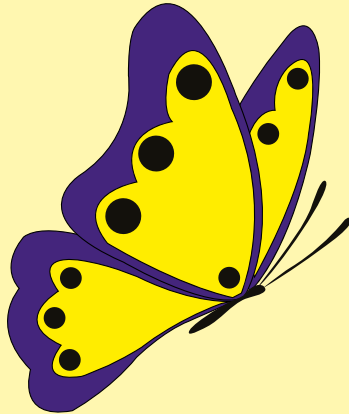


Employer's Guide

Working with fibromyalgia

FIBROMYALGIA ACTION UK

Registered Charity No. 1042582



Fibromyalgia Action UK

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Dear Employer / Line Manager,

Thank you for taking the time to read this booklet which has been designed by people with fibromyalgia and by the national UK charity for this condition, Fibromyalgia Action UK.

People with fibromyalgia tell us that their work is important to them, even though they have this condition and that an understanding, supportive employer can make a world of difference in enabling them to cope. We also know that even when people have health conditions, participating in work can improve health and wellbeing. However, fibromyalgia is a condition which is not much talked about or well recognised in normal life and one of the problems for people with fibromyalgia is finding a way to explain to their colleagues or managers about the condition. That is why we have produced this booklet, together with some suggestions that may help you to support your employee.

What is fibromyalgia (fi-bro-my-al-gia)?

You have possibly never heard of fibromyalgia. It is however more common than you might imagine – possibly as many as 5% of people can be affected. Medical science has struggled to fully understand what is happening in the body when a person develops fibromyalgia but the symptoms are remarkably consistent. Your employee experiences pain “*all over the body*” and profound exhaustion. Typically these symptoms fluctuate from day to day. This makes it very difficult to understand as people with fibromyalgia can be incredibly debilitated one day (hardly able to get out of bed with fatigue and pain) and much better the next day. Different people have different versions of fibromyalgia can find it hard to predict when symptoms will get worse.

Because we do not currently fully understand the “*cause*” of fibromyalgia, there is some confusing and misleading information around and even some doctors are not fully aware of the condition. This too can make it hard for people living with the condition to get the support they need.

Medical scientists believe that fibromyalgia affects the nervous system causing the amplification of signals causing pain and fatigue. This means that there are changes in the way the brain, spinal cord and nerves process these signals. Pain tends to be felt as diffuse aching or burning, often described as head to toe. The pain 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 when it is at its worst. It may come and go and people can suddenly feel drained of all energy – as if someone just “*pulled the plug*”. One of the main challenges is that both pain and fatigue are invisible to others so that the outsider cannot “*judge*” how the person is feeling without asking them. Despite these symptoms, many people with fibromyalgia can live a normal life, given support and understanding.



How might fibromyalgia affect your employee's ability to do their job?

Fibromyalgia affects everyone differently, with some people being more severely affected than others. Put simply, there is no “one rule”. To promote healthy working relationships, it is helpful to discuss with the employee how to best cope with the fluctuating nature of fibromyalgia. To reduce pain, it might help, for example, to allocate work tasks for a week and then allow the individual to choose what to do and when to do it. Flexible working hours may be helpful so that they can “pace” their work. If possible, the option to work at home sometimes can be helpful as commuting to/from work can itself be a challenge. In general, jobs that offer some flexibility and control to the person suit people with fibromyalgia better than jobs requiring high-intensity repetitive tasks. If these are necessary, it would be helpful to think about rotation of tasks with other employees. For example consider reallocating minor duties, which the employee finds difficult for reasons related to their condition to other members of the team e.g. lifting and carrying. Some manual jobs may be more difficult to manage, particularly if they require heavy physical work, standing or lifting. In this situation, it may be necessary to consider other options, such as changing duties or having additional training.

Most healthy people experience tiredness from time to time but it is difficult for us to understand the fatigue of this condition from the perspective of the person. It is important to be understanding and supportive and offer flexibility where possible to enable the employee to cope. As above, flexible working hours or working from home may help and allowing the employee to “pace” themselves through a shift or week will enable better productivity. Fatigue amongst healthy employees is a recognised cause of workplace accidents (although there is no data specific to fibromyalgia). It is up to the employer to manage any risk to the individual or others if the person with fibromyalgia is reporting severe fatigue, like any other hazard, through risk assessment and risk management strategies. For example **one** solution could be a later start time to avoid rush hours, which could help the employee cope better with their life and may mean they feel less tired. Rotation of work tasks, provision of additional seating or a perching stool, regular brief breaks or other simple adjustments can all be helpful.

One of the other common symptoms of fibromyalgia is described as *fibro fog*. It may relate to sleep disturbance but those with fibromyalgia might have fluctuating difficulties with short-term memory and concentration. This may be helped by giving your employee opportunities to write notes or record meetings, making instructions clear and structured so that they are easy to remember and carry out whilst they are affected.

Some other symptoms may include: irritable bowel syndrome (IBS), increased sensitivity to light, temperature, noise and vibration. If the person with fibromyalgia has a sensitivity to temperature you could keep the workplace at a comfortable temperature or install efficient extractors if fumes or strong smells are produced.



Most people living with fibromyalgia are encouraged to learn to pace themselves. Because of its fluctuating nature, people affected can feel that they must achieve as much as possible on a *good day* to make up for having achieved less on a *bad day*. Unfortunately, this *boom and bust* approach tends to make them more likely to have more bad days that last longer. Pacing themselves to aim for an average level of achievement most days balances the condition better and allows them to cope much more effectively. As the employer, you can support this by for example, encouraging employees to take regular short breaks from their workstation and Display Screen Equipment. These breaks should be used for body stretches, blinking the eyes and focusing on distant objects. For more details see page 24 paragraph 61 of the publication *Work with display screen equipment* on this link www.hse.gov.uk/pubns/priced/l26.pdf

Many of these issues can be overcome. With the right support from you (the employer), their medical team and FMA UK many people find issues in the workplace can be successfully managed so employees can remain in their job and be productive.

For more information about fibromyalgia see: www.fmauk.org/whatisfm or request the 'Information pack' from FMA UK at www.fmauk.org/resources or see: www.nhs.uk/conditions/fibromyalgia/

Tips for providing a supportive work environment

There are a range of ways that you can support your employee in the workplace:

- **Listen** - Employers should aim to provide a safe and supportive environment for all workers, with or without a disability. Employees should be enabled to disclose any health condition without fear so that they can receive the appropriate adjustments. The ARMA Musculoskeletal Health Toolkit for Employer's, says "Open communication is encouraged in the workplace if all employees feel assured they will be listened to and action will be taken. Management and other colleagues should not dismiss an employee's disclosure and should be a welcoming listener to whatever they have to say – many problems are overlooked simply because a manager or other colleague has no experience of what an employee is talking about. This kind of negative culture should be actively stamped out and employees assured that they will be listened to".
- **Communication** - If the employer and employee don't agree on what are appropriate and reasonable adjustments the employees should be given a full justification regarding the decision, and have the opportunity to feedback if they are dissatisfied with the decision.



- **Consult** - In workplaces where trade unions are recognised there are likely to be union health and safety representatives and union equality representatives. It is crucial that employers consult and involve them particularly when formulating a policy on fibromyalgia or any other health condition and they are made aware that it is likely that an employee may seek the support of their representative when trying to deal with their issues.
- **Workplace Assessment** - Your workplace may have its own Human Resources or Occupational Health department who can arrange for an Occupational Health practitioner to carry out a workplace assessment. If this is not available some NHS therapy services have Occupational Therapists and Physiotherapists who specialise in work assessment. An alternative is to arrange a private consultation with an independent specialist practitioner such as a local independent Occupational Therapist. Please visit www.rcotss-ip.org.uk look for a therapist specialising in ergonomics/vocational rehabilitation and/or rheumatological or musculoskeletal conditions.

What are my responsibilities?

As an employer you will know that happy workers are productive workers and that you have legal responsibilities to protect the health and safety of your workforce at all times. You will also know that you need to be able provide evidence to the Health & Safety Executive (HSE) that you are taking all reasonable steps to do so and that you can be prosecuted if negligence is demonstrated. This legislation applies to every employee, with or without a disability.

You will also be aware that you have responsibilities under the Equality Act 2010 to be able to demonstrate that you treat people fairly whatever their age, race, gender, sexual orientation, religion or belief, marital status, if they are pregnant or whether or not they have a disability. A brief guide to your responsibilities to people with fibromyalgia under this Act is provided below but you should seek advice from Human Resources or a legal adviser if there is any doubt.

Is fibromyalgia covered by the Equality Act 2010?

Under the Equality Act 2010, a person has a disability if an individual has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities. Fibromyalgia is a condition which varies widely from one individual to another but where people have moderate to severe fibromyalgia which impacts on their ability to carry out normal daily activities, they are likely to be covered by the Equality Act 2010.



The publication *Equality Act 2010 Guidance - Guidance on matters to be taken into account in determining questions relating to the definition of disability*. Page 8 Paragraph A5 says *A disability can arise from a wide range of impairments which can be impairments with fluctuating or recurring effects such as rheumatoid arthritis, myalgic encephalitis (ME), chronic fatigue syndrome (CFS), fibromyalgia, depression and epileps.*

See: www.gov.uk/government/publications/equality-act-guidance

However, an employee must have disclosed their condition to the employer if they wish to be protected under the terms of the Act so you cannot be expected to guess that your employee has a disabling condition. Under the Act however, if they fulfil the criteria, you are required to provide *reasonable adjustments* to enable them to participate in their job without being put at a disadvantage compared to non-disabled people in the workplace. In Northern Ireland, the Disabilities Discrimination Act 1995 applies. In the Republic of Ireland, the Employment Equality Acts 1998 – 2015 apply. Visit www.ihrec.ie for more information.

What are reasonable adjustments?

The terms of the Act do not specify which adjustments are *reasonable* and this definition is slowly being tested in the law courts and clarified through case law. It is clear that the courts take a dim view when no attempt at adjustments has been made. However, they accept that there can be a balance between the needs of the employee and what the business needs can allow. An employer would need to give reasons for not giving adjustments. Following an assessment, the Occupational Health practitioner/Occupational Therapist will be able to recommend reasonable adjustments for the individual's needs. If an assessment has not been arranged, you could possibly ask an employee to describe which actions at work would help with the management of their condition, and how adaptive work adjustments – such as short breaks, task rotation, flexible working hours, items of equipment, or a safe zone for the employee to perform helpful condition management movements or stretches, might make a difference. For example it is probably a reasonable adjustment to be asked to provide a light-weight laptop, adjustable chair, voice-activated software or ergonomic mouse, particularly if recommended by a qualified assessor. If more expensive items are required, many employers (particularly in small and medium-sized enterprises) will qualify for support from the Government's Access To Work scheme. A car parking space near to the workplace can also be enormously helpful. If the job cannot be made suitable for your employee and it is deemed appropriate to offer an alternative job within the organisation, it is advised to offer work at a level equal to their qualifications and ability as poor-quality work can have a worse impact on health than having no job.



Making reasonable adjustments can help to improve attendance by addressing the causes of absence and also to ensure the person with fibromyalgia is not unjustifiably discriminated against. This could be done by allowing time off to attend appointments for assessment, treatment or rehabilitation. Informing employees of any private healthcare provision they may be entitled to access especially those offering therapeutic assessments and support. Putting in place provision for short notice cover for employees known to have fluctuating conditions such as fibromyalgia.

What if fibromyalgia cannot be shown to be a disability for legal purposes?

Many employers will make adjustments for their staff even though they are not under a legal obligation to do so. They **do not** have to have proof or even accept that the person is disabled under the Equality Act 2010 in order to make adjustments. They simply meet requests which make sense to them without getting involved in the detail of whether someone meets the legal definition. For example, a car parking space nearer the office or changing a stiff door handle. They do this to ensure that they can get and keep the best person for the job, to ensure they are seen as a business that wants to engage with the whole community, or simply because it is the right thing to do. Although employees may not be protected by the Equality Act 2010, as an employee they may need changes under the Health and Safety at Work Act for things such as a heavy door or regular breaks from their computer screen. Making these reasonable adjustments and providing access to benefits **all** workers.

The benefits to your business

Supporting your employee to continue working with their fibromyalgia has a number of benefits:

- Retain a skilled and valuable employee, saving both time and money recruiting a replacement
- Loyalty
- Increased productivity from your employee
- Reduced sick leave



Support for you the employer

- The Government's **Access to Work** scheme helps employers to employ and retain disabled staff by offering help and financial support for disabled employees in the workplace. If an employee's impairment affects their ability to perform in a role and a reasonable adjustment requires funding, the Access to Work scheme may help meet the costs. For more information see:

www.gov.uk/government/publications/access-to-work-guide-for-employers

- Fibromyalgia is treated as a musculoskeletal condition (MSK) and ARMA (Arthritis and Musculoskeletal Alliance) has produced a webpage: **Musculoskeletal Health Toolkit for Employers**. Dawn McDonald, UK Power Networks says *"I think this toolkit is a fantastic resource for employers. It's really easy to read and has some excellent resources, links and information. At UK Power Networks, we believe it's really important to recognise the impact MSK issues can have on mental as well as physical health, and the toolkit really helps identify this. I would urge all employers to use the toolkit to identify where they are taking positive actions, and where they could go further."*

For the full Toolkit see:

www.bitc.org.uk/toolkit/musculoskeletal-health-toolkit-for-employers

- For more information on musculoskeletal pain, how this can be managed and what can be done to prevent further problems see www.sheffieldachesandpains.com
- **Commercial Occupational Health Providers Association**, COHPA can assist and advise on suitability of different providers in your area or Independent Occupational Therapists website or The Society of Occupational Medicine.
- **The Workplace Wellbeing Charter** is an opportunity for employers to demonstrate their commitment to the health and well-being of their workforce. The positive impact that employment can have on health and wellbeing is now well documented. There is also strong evidence to show how having a healthy workforce can reduce sickness absence, lower staff turnover and boost productivity - this is good for employers, employees and the wider economy. There is lots of free guidance on the following website as well as support from your local provider: www.wellbeingcharter.org.uk
- **Disability Confident** - The Disability Confident scheme aims to help you successfully employ and retain disabled people and those with health conditions. Being Disability Confident is a unique opportunity to lead the way in your community, and you might just discover someone in your business you couldn't do without.

www.gov.uk/government/collections/disability-confident-campaign

