



Fibromyalgia

An Advice Guide
for Usdaw Reps

What is Fybromyalgia?

Fibromyalgia is a long-term health condition where people experience chronic, widespread pain all over their body.

The pain can take the form of aching, burning sensations or sharp stabbing pains. Symptoms may also include extreme fatigue, disturbed sleep and cognitive issues such as difficulty focusing and remembering - often called 'fibro-fog'.

- Estimates suggest nearly 1 in 20 people are affected by fibromyalgia.
- Fibromyalgia can occur at any age but usually affects people aged 30 to 50.
- Although anyone can develop fibromyalgia, it is seven times more likely to affect women than men.



What Causes Fibromyalgia?

The exact cause of fibromyalgia is still unknown. It is understood to be related to levels of certain chemicals in the brain and changes in the way the central nervous system processes pain messages. In many cases the condition develops after being triggered by a traumatic or emotional event such as a serious accident, infection, operation, childbirth, bereavement or breakdown of a relationship. When fibromyalgia pain flares up, every activity can seem more difficult and for some the pain can be completely debilitating. People

with fibromyalgia often struggle to make people understand the severity of their pain because there is no obvious physical cause and it can't be seen.

As fibromyalgia has several symptoms, no one treatment will fix them all and a treatment that works for one person may not work for another. Treatment for fibromyalgia is usually a combination of medication to help control pain and aid sleep, along with talking therapy, exercise and relaxation techniques. Though treatment can improve the quality of life for people living with fibromyalgia, there is currently no 'cure' for the condition.



Symptoms of Fibromyalgia

The main symptom of fibromyalgia is widespread chronic pain, however there are several other symptoms. Each person's experience of fibromyalgia will be different and symptoms may change depending on whether a person is having a good or a bad day. Fibromyalgia can be difficult to diagnose as the symptoms are similar to those of many other conditions and there is no one simple test for it. Doctors are likely to test to rule out other conditions before confirming a diagnosis of fibromyalgia.

The most common symptoms of fibromyalgia include:

- Widespread chronic pain.
- Extreme sensitivity to pain or touch.
- Stiffness.
- Muscle spasms.
- Fatigue (extreme tiredness).
- Poor quality sleep.
- Cognitive problems (difficulty with concentration, thinking and memory sometimes referred to as 'fibro-fog').
- Headaches.
- Irritable Bowel Syndrome (IBS).

Other symptoms can include dizziness or clumsiness, an inability to regulate body temperature, restless legs syndrome, tingling or numb sensations in hands and feet, painful periods for women and anxiety. People with fibromyalgia may also be more likely to experience depression. This is because fibromyalgia can be very difficult to cope with and because of the low level of some hormones associated with the condition.

Supporting Disabled Members in the Workplace

Someone with fibromyalgia may be entitled to the protection of the Equality Act (Disability Discrimination Act in Northern Ireland). This can help them get the right support at work because the Equality Act gives members important legal rights.

Members with fibromyalgia may need the support of their union rep. Their condition may affect their attendance or performance and this may lead to them being disciplined under capability procedures or absence management policies. They may also find that aspects of their job make their condition worse.

Unfortunately, managers sometimes do not realise that members with fibromyalgia may have rights under the Equality Act. This leaflet explains what fibromyalgia is and how reps can use the Equality Act to help support members with this condition.

Supporting Members With Fibromyalgia

Members with fibromyalgia may not think of themselves as disabled. However, people with long term health conditions such as fibromyalgia may have rights under the law that can help them stay in work.

The Equality Act has replaced the Disability Discrimination Act (the DDA) in England, Scotland and Wales, but all the rights members had under the DDA still apply and in some cases have been strengthened. The DDA still applies in Northern Ireland.

A member with fibromyalgia would be entitled to the protection of the Equality Act if they meet the definition of a disabled person as set out in the Act. If you can show that the member meets this definition, you will have a much stronger case in arguing that the employer should support the member.

Most members with fibromyalgia will be covered by the Equality Act, though not all. Very few conditions are automatically covered under the Act and fibromyalgia is not one of them. Instead you have to demonstrate that a member meets the definition of a disabled person as set out in the Act. When deciding if a member is covered by the Equality Act (DDA in Northern Ireland) look at the following five points:



1. Does the member have a physical or mental impairment?

Members with fibromyalgia would normally meet this part of the definition. A person with fibromyalgia may not look disabled and managers may therefore not believe they are experiencing difficulties. It is not always obvious to others that someone is disabled, however they can still be covered by the Equality Act.

2. Is it more than a trivial condition?

Some members may find that their fibromyalgia is not too much of a problem, but for many others it can have a significant impact on their lives. You would have to show that the impact on the member's life is more than trivial. Keeping a diary can help to document the effects of fibromyalgia on the member and aid with getting a diagnosis from their doctor.

3. Has the condition lasted or will it last for more than a year?

Fibromyalgia is characterised by a person's long-term experience of pain and most people will live with fibromyalgia for several years. The member does not have to be constantly in pain or experiencing symptoms. People may feel better or worse at certain times, therefore conditions that fluctuate like fibromyalgia can be counted.

Official guidance to the definition of disability published by the Office for Disability Issues makes it clear that impairments with fluctuating or recurrent effects such as fibromyalgia can be covered by the Act. Where a person has a condition that fluctuates or comes and goes then it is to be treated as continuing throughout if it is 'likely to recur'. Likely in this context simply means it could well happen. This is particularly important given that people with fibromyalgia often experience flare-ups during which time their symptoms become much worse.

4. What would happen if the member stopped taking medication?

This is a key issue for someone with fibromyalgia, as medication often helps them to manage their condition. Employers sometimes argue that a person is not disabled because their condition is controlled by medication. However, in deciding whether or not someone is disabled they must be assessed as if they were not taking their medication. In other words, the positive (and negative) effects of medication and treatment are to be disregarded when assessing whether or not someone's fibromyalgia has a substantial impact on their ability to carry out day-to-day activities. This is because medication controls the symptoms of fibromyalgia; it does not make the condition go away.

5. Does the condition affect the member's everyday life?

If you can show that the member's fibromyalgia has a substantial effect on their day-to-day activities they should meet this definition. As fibromyalgia will affect each person differently, it is important to ask the member to outline how the condition affects them at work and in their daily life.

Go through the list of common symptoms in this leaflet and ask the member to mark off which they experience. Then go through a typical day with them and ask how their symptoms affect their day-to-day activities. It does not matter if the effect is not there every day.





Reasonable Adjustments

If you can show that the member meets each of the five criteria listed, then they will be entitled to the protection of the Equality Act (DDA in Northern Ireland). Their employer then falls under a legal duty to make reasonable adjustments in the workplace that take account of the member's fibromyalgia and ensure that they are not disadvantaged by it at work. This means that they should look at the workplace environment, the member's job duties and working arrangements, including hours, and their own company's policies and procedures to see whether or not they can be reasonably adjusted to enable the member to stay in work or get back to work.

It is impossible to list all possibilities for reasonable adjustments in this guide, because there isn't 'a one size fits all' approach, particularly for members with fibromyalgia. Fibromyalgia will affect each person differently so it is best to speak to the member about their experience when discussing adjustments. They will be the expert on how their condition affects them and what support would help them at work.

- **Changing elements of their job:** Where a member is struggling in work as a result of their fibromyalgia it may be reasonable to provide a seated role and more frequent/extended rest breaks to help with pain and fatigue.
- **Transferring to a new role:** Over-exertion can trigger a flare-up in some people with fibromyalgia. If the member's job is very physical they could be transferred to a less physical role.
- **Changed, reduced or flexible hours:** If a member's fibromyalgia is aggravated by irregular sleep patterns it may be reasonable to adjust their hours to ensure they can work the same hours each day/week.
- **Adjusting the sickness absence formula:** To ensure that absences related to the member's fibromyalgia are counted separately and are not used to trigger disciplinary action.

Member's Experience

I don't look like I have fibromyalgia, because it's a hidden disability. So I carry a card that explains what my illness is.

It is a complex condition that affects my whole body. The pain can be constant or will come and go. It makes me exhausted and clouds my thinking, judgement and memory. I have days where just walking can feel like walking on broken glass and I'm always tired even if I've had eight hours sleep.

People like me don't know when we going to have a flare-up or how long it's going to last. When I'm having a bad flare-up I worry about taking time off work. Managers don't always understand

fibromyalgia because they can't see the pain or the chronic tiredness. People need to think twice and speak to me if they want to know more about my condition. I ask people to make allowances when I am struggling. Things may take longer for me but I will get there. I'd like to raise awareness and make sure employers and others have a better understanding of fibromyalgia at work.



Jean Bridger
Usdaw rep

Support and information

For further support and information about fibromyalgia members can contact:

Fibromyalgia Action UK

Web: www.fmauk.org

Helpline: 0300 999 3333

(10am - 4pm, Monday to Friday)

The Social vs the Medical Model of Disability

For some time now disabled people have emphasised that it is not so much their disability that prevents them from fully participating in society, but instead it is the way in which society fails to make adjustments for their disability that excludes them.

This emphasis on changing the barriers put up by society, rather than seeing the disabled person as the 'problem', is known as the 'social model of disability'. In other words, disabled people are people with impairments/health conditions who are disabled by discrimination, exclusion, prejudice and negative attitudes towards disability. Their impairment is not the problem.

The 'medical model' attributes the problems resulting from a disability to medical conditions alone. It concentrates on a person's impairment. Rather than focusing on the barriers society throws up that prevent disabled people from participating equally, the 'medical model' focuses on what disabled people should do to adapt to fit into the world as it is. If they are unable to adapt, the medical model accepts their exclusion.

For example, while a mobility difficulty can have an adverse effect on a person's ability to walk, the fact that the transport system is inaccessible to them has a far greater effect on their ability to get around.

The law is unfortunately rooted in the medical model. It has been rightly criticised for focusing on an individual's impairments and their ability to carry out normal day-to-day activities, rather than on getting rid of the barriers society puts in the way of disabled people.

This leaflet is designed to help understand how the law can support disabled members in the workplace and therefore tends to focus on the medical model.



More Information

Usdaw Nationwide

Wherever you work, an Usdaw rep or official (Area Organiser) is not far away. For further information or assistance, contact your Usdaw rep or local Usdaw office. Alternatively you can phone our Freephone Helpline **0800 030 80 30** to connect you to your regional office or visit our website: www.usdaw.org.uk

You can also write to the Union's Head Office. Just write **FREEPOST USDAW** on the envelope and put it in the post.

Join Usdaw

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What Happens Next

Once we process your application, you will receive a membership card with our Helpline telephone number and a New Member's Pack giving details of all the benefits and professional services available to you.

