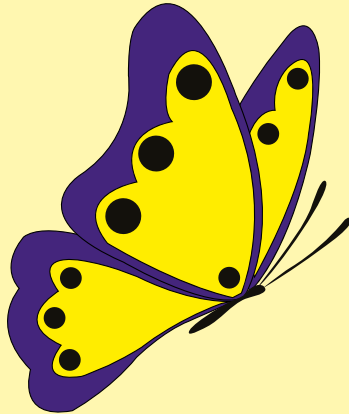


Employee's Guide

Working with fibromyalgia

FIBROMYALGIA ACTION UK

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Introduction

The aim of this guide is to provide those with fibromyalgia with the basic information they need to understand their rights in employment, plus suggestions how to manage their fibromyalgia whilst working. It is also designed to help employers know what they can do to assist their employees who have fibromyalgia.

FMA UK would like to thank all those who have contributed to this booklet: FMA UK trustees, employees with fibromyalgia, the UNITE Union and Health Care Professionals.

Legal Disclaimer

Although great care has been taken in the preparation and compilation of this guide to ensure accuracy, FMA UK cannot accept responsibility for any errors or omissions. All information provided is for educational/informative purposes and is not a substitute for professional advice.

For errata relating to this booklet go to www.fmauk.org/errata

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Why work?

Work isn't only about the money. Of course, it is better financially if you can stay in work, but there are other important benefits of working. Research has shown that people who are able to work are more likely to have better self-esteem which can reduce levels of depression, pain and isolation.

It may be possible to adapt your job and working environment so you can continue working.

Here are some possible adaptations:

- A change in duties.
- Being able to vary the pace of work.
- Support from special equipment, help with transport or improved workplace access.
- Reduction in hours, or become self-employed.
- Taking paid disability leave.

However, many people with fibromyalgia are reluctant to talk to their employer about their health and as a result they don't get the help they need. This can be because they have a fear of being found unfit for work and being dismissed and a sense that colleagues and employers can not improve the situation. This booklet is to help raise awareness of fibromyalgia in the workplace and offer suggestions to enable people with fibromyalgia to remain in or return to work.



“Being in good employment is protective of health. Conversely, unemployment contributes to poor health” Marmot Review 2010, P26

How can fibromyalgia affect my employment?

Fibromyalgia affects everyone differently. Some people are 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 you can continue your job normally are:

- Wide spread pain
- Fatigue
- Fibro fog - Cognitive dysfunction
- Other symptoms which may include: Irritable Bowel Syndrome (IBS) and increased sensitivity to light, temperature, noise and vibration.

Barriers people face in the workplace can be:

- Taking time off when they are having a flare-up of symptoms
- Getting to and from work
- A lack of understanding from employers
- Employers’ reluctance to make adjustments
- A lack of understanding from colleagues

This booklet is to help you find ways of overcoming these problems.

Case history

Lynn said *“I am a domiciliary carer. I look after people in their own homes. I work 4-5 hours a day. Usually 2-3 hours in the morning and 2-3 hours at teatime as I couldn’t work those hours in one go. Work are very understanding if I have a flare (or I’m just too exhausted to work) which luckily happens rarely at the moment because I love my job and want to continue as long as I can”.*



What I can do to help myself?

There are several things you can do for yourself, such as trying to find a way to carry out your job that allows you to manage your pain, fatigue and reduce stress. You could also talk things over with the FMA UK helpline or a local support group.

Here are some suggestions you could try.

Problem solving

It's not what you do, it's the way that you do it that makes a difference.

Look at your daily work routine. Start to notice if you spend all morning doing the same type of repetitive tasks or if your working position causes you pain or discomfort. If a task causes you a problem, ask yourself how you can do it differently. For example, if you have a physically active job, such as a gardener or carer, rotating the type of tasks you do at regular intervals could lessen the strain on your body.

Could the environment you are working in be causing a problem? People with fibromyalgia sometimes have sensitivity to temperature, lighting or chemicals. For example, could you change your work position away from sitting or standing in a cold draft, or where the lighting is too bright, or where there are strong smells such as paints or perfumes?

Prioritising

If you list the tasks you need to do you can prioritise them and decide what tasks you can remove, delay or hand over. This can help prevent the feeling of being overwhelmed. Ask yourself: does this need to be done today? Does it need to be done at all? Does it need to be me who does it? Can I get someone to help me with some parts of the task? Would more help at home take the pressure off me? For example, help with housework or organising home delivery of shopping.

"It's only by saying 'no' that you can concentrate on the things that are really important"

Steve Jobs

Pacing and stress reduction techniques

Try to avoid the *boom and bust* pattern of working.

Relaxation techniques and managing your tasks will help you stay calm and enable you to be more productive at work. It may help to keep a diary for a couple of weeks detailing when you do a task that takes a lot of your energy and others that don't.



This should help you work out when you are doing too many high energy tasks in a day. If possible try to alternate a high energy activity with a low energy activity or a rest. Learn to watch out for signs your body is giving you rather than trying to push through. Take your breaks ideally before pain and fatigue interferes with your work. If possible, take 10 - 30 minutes after lunch to sit or lie down and rest. You don't have to sleep - just slow your mind down and think peaceful thoughts or take a walk outside. Many people with fibromyalgia find breathing techniques help reduce stress, pain and improve concentration. One simple example is to try 5 slow deep breaths. Mind-body sessions such as relaxation and mindfulness have the ability to reduce the feelings of being overwhelmed.

The following are examples of how to add in calm and positive experiences during your working day to reduce pain and fatigue:

- Use a sticker to remind you to do a mini relaxation such as breathing. If pain increases on your drive to work, plan ahead by allowing more time for your journey. Place a sticker on your keys and do a mini mind-body session as you pick up your keys. Place another sticker on your steering wheel and do a session before you start to drive. If you get pain after driving for 20 minutes plan in a break on the journey at 15 minutes to possibly stop for a coffee or look at a beautiful view. Play your favourite music on the journey rather than listening to the radio news that might cause your muscles to tense. Other places you could place a sticker are on your computer or phone. It is ideal if you can plan to do mini relaxation sessions as soon as you have a tinge of pain.
- Find ways you could reduce the effects of fibro fog, such as keep a note book either on paper or electronically on your mobile phones or Amazon Echo etc. to remind you of your priorities. For example you could use *Siri* on an iPhone to set reminders, set up meetings into calendar, set the timer to remind you to take breaks to prevent *Boom and Bust*
- If you need help to improve your coping skills many areas have programmes run by Psychologists or Occupational Therapists such as Pain/Fatigue management programmes or *Living well*. The name may vary in your local area. These programmes teach self-management skills to those with long term conditions, they may teach Mindfulness, Cognitive behavioural therapy (CBT) or Acceptance and Commitment Therapy (ACT) which are techniques that could help you stay in your current job or look for a new type of work.
- Take time out for yourself. Many people with fibromyalgia have the pattern of work/rest, work/rest. This is not good for long term health and time for you to have *fun* should help you stay in employment for longer and have a better quality of life
- Many people with Fibromyalgia have reactive hypoglycemia which means symptoms can increase if your blood sugar level drops. Eating healthy snacks regularly throughout the day and not skipping meals could reduce this happening.
- For further suggestions, see www.paintoolkit.org



Case history

Lesley said *“Get a cleaner. One less thing to do when you have some energy”.*

When should I get help with my job?

It's a common feeling to want to battle on but it's important that you get the right advice and support early on. The decision whether or not to tell your employer can be difficult but you cannot access any reasonable adjustments unless you have disclosed that you have a condition that might be severe enough to be covered by the Equality Act 2010. It is important to remember that you are a valued member of the workforce and an employer will not want to lose an experienced and loyal employee.

Case history

Sarah said *“I have always worked and never told any of my companies that I have it, just have to cope”.*

When to tell your employer?

There is no *one size fits all* answer. You will need to make a judgement call about the best time to tell your employer. Your decision will of course be influenced by the type of work you do and whether, or how much, your symptoms affect your ability to do the job.



Some employment contracts request that you tell your employer if you have been diagnosed with a chronic condition so it is important you check. Other than this a person is not currently required to tell their employer about their condition unless there are specific health and safety risks. For example, if your symptoms or medication cause cognitive problems, there would be an issue if you couldn't concentrate and your safety or someone else's (particularly if you operate heavy machinery) might be at risk as a result.

Telling your employer could avoid the possibility of your employer treating any future problems with your work as a disciplinary issue. For example, they may be questioning why you have needed to take time off and think you are looking for another job or come to the wrong conclusion as to why you are not being as productive as usual.



You also have duties under the Health & Safety at Work Act (1974).

These include:

- To take reasonable care of your own health and safety and of anyone who may be affected by what you are doing at work
- To co-operate with your employer on health and safety
- To inform your employer or manager if you see something that might be a danger to you or someone else

This may mean telling your employer about your illness so that a more individual risk assessment can be carried out and reasonable adjustments can be made if necessary.

You have a right to confidentiality in relation to the diagnosis of fibromyalgia and your employer must not disclose confidential details about you without your explicit consent.

Enforcing your rights can be very stressful and could put you in a difficult position with your employer. The first recommendation is to talk to your line manager and be open about things that may affect you in your work. Issues can often be resolved without going to formal disciplinary action and you having to enforce your rights.

If an employer starts looking at performance management and disciplinary action, they must take your condition into account and look at the whole picture. Working with fibromyalgia is very difficult to begin with and the increased stress and anxiety a situation like this can cause may have a negative impact on you, putting this in the form of an Occupational Health report will ensure it is documented correctly.

If you decide to disclose your diagnosis to your employer it may help to set up a meeting with support from a colleague, Occupational Therapist, or a union representative. Be well prepared with all the information you may require.

Am I covered by the Equality Act 2010?

The Equality Act passed in 2010 provides a legal definition of disability. Some people with fibromyalgia will be covered by this definition. Others with fibromyalgia may regard themselves as disabled, but they may not meet the legal definition of disability under the Equality Act 2010. However, even for such people there are actions that employers can take to provide support.



FMA UK encourages employers to focus on meeting the special circumstances of each individual, without spending too much time and resources on determining if an individual meets the legal definition of disability. We suggest that the way forward for individuals with fibromyalgia and their employers is to work together for mutual benefit.

The following is basic legal information and where to go for more information. However, for detailed legal advice you should always consult a legal adviser.

Under the Equality Act 2010, people with disabilities are protected against discrimination when applying for employment, during employment and when their employment is terminated. The Act says it is unlawful for employers to discriminate against people with disabilities in the following areas: employment application forms; the interview process; the offer of employment; terms and conditions of employment including pay; general employment policies such as training; promotion and transfer opportunities; work-related benefits; discipline; dismissal or redundancy.

The Equality Act 2010 also imposes a duty on employers to make reasonable adjustments. Please note the wording “reasonable.” You may have to reach a compromise with your employer when deciding what is an ideal adjustment and what is practical for your employer. The Act says an employer must also consider making “reasonable adjustments” for people with disabilities or job applicant if:

- The employer becomes aware of the employee’s (or applicant’s) disability, and/or
- The employee (or applicant) asks for adjustments to be made, and/or
- People with disabilities are having difficulty with any part of their job, and/or
- Either an employee’s sickness record, or delay in returning to work, is linked to their disability.

For example, many employers, when deciding which staff to make redundant, will have a redundancy policy. This will usually contain a number of criteria such as time keeping, performance level and sick leave, which are applied against all of those in the potential redundancy pool. Disabled workers may have had more sick leave than other employees as a result of their disability. Employers should follow best practice and ensure disability-related leave is recorded separately from sick leave, and in no case should disability-related leave be used as part of any criteria for redundancy, disciplinary, promotion, or performance appraisals, otherwise the disabled employee may suffer detrimental treatment for a reason related to their disability.

If you are concerned about this, please go to page 22

What can I do if my employer treats me unfairly?



A brief definition of people with disabilities

- Does the individual have an impairment? An individual who is depressed as a result of having fibromyalgia may regard themselves as having a mental impairment, whereas someone who has severe chronic pain as a result of fibromyalgia may say that they have a physical impairment.
- Is the impairment substantial? The meaning of substantial has to be interpreted and considered in each case. It is vital to note that the impact of the impairment must be considered without the impact of any medications currently being taken to manage the impairment.
- Is the impairment long-term? The substantial adverse impact must be long term, which means 12 months or more, or for the rest of the individual's life if this is less than 12 months.
- Does the impairment have a substantial adverse impact on the ability of the person to carry out normal day to day activities?
- 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 epilepsy". See: www.gov.uk/government/publications/equality-act-guidance

It is not necessary that the worker with fibromyalgia is entirely unable to carry out a particular activity. It is sufficient that the activity causes pain or it causes fatigue, either on doing the activity once, or on repeating it over a period of time. It may be that the adverse effect only emerges under stress or the effect is worse at certain times of the day or at certain temperatures.

In summary, proving that fibromyalgia is a disability for legal purposes is not a simple or generic process. It is specific to each person and must be determined by an individual's symptoms. Each person with fibromyalgia must examine their own individual situation to determine if they feel that their fibromyalgia is a physical or mental impairment which has a substantial and long-term adverse impact on their ability to carry out normal day to day activities.



If an individual does not meet this definition then they are not regarded as disabled for the purposes of the Act. This means that whether a person with fibromyalgia is regarded as having a disability depends on the extent and nature of the symptoms they have.

It is important to note that even though an individual may be in receipt of disability benefits this does not automatically mean that they meet the Equality Act 2010 disability definition.



Who can help?

There are organisations and health professionals who can help with *reasonable adjustments*. Some of these professionals can provide workplace advice and/or job analysis and assessments. Assessments can be carried out by visiting you at work or by a structured interview. The therapist can analyse how fast you do things, your movements, the positions you're in, and the order of your tasks. Based on this, they can recommend changes to these to make your work easier.

If you have not yet disclosed your diagnosis to your employer you could ask your GP to refer you to an Occupational Therapist.

Therapists can also discuss issues with colleagues and employers, with your consent, in a sensitive manner. They can advise you on how to negotiate with your employer about adjustments and provide advice to help them appreciate your difficulties. For contact details see **page 14, How do I find a therapist or other specialist practitioners?**

You could consider joining a trade union once you start working, as you may not be covered if you join when you are already having a problem at work. Some unions require you to be a member for 6 weeks before official representation can be made. If you are a member of a trade union you could seek the support of their representative when trying to deal with work issues. In workplaces where trade unions are recognised there are likely to be union health and safety representatives and union equality representatives. Employers should consult and involve these representatives when formulating a policy on fibromyalgia.



What kind of changes can be made at work?

When and if an adjustment is made for you by your employer you should be consulted to obtain your view. The possible adjustments would be considered with reference to your symptoms, job and the work environment. The following are examples of possible adjustments:

- Learn how to conserve energy by managing your activities so that you increase your endurance. Take your breaks and consider if you would cope better with flexible working hours, or possibly working from home.
- Use stretches and changes to your posture to prevent pain and fatigue. Learn how to use your skeleton to support the body rather than putting too much strain on muscles. For example, this can be done by being aware that when your neck is extended backwards it causes strain. See the first image showing working at a desk. A good back rest will support the spine and will bring you to a position that should enable you to work in more comfortable way.
- Stress reduction techniques such as memory aids for example: notepads, voice recorders and whiteboards. Training in communication skills could help you negotiate support from your colleagues and employer.



Case history

Claire said *“Part time is great, allows pacing and recovery!”*

Changes to equipment, including:

- Anti-fatigue matting if you are standing a lot in your job. Day light bulbs may be better for you than artificial lights.
- Adapted computer equipment, such as: ergonomic keyboards, an ergonomic mouse and voice-activated software. Headsets for those who spend a large amount of time on the phone. Or providing memory aids such as; personal organisers where Fibro fog is a problem.
- If the person suffers from eye strain perhaps less severe lighting or reducing the brightness on the computer screens or tinted glasses. An anti-glare screen can be helpful such as: the Ephy anti-glare, anti-blue light screen see www.ephyprivacy.com
- Better ergonomic seating or changing the position of office equipment and furniture to reduce pain and fatigue.
- Equipment to help with driving, for example specialist car seats or cushions. Consider ways to relieve repetitive strain whilst driving or a blue badge.



The pictures of driving show how strain on the neck, shoulders, hips and back can be reduced by using a wedge and back cushion.



Changes in getting to and from work, including:

- A Blue Badge or parking space nearby, change in working location to reduce distance walked or to avoid stairs.
- Discuss flexible hours for example to avoid the difficulty of getting to and from work during the rush hour.



Changes to the physical environment:

- Perhaps the work environment is too noisy. Would it help to move the work station to a quieter area or to use head phones for phone calls and to reduce noise?
- Is there a draft from a window or air conditioner? Or heating if the office is too cold.
- Is the lighting optimal for you? Some people work better with daylight bulbs.

How do I find a therapist or other specialist practitioners?

Your workplace may have its own Human Resources (HR) or Occupational Health departments 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 who may charge a fee.



The following is a list of specialist practitioners:

- **Occupational Therapists (OT)** specialise in enabling people with illness or disabilities to perform work, leisure, daily activities and social roles more easily. They can provide both physical and psychological interventions (such as stress management) and information. They can assess the impact of your fibromyalgia and suggest ways to help you reduce your pain and fatigue and help you achieve a good work/life balance.
- Your local rheumatology or pain clinic department may have an OT in the team or in a separate unit in the hospital. Or ask your GP, nurse, Social Worker or other health or social care professional to refer you to an Occupational Therapist. You can self-refer to a social services Occupational Therapist by contacting your local council* to arrange an appointment. To arrange a private consultation with an independent Occupational Therapist, who will charge you a fee, please visit www.rcotss-ip.org.uk to find a local independent Occupational Therapist. Look for a therapist specialising in ergonomics/vocational rehabilitation and/or rheumatology or musculoskeletal conditions.

* Social Care and Health Department of your local council in Scotland Department of Health, Social Services and Public Safety in Northern Ireland



- **Physiotherapist** - Occupational Health Physiotherapists specialise in work problems. You can find a therapist via The Chartered Society of Physiotherapists www.csp.org.uk or the Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) www.acpohe.org.uk. This website has a directory of private practitioners in their Physio Near You section.
- **Human Resources (HR) or Occupational Health departments** may employ therapists or **Occupation Health nurses** who specialise in work-related health issues. If not you can ask either of these to refer you to an Occupational Therapist.
- **Access to Work scheme (AtW)** (this is called the Disablement Advisory Service in Northern Ireland). This scheme provides practical support to disabled people, people with long-term health conditions and their employers, to help overcome work-related obstacles resulting from a disability or health condition. They may be able to act on an existing report from a therapist, or they may need to arrange for an assessment to determine how much and what type of help you need. To find out what help and grants are available see: www.gov.uk/access-to-work

Case history

Fiona said “Get seen by occupational health, ask for reduced hours, and flexible hours. I start later in day if I’m very tired and finish later, or make up my time on a day I feel okayish. Pace yourself, rest on days off in between kids and housework”.

- Your employer may have a contract with an **Employment Assistance Programme (EAP)**. An EAP provides confidential information, support and counselling to staff with personal or work-related issues.
- The Jobcentres can provide specialist support to people who are recently disabled or whose disability or health condition has deteriorated and who need help in finding a job or gaining new skills. They can also tell you about programmes and grants to help you. Check at www.gov.uk/looking-for-work-if-disabled.
- The National charity **AbilityNet** provides advice on computing and disability. They help people with a wide range of disabling or limiting conditions to continue using computers. They provide an advice and information service and individual assessments to help people find the right solution. For more information **freephone 0800 269 545**, or visit www.abilitynet.org.uk



- **Driving Mobility** is a network of 16 independent organisations covering England, Scotland, Wales and Northern Ireland, which offer professional, high quality information, advice and assessment to people who need to gain or retain independence through mobility. Employers whose employees are drivers within the course of their work may wish to have a formal report about their employee's fitness to drive for liability reasons. If someone with physical limitations requires vehicle adaptations on their work vehicle, to enable them to do the same work as before being diagnosed with fibromyalgia, they might find this comes under reasonable adjustments and the company can get them fitted. This would not exclude other drivers using the vehicle in most cases. For more information and to find your nearest centre, Freephone 0800 559 3636 or visit www.drivingmobility.org.uk
- Another organisation that can help with adaptations to cars is Motability. These include Higher Rate Mobility Component of Disability Living Allowance, Enhanced Rate Mobility Component of Personal Independence Payment, War Pensioners' Mobility Supplement or Armed Forces Independence Payment. Visit www.motability.co.uk for more information.
- **Work/career coach** - If you need more support you may find talking to a coach is helpful, this usually requires paying a fee. There are various organisations (it is best to find an organisation that regulates and supervises their coaches). There is one specifically for people with fibromyalgia see: www.FindAFibroCoach.com

Am I allowed time off for appointments?

It is important to discuss your symptoms with your GP. They may be able to change medication etc. to try and stabilise your symptoms and can also temporarily reduce your working hours to give you time to adjust to changes in medication and/or life style therefore allowing you to stay in work in the long run.



The Equality Act 2010 obliges employers to make reasonable adjustments, one example of which is to allow a person to *be absent during working or training hours for rehabilitation, assessment or treatment*. There is no automatic right to be paid for time attending such appointments, though many organisations do pay it.

If you take sick leave because of your fibromyalgia, your employer might discount some or all of these absences when considering any disciplinary issues, performance measures or selection criteria for promotion or redundancy.



However, you will be subject to the company's normal sick pay policy. An employer does not have to pay more sick pay to a disabled person (although they can choose to do so). For more details about the Equality Act 2010 see: www.gov.uk/guidance/equality-act-2010-guidance

Case history

Lorraine said "I work full time. I need the money and want to provide for my family... But it's hard. I'm not sure how I actually get up some days but I have to. My employer is a large company with a union and they do make adjustments for me. I am always permitted time off for appointments which have been 'three per week sometimes'".

Am I entitled to benefits whilst working?

You may be able to claim the Personal Independence Payment (PIP) disability benefit (which is not means tested) or Universal Credit (which is means tested) whilst working. See: www.citizensadvice.org.uk under the section *Benefits*.



You could use the Turn2us Benefits Calculator, you can also find out about grants on this webpage: www.turn2us.org.uk/find-benefits-grants

Another helpful website is www.entitledto.co.uk which gives information on non means tested benefits.

If you are unable to work because of an illness or disability, you may be able to get Statutory Sick Pay. Some employers have their own sick pay scheme.

For more information please request the *First Enquiry pack* from FMA UK at www.fmauk.org/resources

Should I consider a different type of work, or reduce my hours?

Deciding whether to keep working isn't an easy decision. You need to weigh up a number of factors, including your reasons for working, your present circumstances, your options and your finances. You may find that there are more choices available to you than you first thought.



Try not to make a hasty decision. You may be going through a particularly difficult patch with your fibromyalgia or your job, but you should try and stay positive – things may improve given time and patience.

Before you make a decision, you need to be clear in your mind about two important questions:

Firstly - Do I want to work?

Secondly - Do I need to work?



Most people work not only for money, but also because working gives:

- A sense of achievement
- Social contact
- Structure to the day
- Social status

You need to bear in mind that giving up work may also mean giving up some of these things. However, for many people there's the financial reality of needing to work. Some people with fibromyalgia keep working by changing their working hours, changing jobs or by becoming self-employed to give themselves more control over their working patterns.

Changing your job?

Things to consider if you are thinking about changing your job or are looking for employment:

It's a good idea to check:

- Your financial situation before you make any decision.
- Check your contract or terms of employment.
- Do you have health insurance cover provided by your employer?
- What is your sick leave entitlement?
- How much do you/your family need to live on?
- What benefits would you be eligible for if you reduced your hours?
- What benefits would you be entitled to if you did stop work?
- Can you take early retirement on health grounds?

Try to find someone you can trust, and who can be objective, to talk it over with. You could seek the advice of an Occupational Therapist or your Occupational Health department.



The following points may help you come to a decision?

- **What are the advantages or disadvantages of staying in your current job?** For example, if you are a person who enjoys the company of others what would be the impact on your mood if you were more isolated at home? Perhaps flexi time might be a solution or similar part-time work or voluntary work which would give you the opportunity to get out of the house and meet people.
- **Type of work** - is it the type of work you enjoy? It is much more difficult to get out of bed when you have fatigue and morning stiffness if you are going to a job you dislike or are doing a job where you don't feel you are of value. Do you have difficulty meeting your deadlines, can these be made more flexible? Stress reduction is a vital part of controlling fibromyalgia symptoms, consider what you enjoy when working and concentrating on these positive aspects will help. It is important to discuss your decision with your family as it may involve large changes for them as well which can bring added stress if not managed and discussed properly.

Being self-employed?

Questions to ask if you are thinking about being self employed:

- What is the volume of work? Is it enough to live on rather than make money?
- Does it fit into your pacing? For example, you may be able to do an hour of work but need 2 hours to rest afterwards
- Will you get a return on investment? Would you need to buy special equipment such as a locked filing cabinet if working from home or you may need retraining in computer skills?
- How physically demanding is the job? Are you on the phone all day or sitting typing at the computer?
- How mentally demanding is the job? It mustn't be too easy but challenging enough to not get bored. Is it flexible enough to cope with episodes of fibro fog?
- How much interaction with people is there? Working at home can be isolating, solutions could be to find opportunities to meet people face to face or use applications like Skype when working from home
- Is it a job you would enjoy?



Case history

Tami Stackelhouse, fibromyalgia coach *“Spending all my energy on simply making enough to pay the bills, but not being able to enjoy my life, is not a good return on investment!”*

The final answer may not be perfect, but it may be a positive one made on the basis of all the best information you can gather. It needs to be the right decision for you, taken at the right time, and supported by those around you.

(This could range from your fibromyalgia affecting your ability to leave a building easily in case of fire which would need to be formally recorded in a personal emergency evacuation plan. Or door knobs could be altered which are difficult to turn) see www.hse.gov.uk/pubns/books/l26.htm

For more details on available funding for adjustments see **page 12**

What kind of changes can be made at work?

The Jobcentres can provide specialist support to people who are recently disabled or whose disability or health condition has deteriorated and who need help in finding a job or gaining new skills. They can also tell you about programmes and grants to help you. Check at www.gov.uk/looking-for-work-if-disabled

Please note Access to Work provisions are not automatically transferred between employers and you may need to re-apply through the new employer?



Applying for a job

As a general rule, you should be upfront with a prospective employer about the fact that you have fibromyalgia. However, it is not a requirement and some people choose to wait and see how the recruitment process goes before deciding whether to tell them or not. Many organisations have used health screening processes as part of their recruitment process. However, as part of the Equality Act 2010, employers should, generally, not ask candidates to complete any health questionnaire, or attend a medical, until they have made a formal job offer.

According to government guidelines:

Employers must not ask candidates about ‘protected characteristics’ or whether they:

- are married, single or in a civil partnership
- have children or plan to have children

Employers can only ask about health or disability if:

- there are necessary requirements of the job that cannot be met with reasonable adjustments
- the employer is finding out if someone needs help to take part in a selection test or interview
- the employer is using ‘positive action’ to recruit a disabled person

Employers may also ask specific questions to establish whether or not an applicant will be able to carry out an “intrinsic” function of the work, however, such questions should be clearly relevant to candidates. If, after a job offer has been made, you are asked specifically about your health, you must of course answer truthfully, and discussions at this point in the process should include reasonable adjustments that may be made to the role. A new requirement for employers to make reasonable adjustments is for them to provide an auxiliary aid¹ in circumstances where a disabled person would, but for the provision of the auxiliary aid, be put at a substantial disadvantage in comparison with people who are not disabled. If your fibromyalgia means that you will need adjustments to the job you are applying for, you should discuss this with the employer and in advance consider any reasonable adjustments or auxiliary aids you may require. This is particularly important if there are health and safety considerations. There is an obligation under the Health and Safety Act on you as the employee to do as much as you can to stay safe in the workplace as well.

¹ See the citizens Advice site’s page about ‘Reasonable adjustments’ <http://sh.fmauk.org/employeradjustments>



What can I do if my employer treats me unfairly?

If you feel you are being treated unfairly because of your fibromyalgia you should first discuss this informally with your manager. If necessary you can then register your grievance following the company's grievance procedure. If you belong to a trade union, your representative can support and advise you. If the grievance procedure does not lead to an acceptable solution, as a last resort you may have the option to take a case of discrimination through an employment tribunal. Before taking this action please carefully consider if your fibromyalgia symptoms will be exacerbated by the stress of legal action. It is advisable to make meticulous notes and records for a tribunal. You must take account of the fact that there are strict timelines with regard to the taking of a case.

If you have been dismissed for a reason relating to your impairment or disability, it might be possible to claim for unfair or constructive dismissal. To take such a case requires that you have worked for your employer for a certain period of time (for example this could be 2 years). In an unfair dismissal case, a tribunal will look at whether your employer's decision to dismiss you was reasonable and whether a fair procedure was followed. Your claim must be submitted within three months from the date of dismissal.



The following are useful organisations that offer legal advice:

- Advisory Conciliation and Arbitration Service (ACAS)
www.acas.org.uk/index.aspx?articleid=1339 or telephone 0300 123 1100
- Citizens Advice Bureau (CAB) www.adviceguide.org.uk or telephone local CAB office
- Equality Advisory and Support Service. Their aim is to provide bespoke advice to those facing discrimination issues. Telephone 0808 800 0082 or www.equalityadvisoryservice.com
- The Equality and Human Rights Commission (EHRC) publish excellent resources for finding out about your employment rights. For more information visit www.equalityhumanrights.com see *Advice and Guidance*.

There are limited circumstances where an employer may act in a way which is discriminatory if they can prove this is a *proportionate means of achieving a legitimate aim*. Employers should note that this can be a difficult process.

The scope of what constitutes discrimination is broad. Employers must not show:

- Direct discrimination, where an employer treats an employee less favourably directly because of their disability.
- Discrimination arising from a disability. For example, an employer fails to put in place an adapted keyboard for a secretary with a disability, and then dismisses her because she is unable to carry out her role. In this case the immediate reason for dismissal is the inability to fulfil the role. However, that inability is caused by the disability and therefore the dismissal is discrimination.
- Indirect discrimination, which occurs when an employer applies a policy to all employees or applicants but it would place a disabled person at a particular disadvantage.
- Victimization. The Equality Act 2010 makes it unlawful for an employer to victimize a worker for making an allegation or bringing a claim for disability discrimination.
- Harassment which occurs where, for a reason related to a disability, an employer creates an intimidating, hostile, degrading, humiliating or offensive environment.





Other free booklets:

- Patient booklet
- Information booklet for Young People.
- Information booklet for health care professionals (please supply details for this to be sent directly).
 - A4 poster with common symptoms.
 - A5 flyers with symptoms and brief description.

Fibromyalgia Action UK

Studio 3006, Mile End Mill,
12 Seedhill Road, Paisley PA1 1JS

National Helpline: **0300 999 3333**
Weekdays 10am – 4pm

Benefits Helpline: **0300 999 0055**
Email: **benefits@fmauk.org**
Monday, Wednesday & Friday 10am – 12 noon

Email: **charity@fmauk.org**
Website **www.fmauk.org**
Support Group Information: **www.fmauk.org/groups**

Please provide feedback on this resource
or any other provided by FMA UK at
www.fmauk.org/feedback

Registered charity number 1042582