

Fibromyalgia

A guide for Unite members



Introduction



Many people with fibromyalgia continue to work despite the condition. Unite members want to ensure that members who have fibromyalgia have suitable help and support in their workplace. This means providing all our members with information and raising awareness about the condition to help members approach their employers with a view to making improvements for all.

There are many aspects to this, including ensuring that health and safety requirements (such as carrying out risk assessments, providing suitable equipment and work clothing and paying attention to working hours) are complied with, the members are consulted and Equality Act 2010 duties are respected in particular in relation to making reasonable adjustments, gender and disability discrimination.

This guide forms part of a Fibromyalgia information pack and has been developed with the support of charities, members and safety reps.

The pack contains:

- This guide
- A model Fibromyalgia disability equality workplace action plan and model agreement which you can adapt for your workplace
- Various posters

The information in this guide was obtained from:

- Arthritis Research UK
- Arthritis Ireland
- Fibromyalgia Action UK

What is Fibromyalgia?

Fibromyalgia is a collection of several symptoms. The main symptoms include chronic widespread pain and profound fatigue. There is an increasing body of evidence demonstrating that fibromyalgia is a disorder related to the Central Nervous System, which causes an amplification of messages around the body.

The pain tends to be felt as diffuse aching or burning, often described as head to toe. It may be worse at some times than at others. It may also change location, usually becoming more severe in parts of the body that are used most. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. It may come and go and people can suddenly feel drained of all energy – as if someone just “pulled the plug”.

Fibromyalgia is a common illness. In fact, it is more common than rheumatoid arthritis. A survey in five European countries (see www.fmauk.org/prevalence for details) estimated the prevalence of fibromyalgia at between 2.9 and 4.7%. People with mild to moderate symptoms are usually able to live a reasonably active life, given appropriate treatment and guidance. However, it is worth recognising that the condition is hugely unpredictable, with symptoms varying in terms of duration, location and severity, making it extremely difficult for people living with fibromyalgia to plan ahead.

Fibromyalgia is currently managed primarily alongside musculoskeletal conditions. Current theory points towards a neurological origin; however, presentation and chronic pain clinical pathways lead patients to be seen by rheumatology teams. Some doctors are not as aware of fibromyalgia as others; however ongoing efforts to educate healthcare professionals within the National Health Service is slowly improving this situation, but there is still significant room for improvement.

The Department for Work and Pensions currently has training resources that the charity Fibromyalgia Action UK has provided feedback on. In addition, all healthcare professionals facilitating support and work decisions between employers and employees with fibromyalgia should have received adequate training about fibromyalgia.

What causes fibromyalgia?

The exact cause of fibromyalgia is unknown. There is increasing evidence to suggest that it is a disease of the central nervous system, indicated by abnormal levels of certain chemicals in the brain, and functional MRI scans that suggest there are changes in the way the brain, spinal cord and nerves receive, process and deliver messages.

It is thought some people are more likely to develop fibromyalgia because of genes inherited from their parents.

In many cases, the condition appears to be triggered by a physically or emotionally stressful event, such as:

- an injury or infection – which makes it even more essential that Unite members work in safe and healthy workplaces;
- giving birth;
- having an operation;
- the breakdown of a relationship;
- the death of a loved one.

Fibromyalgia can also co-exist with other conditions such as rheumatoid arthritis (RA), systemic lupus erythematosus (SLE) and other autoimmune and autoinflammatory diseases, as well as anxiety and depression.

What are the main symptoms of fibromyalgia and their consequences?

Action Point

If you think you have fibromyalgia, visit your GP and contact the national charity Fibromyalgia Action UK who have literature, helplines and support groups. Treatment and life style changes can often help to improve symptoms. Talk to your GP and your family about all of this, and visit www.fmauk.org for more information.

The main symptoms of fibromyalgia include pain and fatigue. The pain is widespread this means it can involve both sides of the body, above and below the waist as well as the neck and/or back. The pain may also change location for example one day it could be in the legs only, the next day it could be in the back, neck and arms.

Though usually it can become more severe in parts of the body that are used the most, therefore adaptations to the workstation and frequent breaks could reduce the pain of fibromyalgia.

There can also be several other possible symptoms that are outlined below. Not everyone with fibromyalgia will have all of these other symptoms, or consequences of having to live with fibromyalgia.

Depression

In some cases, having fibromyalgia can lead to depression. This is because fibromyalgia is often difficult to deal with. Feeling depressed, stressed or anxious may aggravate pain levels, which may in turn increase the levels of stress and anxiety that individuals experience.

Depression can cause many symptoms, including:

- poor mood, or constantly feeling 'low';
- feeling hopeless and helpless;
- losing interest in the things you usually enjoy.

Extreme sensitivity

Fibromyalgia can cause extreme sensitivity to pain throughout the body. Even the slightest touch can be painful.

The pain associated with the condition might be described in the following medical terms:

- hyperalgesia – when people are extremely sensitive to pain;
- allodynia – when people feel pain from something that shouldn't be painful at all, such as a very light touch.

There may also be increased sensitivity to light, temperature, noise and vibration. In the workplace, this could be things like smoke, the smell of paint, certain foods, bright lights and travelling on public transport in rush hour. Being exposed to these can cause fibromyalgia symptoms to flare up.

Stiffness

Fibromyalgia can increase the feeling of stiffness in muscles. The stiffness may be most severe after having been sitting in the same position for a long period of time or when first waking up in the morning. It can also cause muscles to spasm, which is when they contract (squeeze) tightly and painfully. Gentle stretching and activity can help.

Fatigue

Fibromyalgia can cause fatigue. The fatigue ranges from feeling tired, to the exhaustion of a flu-like illness. This can happen after too much exertion or stress, as well as unexpectedly.

Poor sleep quality

Fibromyalgia can affect sleep. People with fibromyalgia often wake up tired, even when they have had many hours of sleep. This is described as "non-restorative sleep", because the condition can prevent those with fibromyalgia reaching what is called deep sleep.

Cognitive disturbance ('fibro-fog')

Fibro fog is a type of cognitive disturbance including a lack of concentration, temporary memory impairment and getting words mixed up. This may cause:

- trouble remembering and learning new things;
- problems with attention and concentration;
- slowed or confused speech.

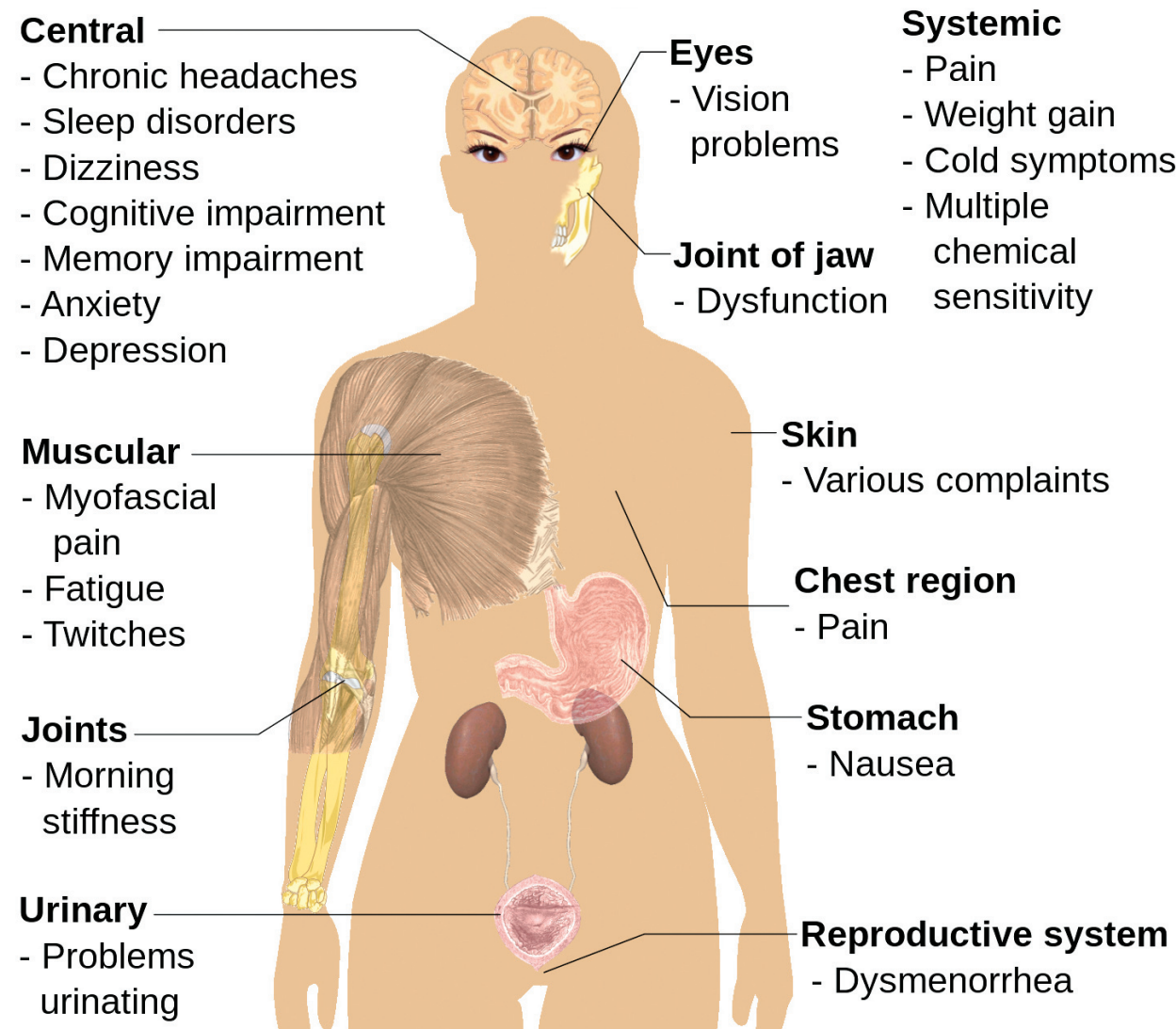


Other symptoms

Other symptoms that people with fibromyalgia sometimes experience include:

- dizziness and clumsiness;
- feeling too hot or too cold – this is because of not being able to regulate the body's temperature properly;
- tingling, numbness, prickling or burning sensations in the hands and feet (pins and needles, also known as paraesthesia);
- in women, unusually painful periods;

Symptoms of Fibromyalgia



Co-morbid conditions

As well as a range of symptoms that someone with fibromyalgia will experience there are other conditions that they may have alongside it. The line between an additional symptom and a co-morbid condition can be a thin one. Some of these additional conditions are listed below.

Headaches

Pain and stiffness in the neck and shoulders can cause tension headaches. Headaches can vary from mild headaches to severe migraines, and could also involve other symptoms, such as nausea (feeling sick).

Irritable bowel syndrome (IBS)

Some people with fibromyalgia can have irritable bowel syndrome (IBS). IBS is a common digestive condition that causes pain and bloating in your stomach. It can also lead to constipation and/or diarrhoea.

Other Conditions

Other conditions that people with fibromyalgia sometimes experience include:

- restless legs syndrome (an overwhelming urge to move your legs);
- anxiety;
- allergies.

Who is affected by Fibromyalgia?

Anyone can develop fibromyalgia, although it tends to be diagnosed in around seven times as many women as men. The condition typically develops between the ages of 30 and 50, but can occur in people of any age, including children and the elderly.

It is not clear exactly how many people are affected by fibromyalgia, although research has suggested it could be a relatively common condition. Some estimates suggest 1 in 25 people may be affected by fibromyalgia to some degree.

One of the main reasons it is not clear how many people are affected is because fibromyalgia can be a difficult condition to diagnose. There is no specific test for the condition, and the symptoms can be similar to a number of other conditions.



Does Fibromyalgia affect an employee’s ability to do their job?

Fibromyalgia affects everyone differently, with some people more severely affected than others. Due to the fluctuating nature of fibromyalgia, the symptoms can vary day-to-day. This can make it difficult to maintain a consistent level of working.

The most common symptoms that can affect whether a person with fibromyalgia can continue their job normally include:

- Wide spread pain;
- Fatigue;
- Cognitive disturbance, also referred to as ‘fibro fog’ or ‘brain fog’, which may cause problems with memory and concentration;
- Other symptoms or co-morbid conditions, including: Irritable Bowel Syndrome (IBS); headaches; and heightened sensitivity to light, temperature, noise and vibration.

Many of these issues can be overcome with the right support in place including reasonable adjustments for the individual needs of the employee. Indeed, many people with fibromyalgia find that if issues in the workplace are successfully managed, they can remain in their jobs.

Unite case study: providing support for a member diagnosed with fibromyalgia

Our member was diagnosed with fibromyalgia approximately 20 years ago. Over many years her symptoms have deteriorated, with neck and shoulder issues as well as other skeletal issues, severe joint pain, problems with ‘fibro fog’ leading to memory issues, and many other symptoms.

For years she has just ‘got on with it’. However, she hit the triggers for the company’s absence management procedure again and decided this time to contact the union and ask for help.

Following the most recent occupational health referral, significant assistance and adjustments have been put in place recognising fibromyalgia and the impacts it has on someone at work. The person who carried out the assessment advised further referrals to Job Centre Plus and then Access to Work.

Assistance provided: a six session course to help with the fibro fog and memory issues.

Adjustments include:

- a headset and voice recognition software to assist with producing documents for when the member is suffering severe joint pain and struggling with typing
- smaller keyboard requiring less hand movement
- modified mouse (penguin)
- specialist chair with head and neck support has been confirmed as appropriate; this was provided following a previous occupational health referral a few years ago
- fully electronic desk that can be raised and lowered, allowing the member to work at a standing desk or sit, depending on how they are feeling on the day. Access To Work insisted on a fully electronic solution due to our members joint pain and skeletal issues - she was unable to raise a manual raised desk add-on unassisted on most days
- evacuation assistance plan put in place for the member

Prior to the occupational health referral the rep sat down with the member and we went through all of the issues and the rep advised on what should be raised in the meeting. Our member made notes as she was going to use this to overcome the ‘fibro fog’ symptoms that she suffered from.

For at least one of the adjustments (new desk) this was part funded by our employer and part funded by Access to Work. As you can see, the adjustments put in place are costly, but will make so much difference to our member.

Given the lack of awareness of Fibromyalgia, and the invisible nature of the illness on many days, we had no idea what would result from the occupational health referral. It hasn’t been a quick process to get all of the adjustments put in place, but our member has really benefitted from them as they are finally being introduced.

For years, she believed that people did not recognise Fibromyalgia as a genuine illness. Now she knows that they do, and that changes can be put in place to help her at work. This is why it is essential that we make more and more people aware of the condition and the impact that it can have on people at work, and what can be done to help them.

Occupational health and safety protection is needed

It will be apparent from the above that the health and safety of a member suffering from fibromyalgia could be impacted adversely by their workplace conditions. These may exacerbate their symptoms and potentially put them and others at risk.

For example

Stress: It is essential that the employer puts into place appropriate measures to control and prevent occupational stress in consultation with Unite members and their representatives.

Fatigue: Fatigue is often identified as a cause of accidents but most fatigue is caused by demands on people by the employer and can be prevented by ensuring that workers are not fatigued or having systems in place to stop them working when fatigued, including members with fibromyalgia. Fatigue needs to be managed, like any other hazard, through risk assessment and risk management, in consultation with Unite members and their representatives.

Sources of further help and information

Unite disability equality negotiator's guide

<http://www.unitetheunion.org/uploaded/documents/DisabilityEqualit%20NegotiatorsGuide11-12244.pdf>

Unite health and safety guide includes a chapter on disability and health and safety See www.unitetheunion.org

TUC – Fatigue – a guide for health and safety representatives

<https://www.tuc.org.uk/workplace-issues/health-and-safety/fatigue-guide-health-and-safety-representatives>

NHS Choices

<http://www.nhs.uk/Conditions/Fibromyalgia/Pages/Introduction.aspx>

Republic of Ireland Health Service Executive

<https://www.hse.ie/eng/health/az/F/Fibromyalgia/Treating-fibromyalgia.html>

Fibromyalgia Action UK

<http://www.fmauk.org/>

Fibromyalgia Action UK's Helpline: Monday to Friday 10am – 4pm 0300 999 3333

Arthritis Research UK

<http://www.arthritisresearchuk.org/arthritis-information/conditions/fibromyalgia.aspx>

Arthritis Ireland: Living with Fibromyalgia

http://www.arthritisireland.ie/assets/73/6873BE2A-9A66-3FBC-14F3E5532AC8F6E3_document/Fibromyalgia.pdf

Arthritis Ireland's Helpline: Monday to Friday 10am -4pm LoCall 1890 252846 HSE Stress – www.hse.gov.uk/stress




Example poster

Unite the Union Raising Awareness of Fibromyalgia

Most of us have had flu and suffered aches and pains all over our bodies, and just wanted to sleep until it all goes away. Imagine feeling like that most of the time

Many health professionals do not have the expertise to diagnose or treat people with Fibromyalgia


1 in every 50 of the population are likely to develop this condition, seven times more women are diagnosed than men, far fewer are likely to be properly diagnosed.



Please raise awareness amongst the workforce and general public
Fibromyalgia Suffers should get the help they need.

Common symptoms are:

- Muscle pain and stiffness
- Fatigue
- Specific 'tender points'
- Disturbed sleep
- Poor concentration
- Irritable Bowl Syndrome



www.unitetheunion.org