Information Booklet

For people affected by Fibromyalgia

FIBROMYALGIA ACTION UK

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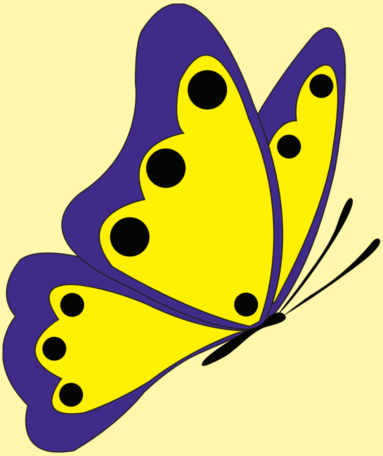

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Health & care information you can trust
The Information Standard Certified Member

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

Fibromyalgia is a chronic condition of widespread pain and profound fatigue, recognised by the National Health Service (NHS) and Department for Work and Pensions (DWP).

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 and can even be more painful. Prevalence of Fibromyalgia: A Survey in Five European Countries **(see www.fmauk.org/prevalence for details)** put the prevalence of Fibromyalgia at between 2.9 and 4.7%. People with mild to moderate cases of fibromyalgia are usually able to live a normal life, given the appropriate treatment. If symptoms are severe, however, people may not be able to hold down a paying job or enjoy much of a social life. The name fibromyalgia is made up from “fibro” for fibrous tissues such as tendons and ligaments; “my” indicating muscles; and “algia” meaning pain.

Symptoms:

Besides pain and fatigue fibromyalgia symptoms often include:-

- Unrefreshing sleep – waking up tired and stiff
- Headaches – ranging from ordinary to migraine
- Irritable bowel – alternating diarrhoea and constipation, sometimes accompanied by gas in the abdomen or nausea
- Cognitive disturbances including lack of concentration, temporary memory impairment and word mix up
- Clumsiness and dizziness
- Sensitivity to changes in the weather and to noise, bright lights, smoke and other environmental factors
- Allergies

Diagnosis

Fibromyalgia is not new, but for most of the last century it was difficult to diagnose. Part of the problem has been that the condition could not be identified in the standard laboratory tests or x-rays. Moreover, many of its signs and symptoms are found in other conditions as well – especially in chronic fatigue syndrome (CFS).

Two Canadian doctors developed a way of diagnosing fibromyalgia in the 1970's and in 1990 an international committee published requirements for diagnosis that are now widely accepted. Once other medical conditions have been ruled out through tests and the patient's history, diagnosis depends on two main symptoms:

1 Pain in all four quadrants of the body for at least three months together with

2 Pain in at least 11 out of 18 tender point sites when they are pressed. The "tender points", or spots of extreme tenderness, are rarely noticed by the patient until they are pressed.

Recently this has been updated with the new ACR 2010 criteria to include more emphasis on the patient's history and the need for the tender points removed.

What causes fibromyalgia?

Fibromyalgia often develops after some sort of trauma that seems to act as a trigger, such as a fall or car accident, a viral infection, childbirth, an operation or an emotional event. Sometimes the condition begins without any obvious trigger. The actual cause of fibromyalgia has not yet been found. Over the past several years, however, research has produced some insights into this puzzling condition. For instance, it has been known that most people with fibromyalgia are deprived of deep restorative sleep.

Current studies may find out how to improve the quality of sleep and some of the prescribed medicine is specifically aimed at addressing the lack of restorative sleep.

Research has identified a deficiency in Serotonin in the central nervous system coupled with a threefold increase in the neurotransmiter substance P, found in spinal fluid and which transmits pain signals.

The effect is disordered sensory processing. The brain registers pain when others might experience a slight ache or stiffness. It is hoped that more research will discover the cause and result in more effective treatment.

Current treatment

At the present time treatment for fibromyalgia aims at reducing pain and improving sleep. In other words, some of the symptoms are being treated, rather than the condition itself. See the current EULAR Recommendations for the Management of Fibromyalgia: **www.fmauk.org/eular2016early** with the original accessible at **http://sh.fmauk.org/eular2016early.**

Pharmacological management

Over-the-counter medications may help relieve the pain of fibromyalgia but severe pain may require the expertise of a pain clinic. It is best to discuss any form of painrelief with your specialist or GP. It is most important to note that medications work for some people and not others.

Pharmacological management of Fibromyalgia in the UK often involves ‘off-label’ medications focused on the relief of discrete symptoms rather than treatment of the condition. A number of drug therapies have shown effectiveness in randomised clinical trials, leading to approval by the Food and Drug Administration in America of *pregabalin*, *duloxetine* and *milnacipran* for the treatment of fibromyalgia. Medications most often prescribed for fibromyalgia are tricyclic drugs also used to treat depression although doses for fibromyalgia are much lower than for depression. In some cases these drugs will help both sleep and pain.

However, many people find available medications either insufficient to control their symptoms or difficult to tolerate due to a high incidence of adverse effects. Thus, all medications should be reviewed at regular intervals to monitor their efficacy. For more information on medications please visit **www.nhs.uk/Conditions/Fibromyalgia/Pages/Treatment.aspx**

Managing fibromyalgia

Learning to manage the condition seems, so far, to be the most successful way of dealing with fibromyalgia. A combination of heat, rest, exercise and reducing stress can enable some people with fibromyalgia to maintain a productive life.

Support from family, friends and other people who have fibromyalgia is extremely valuable to those who have fibromyalgia.

Various talking therapies and Cognitive Behavioural therapy (CBT) have been found to be beneficial in many long term conditions as psychological factors can have an impact on physical symptoms.

Relaxation is one technique that works really well for almost everybody with fibromyalgia. It reduces tension in the mind and body right away. The results are calming for all the symptoms, especially for the pain. Relaxation can be learned from books, tapes, videos or special courses.

Heat is important. A hot water bottle and hot baths or showers will help reduce pain and banish morning stiffness. Soaking hands and feet in hot water for a few minutes can ease their aching. Exercise is the most common prescription for fibromyalgia and Dr Pellegrino's section on this has invaluable advice about the form this should take.

Although no particular diet has been shown to help fibromyalgia, a healthy, balanced diet is important to provide protein, vitamins and minerals. It is best to avoid or at least cut down on coffee, tea and alcohol.

Some sufferers have a tendency to gain weight and this can be distressing in itself. If you follow a healthy diet this should in turn help with your weight control.

People with fibromyalgia can have good days and bad days. On a good day it is important to pace yourself; overdoing it may simply make matters worse. Rest is also important. Listen to your body when it tells you to slow down.

Exercise

by M J Pellegrino MD

Individuals with fibromyalgia are faced with an exercise dilemma. Because the muscles are so tight and painful in fibromyalgia, they are often aggravated by any attempt to exercise. If the muscles aren't used enough, they can more easily flare up with any attempt to do activity. Often, the person with fibromyalgia will experience increased pain or full-blown flare up when attempting to increase activity. Although it is difficult for individuals with fibromyalgia to exercise, it is not an impossible task.

My experience in seeing and treating thousands of fibromyalgia patients over the years is that most are able to develop a successful individualised exercise programme. Some people are able to be more active than others, but I believe that everyone with fibromyalgia has the potential to improve their activity to decrease pain and improve function.

Telling a patient with fibromyalgia to exercise is part of the often used cliché, "easier said than done". I emphasise to patients that any exercise is better than no exercise and that each individual has to find a proper balance of exercise that works best for him or her.

A prescription for exercise in someone with fibromyalgia needs to be flexible. There is no one type of exercise that works best for everyone, and what works for one may not work for someone else. The key goals of an exercise programme are to find what works, develop a successful home programme and maintain a stable balance or baseline.

I have found that there are two components of exercise that, in combination, seem to work best for fibromyalgia patients. They are stretching and a light conditioning programme.

I consider stretching a form of exercise that is readily available wherever we are. Because fibromyalgia muscles are so tight, they are more vulnerable to sprains and strains, so it is especially important that this tightness be counteracted by stretching. Stretching can be done in bed, in the shower, at work, at home and just about anywhere and anytime. It is a vital part of the fibromyalgia person's home programme and if I had to choose one thing to recommend, it would be stretching.

Stretching should be done regularly and consistently. An initial approach is to train the individual in self-passive stretching techniques. These do not require any specific equipment and can be done on different body parts including head, neck, trunk, shoulders, upper body, low back, hips and legs. Dozens of stretching exercises are possible and all of them can be beneficial for given individuals when properly instructed. With stretching, one should achieve increased flexibility, decrease pain and, ultimately, decrease vulnerability to muscle sprains and flare-ups.

One should move slowly and gently when stretching without jerking or bouncing the soft tissues. We teach patients to find a feeling of stretch within their comfort zone, and they practise deep breathing exercises as part of the stretching. Exercises using elastic bands can combine dynamic stretching with strengthening of the muscles.

Stretches can be demonstrated by a knowledgeable health professional but the individual needs to develop a home programme on a regular and consistent basis. When beginning stretching, one should only do a few stretches a day. No more than three seconds hold at a time, but gradually work over several weeks to where one is able to perform up to ten repetitions per stretch, two or three times a day as needed.

A light conditioning programme means enough exercise to stimulate the cardiovascular system and strengthen the muscles without overworking or exhausting them and increasing pain. A light conditioning programme should not be started until an individual is comfortable with a regular daily stretching programme. Light conditioning does not mean intensive aerobic activity. Usually the activity involves periods of stretching, strengthening, relaxation and conditioning of muscles.

This alternating strategy usually works best for fibromyalgia muscles. A proper warm up, good breathing techniques, proper postures, awareness of the body's response to the exercise programme and cool down period are all necessary components of a light conditioning programme.

Examples of light conditioning exercises could include walking, cycling, aquatics, dancing and low impact aerobics. As a rule, one should try to perform light conditioning exercises at least three times a week for 20-30 minutes. Also, I recommend that one take off every other day with a light conditioning programme to allow the body a chance to rest and recuperate, although different individuals can perform a daily exercise programme depending on the body's abilities and needs.

When starting out, it is best to perform about 10 minutes per session for the first week until at least 30 minutes three times a week is reached.

The exercising individual needs to have realistic goals. I tell patients not to put pressure on themselves to exercise longer and harder in order to feel better. The amount of time spent exercising is not as important as the actual effort to exercise.

People with more severe forms of fibromyalgia usually do not tolerate exercises that involve weight lifting (free weights or machines), or exercise equipment that involve using arm pulleys. These exercises provide a continuous resistance on the muscles and over stimulate them, causing increased pain. Certain exercise equipment can be helpful in fibromyalgia and I always advise people to try the equipment first to determine if it is tolerated and it is helpful before actually purchasing it. Many people with fibromyalgia have nearly-new exercise equipment sitting unused in the basement.

Once a successful exercise programme is under way, the individual with fibromyalgia usually feels better. Even patients who find it too painful to do any light conditioning exercise can usually benefit from a stretching programme.

I believe that fibromyalgia flare-ups are rarely caused by the actual exercise programme. Rather the flare-ups are due to some other cause.

During a flare-up, I recommend that the exercise programme be reduced and emphasise the importance of continuing the exercise programme in spite of a flare-up and not stopping the whole programme altogether. If one stops exercising muscles that are flared-up, these muscles will get tighter and will quickly become de-conditioned and thus will become even harder to reactivate when resuming the exercise programme.

Many people with fibromyalgia have had negative experiences with exercising. The goal is to make exercise a positive experience for someone with fibromyalgia.

Mark Pellegrino M.D. is uniquely qualified to help patients with fibromyalgia. Not only is he a physician whose area of special interest is treating this condition, he has it himself. Elected to Phi Beta Kappa as an undergraduate at The Ohio State University, Dr Pellegrino was also an honours graduate from Ohio State's College of Medicine. At the same institution he served as the chief resident in the Physical Medicine Residency programme.

Dr Pellegrino is Board Certified in Physical medicine and Rehabilitationand he is a member of the American Academy of Physical medicine and Rehabilitation and the American Congress of Rehabilitation medicine. He serves as Medical Director for Rehabilitation at a local hospital in Canton, Ohio where he also practices and lives with his wife and children.

An exercise DVD can be obtained from **www.fmauk.org** that was designed with people with fibromyalgia in mind.

Welfare benefits

If you are unable to get help from your Citizen's Advice please contact the FMA UK Benefits Helpline. If you contact your local council, they may be able to make you aware of other benefits advice services available in your area.

Neither fibromyalgia nor any other illness is an open door to any benefit. What matters is how the illness affects you. It may be that you suffer from another problem as well as fibromyalgia; this should not matter as any judgement should be based on the amount of help required. What the illness is, may however, have a bearing on deciding for how long you should be awarded a benefit.

Disability living allowance (DLA)

As from June 2013 no new claims have been accepted or assessed by the DWP Since October 2013 all working age DLA claimants reporting a change in circumstances; renewal claims and young people turning 16, have been reassessed under Personal Independence Payment (PIP) that has been rolled out nationwide.

Between October 2015 and 2018 all the remaining eligible claimants in receipt of a DLA award will be invited to make a claim for PIP. Indefinite/fixed term awards will be selected randomly to apply for PIP. Even if you have an indefinite claim for DLA and you did not turn 65 before 8/4/2013 you will be invited to apply for (PIP).

Personal independence payment (PIP)

There are two components to PIP - Mobility and Daily Living. The mobility component has a Standard rate: 8 points and Enhanced rate: 12 points. The Daily Living component also has a Standard rate: 8 points and Enhanced rate: 12 points.

Mobility component

The Activities and Descriptors for mobility are:

1. Planning and following a journey and
2. Moving around.

For 8 points re moving around the descriptor states that you can stand and then move unaided more than 20 metres but no more than 50 metres.

For 12 points e.g. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided. An important word re PIP is 'repeatedly' and you have to consider whether you can do these descriptors repeatedly.

Daily living component

The Activities are:

1. Preparing food and drink
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Washing and bathing
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating verbally
8. Reading and understanding signs, symbols and words
9. Engaging with other people face to face
10. Making budgeting decisions.

There are a number of descriptors for each of these and it is the highest descriptor score for each activity that counts i.e. you cannot count 2 descriptors in one activity.

For more information please contact the Benefits Helpline.
If having read this you think you wish to apply for PIP please:

1. Keep a diary.

2. Contact the DWP on 0800 917 2222 who will take basic information over the telephone and check eligibility.

If eligible, a questionnaire form is issued and you are invited to explain how the condition affects you in your own words along with any additional evidence.

It is important that you get help when filling in this form and please remember to retain a copy of the form for your records. Go to or contact your Citizens Advice and get help filling in the forms. Alternatively, you can request a Benefits and Work guide from the Benefits Helpline or through the FMA UK website.

The form is then passed to a health professional who decides what happens next. If a face to face consultation is required it will be at a centre – a home visit will be an exception.

The health professional will then complete a detailed report and send it back to the DWP decision maker. You will be notified by letter. If you are not successful you will have to go through the reconsideration process and you will only have 1 month to get the evidence together. Failing that you can go to appeal. You again have only one month in which to appeal.

Get help from your Citizen's Advice, or request the "Mandatory Reconsideration / Appeal" guide from FMA UK. Ask if someone from Citizen's Advice can represent you. If your appeal fails:

a. You can apply again.

b. You will be told that you can appeal to the Commissioners.

N.B. This can only be done on a point of law, not on the basis that you do not agree with the decision.

Employment and support allowance (ESA)

To qualify for ESA you will first need to show that either you have paid enough national insurance contributions, are a young person or that your household income and savings are low enough. You will also need a medical certificate from your GP.

ESA has different levels depending on your capabilities. Some special cases will immediately be allocated to the support group. Others will be assessed with a questionnaire – form ESA 50. The questions on this form are not as straightforward as they seem. This is why we advise everyone to seek help when completing it. A pack guiding you through its completion can be obtained through our benefit contact on the website or telephone (see back page). You will be given several weeks to complete this form, so use this time to test out what you can do. Also remember to note how much you can do before being in pain or becoming exhausted, as this is used in the assessment.

You may find it useful to note variations in your condition in a diary so you know how many good and bad days you have in a typical week or month.

Once your form is completed, make a copy. If your form is mislaid is saves you filling it in again or if you are called for assessment, you can remind yourself what you put and can explain if you are worse or better than when you completed it.

The medical assessment is initially based on this form. Do not feel you should do things that will cause you pain or exhaustion, including travelling for the medical. Let the assessor know any discomfort the assessment is causing even sitting or standing.

A decision is made to allocate you to the support group, the work related activity group (WRAG) or Job Seekers Allowance (JSA).

If you think the decision is wrong, you can ask for an oral hearing and take someone with you, if you are unable to be supplied with an expert. ESA will not be paid while a claim is under consideration by the DWP for which there is no time limit.

It is also very helpful if your doctor supports you, because if you are turned down, their support whilst you go to review or appeal will be important to you.

If you are already in the process with either of these benefits please firstly go to your local CAB or Welfare Rights for help. If you are then still having problems we will talk these through with you, but the association cannot write letters to support your case, because each person is affected differently.

One of the most frequent comments we hear from people with fibromyalgia is, "The government does not recognise fibromyalgia." This is not true. Both the DWP and Department of Health have stated that they recognise it.

It is often individual doctors' lack of awareness of fibromyalgia that cause difficulties. A medical pack for professionals is available and will be posted directly to them on receipt of their details. **www.fmauk.org/benefits**

For those who care

It can be difficult to live with and care for a person suffering from a chronic painful condition like fibromyalgia – but you need not cope alone. Fibromyalgia Action UK not only cares about those diagnosed with fibromyalgia, but also cares about you, the people who live with and look after us.

This section has been written to allay some of your fears and help you gain a better understanding of some of the problems we face.

Fibromyalgia affects people in different degrees. Those with mild to moderate symptoms can lead a relatively normal life, with a few adjustments. If symptoms are severe our lives are changed drastically, but fibromyalgia is not life threatening.

Symptoms

Now that your friend, partner or relation has been diagnosed with fibromyalgia you will be asking “What is it and what does it mean?” The word fibromyalgia means pain in the muscles and fibres, fibro (fibres) my (muscles) algia (pain). The many ways it can affect the various systems of the body are explained in the section “What is fibromyalgia?”

We look so well

In view of the constantly changing levels and sites of pain you may have thought that the person troubled with fibromyalgia was going mad or simply being idle. Don’t feel guilty if you have, for many of us have had the same thoughts about ourselves. How can we look so well and feel so bad?

Fibromyalgia is often referred to as the invisible condition or the irritable everything because there are no visible signs, but inside we are hurting and our self esteem can be very low. We may feel that we are letting everyone down.

Try to talk about these feelings and learn to recognise mood swings and down days. Work together to reduce daily levels of stress: everyone will benefit.

The two main symptoms of fibromyalgia are pain and fatigue, but muscle stiffness is also a very troublesome symptom. This usually occurs after sleeping or lying in one position. Once we get moving the stiffness will normally ease after an hour or two, but in some people it can last all day. Stiffness and pain can also occur if we sit in one position for too long.

This needs to be considered when planning journeys.

We have our bad days

Flare ups of pain are another problem that can make us feel low. We may be doing all the right things and suddenly the pain will increase. Often there will be no obvious reason, but at other times we will be able to identify the cause, usually overdoing some physical activity such as household chores, DIY or gardening.

Short bouts of depression may occur rom time to time, but this should not last more than a day or two: if it does the doctor should be consulted. Sometimes counselling may be recommended. This is not because fibromyalgia “is all in the mind” but because the syndrome, especially the constant pain, affects the whole person including the mental outlook. It is normal to feel afraid, angry, and anxious when dealing with a chronic condition and talking to a trained counsellor allows these feelings to be brought into the open and dealt with.

No one medication will alleviate all the symptoms of fibromyalgia but a combination of medicines may help to relieve pain and promote sleep. At the moment there is no cure for fibromyalgia, and the best that a doctor can do is to give guidance in ways of coping and treating some of the symptoms. The treatments and medications that work vary from one person to another and the person with fibromyalgia is the only one who can tell what is working. It may take a long time and many appointments to discover the right mix for any individual.

Making the most of a good day

We may not be able to do all the things we used to do, but it is important to have fun and mingle with the outside world. List ideas for short outings to places with room to move around; keep up with visits to and from friends and family; visit parks and gardens where a walk can be enjoyed and then a rest on a bench (or more comfortable seat). There are lots of places to go. Just getting out for half an hour can make all the difference.

It is important that you do not become isolated. You may not be as caring and understanding if you feel trapped and resentful; make sure you keep up with your own social life.

Team work

Fibromyalgia is a very individual illness. It affects people in many different ways and learning to cope is better for all the family and friends. Discuss what action to take to make life better for everybody.

Many people with fibromyalgia have very mild symptoms; they can lead a relatively normal life and can carry on in their employment, but they will need an understanding caring partner, family and/or friends. They will still have bad days.

You may have noticed that a person with fibromyalgia becomes easily confused and has short term memory blanks, perhaps forgetting a birthday or anniversary, getting words mixed up or missing them out altogether, sometimes stopping in the middle of a sentence completely forgetting what was being said. These symptoms are often more distressing than the pain and fatigue.

- Writing can sometimes be difficult; the use of a computer can assist.
- Art and crafts can ease tension.
- Crosswords and games can keep the mind working.
- Keep a good supply of books and anything else that will entertain.
- Encourage the learning of new skills. Change can be very rewarding.

What are the tasks that people with fibromyalgia find most difficult? Even carrying a shopping bag can cause us difficulties. Think about the jobs that you can do together with you supplying the muscle. Working together can be fun. If you can see that fibromyalgia is taking over, suggest a rest or a hot bath and have a cosy meal on a tray to continue the relaxation.

It will unwind you as well. You can also help by making small changes around the home or at work. Simple things like storing items on more accessible shelves will avoid excessive reaching and bending; keeping the floor area clear will avoid nearly tripping or falling which can jar the muscles. Look around the home or workplace together and you will probably be able to identify several ways of making life easier and safer. Remember safety at home and work is important for everyone.

As we have already said, rest plays a vital part in coping with fibromyalgia. Always plan day-to day activities to include rest periods; do a little and rest a little. Gradual exercise also plays an important role in the management of fibromyalgia. Why not exercise together. Make it part of your weekly routine. In order to cope we need to find out what suits us best by trial and error. Nobody else can do this for us but we do need your help and understanding.

The future

Family and friends can help a great deal in the management of fibromyalgia by learning as much as possible about the condition. Not only does the person diagnosed with fibromyalgia have frustrations, so do people who are trying to understand the problems we face.

Discussing problems and working together can make such a difference to our lives and the lives of those that give us their love and care.

It can be difficult to keep cheerful when your life style changes and relationships can become strained. We all have stress at some time in our lives and it is often difficult to complain when a member of the family, friend or work colleague is unwell. Have you got another family member or friend you can talk to?

It's good to talk

It can also be difficult to remember that we are not just a collection of symptoms but a whole person with ambitions and dreams just like everybody else. We don't like having fibromyalgia but we have found that by taking positive steps, people are learning to cope and manage the condition. There is an area on our forums that is specifically for carers and family that you might benefit from participating in. Research is now taking place all over the world; the future is brighter and the only way is forward.

The goal is to live life in spite of fibromyalgia rather than having no life because of it. Take each day as it comes and make the most of it together.

Pregnancy and newborns

Pregnancy and coping with a newborn baby can seem a daunting task when you live with the pain and fatigue of fibromyalgia. You may find yourself asking: how will pregnancy affect my symptoms? And, how will I manage to cope with the demands of a newborn baby?

There are currently very few research studies published on this topic, so the following information has mainly been gathered from women who have experienced pregnancy while having fibromyalgia and is designed to offer encouragement, advice and coping skills for this exciting time in your life. All the women we have spoken to agree that although the experience of childbirth may bring additional discomfort it is so worthwhile and positively encourage other women with fibromyalgia to go for it. They emphasise that the key is forward planning, knowing your limitations and being prepared to ask for help.

Conceiving

Before conceiving it is important to discuss the safety of your current medications with your GP. The majority of drugs prescribed for fibromyalgia are not safe during pregnancy and you will need to discontinue them gradually to allow them to clear your system before you try to conceive. Be sure to also check any over the counter medications you are taking, as some herbs can contribute to a miscarriage.

There is no evidence that fibromyalgia affects conception. It is natural to take up to a year to conceive, but if you are having problems consult your GP who will be able to advise you.

Pregnancy - The early stages

The first three months can be difficult, especially as you have come off your pain and sleep medications. Your hormones are changing dramatically and you may experience morning sickness, fatigue, mood swings and increased sensitivity to smell.

Try heat and cold packs, warm baths, gentle massage and stretching to ease pain and stiffness. Paracetamol is generally considered safe during pregnancy, so ask your GP if you need additional pain relief. On the plus side, your happiness and anticipation of your new baby can lead to the release of endorphins, your body's natural painkillers.

The middle months

In general, women with fibromyalgia report feeling better than ever during this time, with reduced pain and increased energy. The powerful hormone effects taking place in your body can mask your fibromyalgia symptoms making these months of pregnancy more comfortable. The hormone relaxin, for example, allows your pelvic girdle to expand by modifying the connective tissue and the fibres in your muscles and ligaments. This means that your ligaments relax offering welcomed pain relief.

This stage of pregnancy is an ideal time to start planning for your baby's arrival. It is a good idea to ask your GP for a referral to an occupational therapist who will be able to advise you on suitable equipment to purchase, methods of lifting your baby and comfortable positions for breastfeeding. This is also the time to decide what help you will need and to ask friends and family members to be prepared to take on certain roles.

Here is a list of practical tips from mothers with fibromyalgia:

- Treat the coming of your baby as a new project and prepare for it accordingly.
- Choose a cot with a height adjustable base to avoid bending over when lifting your baby in and out of the cot.
- Choose a buggy that is lightweight, easy to fold with one hand and has a handle that adjusts to the proper height for you.
- Buy a grab stick for picking things up off the floor without bending.
- Use a bath unit that allows you to bathe your baby at standing height to avoid bending. These units often come with a changing mat facility.
- Buy baby clothes with zips rather than poppers or consider substituting poppers with Velcro.
- Baby proof your house while you have more time and energy.

The final months

Increasing physical discomfort in the late stages of pregnancy is typical for all women.

As your shape continues to change and the frontal weight increases you may experience lower back pain, limited mobility, and find it hard to find a comfortable position to sleep in. The weight pushing upwards can lead to heartburn and you will need to rest more due to increasing fatigue. This is the time to take it easy, employ your relaxation techniques and take one day at a time.

Giving birth

Labour is difficult for all women and each labour experience is different and individual, therefore it is difficult to judge to what extent fibromyalgia contributes to the pain of giving birth.

Women with fibromyalgia have reported experiencing one easy birth and one difficult one and say that additional pregnancies do not seem to aggravate fibromyalgia symptoms further. Listen to your own body and do what you think is right for you. Decide in advance how you wish to give birth and whether you want to have an epidural, use a TENS machine or have other forms of pain relief.

The powerful hormone effects together with the delight of your new baby can mask any pain and exhaustion for the first 24 hours. However, expect to feel exhausted, your body has just undergone a huge ordeal and your hormones are beginning to crash. Your fibromyalgia symptoms may return with a vengeance, which can be quite a shock if you have enjoyed relief during your pregnancy. This period can be tough and you will need help and understanding from your partner and family.

Practical tips for caring for your newborn

- Find a method of breast-feeding that is comfortable for you. Use pillows to position the baby so you do not have to take the weight or consider breast-feeding lying down.
- Consider bottle-feeding if the constant sleep disturbance of night-time feeds is causing you unbearable pain. Bottle-feeding means that Dad can take a turn and you can restart your medications.
- Sleep when your baby sleeps. Get as much rest as possible.
- Deal with any symptoms of postnatal depression promptly.
- Ask for help when you need it.

Further help:

NHS Choices features information on helping when you are a parent with a disability. This can be found here: **www.nhs.uk/Livewell/Disability/Pages/Disabilityhome.aspx**

Fibromyalgia Action UK features the online resource “The Fibromyalgic Pregnancy and Beyond” by Denyse King RM. It covers from conception through delivery to post-natal considerations. Written by an experienced midwife, with careful consideration of how fibromyalgia affects the pregnancy journey. **www.fmauk.org/FibroPregnancy**

The baby challenge:

A Handbook on Pregnancy for Women with Physical Disability, by M J Campion

Children and Young People

Young people have been diagnosed with fibromyalgia and we have a specific booklet designed for them with information for parents/carers and teaching staff. Please request this from the office, details of which are on the back cover.

Where to get more information

Fibromyalgia Action UK offers a range of support and information including:

- National Helpline
- Benefits Helpline
- Complimentary information booklets for doctors and other professionals
- Books and videos
- Website
- Contacts with legal specialists
- Conferences
- Local support group and helpline contacts

The association is run largely by volunteers, most of whom have fibromyalgia.
Our main aims are:

- To make people aware of fibromyalgia and its affects: to the public at large and to the health professionals that are responsible for diagnosing and treating people with the condition.
- To support people with fibromyalgia through contact with support groups and others with the condition.
- To lobby for more effective, available treatment.

How to be a fibromyalgia survivor

Learn to pace and prioritise your activities / divide tasks into smaller projects.
Try to resist the urge to do "just one more thing".

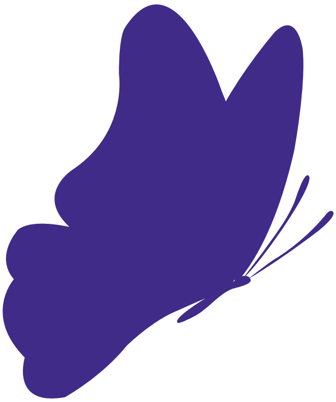
Try to remain positive at all times and eliminate negative thoughts.
Do not give up.

Try to reduce stress, have fun! Participate in activities that you find enjoyable. Try to make sure that you have some exposure to outdoor light every day.

Talk to your family and friends. Learn to ask for help and to delegate tasks.

Expect to have a good quality of life in spite of having fibromyalgia.

Educate Yourself / Learn about the condition / Accept that you have fibromyalgia and it is not life threatening, not deforming, not paralysing / Understand that at this present time there is no cure for fibromyalgia, but you can do a lot to help yourself / Make contact with a Local Support Group.



With the help of medical professionals develop your own home exercise programme. Consider stretching as a form of exercise. Expect some discomfort when beginning exercise, start at a very low level and make sure you build up very, very slowly. Consider varying your exercise programme. Consider undertaking your exercise programme with a friend.

Try to laugh, it is therapeutic. Don't be afraid to use humour to help manage your fibromyalgia.

Do not be afraid to say NO when you cannot do something. Focus on your strengths.

Work with your Medical Professionals to actively discover what works best for you. Learn to self manage your illness.

Try to eat a balanced diet and eat at least 3 regular meals per day. Increase your fluid intake to 6-8 glasses per day.

Learn relaxation techniques. Learn about correct posture and breathing exercises.
Try to find a chair that supports good posture and a bed which is comfortable.

Websites:

www.fmauk.org
www.fmauk.org/legalsupport
www.nhs.uk/Conditions/Fibromyalgia
www.evidence.nhs.uk
www.paintoolkit.org
www.scope.org.uk

You can find a glossary of helpful terms at **www.fmauk.org/glossary**

Summary

- Fibromyalgia can be an invisible condition and you may look well to others. Talking about it with others can make fibromyalgia visible and understandable to them.
- No cure at present but there are treatments for the symptoms
- Maintain a positive outlook and keep active
- Accept support from family and friends
- Support groups provide a supportive environment to find out more information and receive peer support
- Pacing is helpful and it is important to not overdo it
- Be proactive and work with medical professionals to find out what works best for you.

Feedback

- Please provide feedback on this resource or any other provided by FMA UK at **www.fmauk.org/feedback**. (This can also be used to obtain reference information on the contents of this booklet.)

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