore muscles and tissues
- control the hormones that influence healing and inflammation
- support your immune system
- keep good energy levels, mood and concentration

Therefore, when you don't sleep well, you may:

- feel more pain
- get tired more quickly
- do less during the day
- take longer to recover
- gain weight over time

Good sleep helps the body and mind, which helps with your quality of life. Most people feel best with about 7 to 9 hours of sleep each night, but everyone is different.

But it's not only about how long you sleep. Good quality sleep is just as important. Deep sleep is important for your body and mind.

Practical ways to improve sleep

You don't need to change everything at once. Small steps can make a big difference.

Exercise regularly

Regular exercise can help you sleep more deeply.

- Exercise guidelines recommend that adults should perform 150 minutes per week of moderate exercise. This means doing something that makes you warm and a little out of breath.

The best form of exercise is something that you enjoy and can perform regularly.

Think about what you eat and drink

Your food and drink choices can affect your sleep, especially in the evening:

- eat a healthy, balanced diet
- try not to drink caffeine later in the day
- try to cut down or stop smoking near bedtime
- avoid alcohol before bed

Make your bedroom a good place to sleep.

Your sleep environment matters:

- keep the room quiet or use earplugs
- keep the room dark or use an eye mask
- keep your room cool and well-ventilated
- use a comfortable pillow and mattress
- keep your bedroom for sleep only – not for eating, drinking, watching TV or scrolling on your phone

Wind down before bed

Help your brain get ready for bed:

- have a calm bedtime routine
- try to address any worries or stress earlier in the evening so that they do not affect your sleep
- do something relaxing before bed, like reading or listening to calm music

Keep a steady routine

Your body likes a regular pattern:

- go to bed and wake up at the same time each day
- try not to sleep in, even at weekends
- avoid napping in the evening

Manage light during the day and night

Light helps control your body's sleep-wake cycle.

This is your body's natural internal 24-hour clock that tells you when to be awake and alert, and when to feel sleepy and rest.

- avoid bright screens for at least an hour before bed
- dim the lights in the evening
- spend more time outdoors during the day
- try to get natural light soon after waking up

If you can't sleep:

- try not to lie in bed worrying about it
- try slow counting in your head
- if you still cannot sleep after about 30 minutes, get out of bed and do something calm, like reading until you feel sleepy again

Medication

Some people may benefit from certain medications to help control their level of pain. Speak to your GP or pharmacist if you would like advice.

Education and Self-Management

Understanding fibromyalgia can help you feel more in control. Small, steady changes are often the most helpful.

Final thoughts

Fibromyalgia is a long-term condition that causes widespread pain across the body and high levels of fatigue.

The pain experienced is often due to a combination of different factors, which can result in increased pain sensitivity.

Regular exercise, pacing, sleep management and managing your mental wellbeing are all important things to consider in the management of fibromyalgia.

Although there is no quick fix, small, consistent lifestyle changes are often what lead to the best long-term improvements.

If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.



MSK Physiotherapy Service

Find out more about the MSK Physiotherapy Service and what we offer

www.leicspart.nhs.uk/service/musculoskeletal-msk-therapy-physiotherapy/



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