



WHERE TO GET MORE INFORMATION

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

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

The association is run 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.

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Registered charity number 1042582



Fibromyalgia Association UK

INFORMATION BOOKLET For people with Fibromyalgia

WHAT IS FIBROMYALGIA?
 EXERCISE
 WELFARE BENEFITS
 FOR THOSE WHO CARE

PREGNANCY AND NEWBORNS
 CHILDREN AND YOUNG PEOPLE
 HOW TO BE A FIBROMYALGIA SURVIVOR
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WHAT IS FIBROMYALGIA?

Fibromyalgia is a chronic condition of widespread pain and profound fatigue.

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 Syndrome (fibromyalgia for short) is a common illness. In fact, it is as common as rheumatoid arthritis and can even be more painful. 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.

A Collection of Symptoms

Fibromyalgia is known as a syndrome because it is a collection of symptoms rather than a specific disease process that is well understood. Besides pain and fatigue fibromyalgia symptoms often include –

- unrefreshing sleep – waking up tired and stiff
- headaches – ranging from ordinary types to migraine
- irritable bowel – frequent diarrhoea or constipation, sometimes accompanied by gas in the abdomen or nausea
- cognitive disturbances including lack of concentration 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 1970s 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. widespread pain for more than three months *together with*
 2. pain in at least 11 out of 18 tender point sites when they are pressed.
- “Widespread pain” means pain above and below the waist and on both sides of the body. The “tender points”, or spots of extreme tenderness, are rarely noticed by the patient until they are pressed.

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.

Research has identified a deficiency in Serotonin in the central nervous system and a resulting imbalance of Substance P a spinal fluid that 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.

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. 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 pain relief with your specialist or GP. It is most important to note that medications work for some people and not others.

Support from family, friends and other people who have fibromyalgia is extremely valuable to those who have fibromyalgia. Professional counselling may help some people to cope with this illness and to take an active part in their own treatment.

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.

HOW TO BE A FIBROMYALGIA SYNDROME SURVIVOR

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**.

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**.

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.

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.

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 eight ounce glasses per day.

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**.

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



often used in fibromyalgia to help maintain muscle tone.

A physiotherapist can help by teaching both muscle stretching and relaxation techniques, and can also correct bad posture so that back pain does not worsen through fatigue related to posture habits. A very gentle massage can also help to relieve morning pain and stiffness.

Managing the Condition

The two most common errors made by parents and care-givers are panic and over-protection. Common sense is your strongest ally. A diagnosis of fibromyalgia does not mean life has to stop. It only needs re-arranging. A child troubled with this condition still has to grow and learn and just be a normal child. Whether symptoms are constant or come and go, occasionally it may be hard for a child to take part in activities that were once easy and fun. But the child must be encouraged to carry on with as normal a life as possible.

You can help by finding pastimes that can be enjoyed when physical activities are limited. Provide plenty of books, games, crafts and puzzles, and keep plenty of paper, paint and crayons handy for younger children. For older children encourage craft projects that can be completed over a period of time with no pressure to finish. If concentration is not too much of a problem an older child can benefit from board games and Scrabble. These games can keep the brain active and strengthen problem solving skills.

Travel should not be ruled out as holidays are good fun for everybody – so do not be afraid to travel, but do not be over ambitious in your choice of destination. As with adults, break any journey up so that stretching breaks are taken regularly.

Education

It may be beneficial to make an appointment with the school to explain the difficulties experienced with the condition. Each school has one person responsible for ensuring children with special needs are catered for and any necessary special arrangements made. Early morning symptoms such as stiffness, pain and fatigue mean that your child may be unable to get ready for school and arrive on time. It is far better to attend late than non-attendance for the whole day. If your child has a flare up suggest working at home. Teach your child to express physical needs clearly to other care-givers and teachers.

If requests are polite, they will not be regarded as impertinent. You can help with the words to use e.g. “May I have a rest? I am feeling really tired.” Or “May I please finish this tomorrow, as I can’t concentrate today?” Rest periods during the day can improve stamina. Even ten minutes of rest occasionally, can keep pain and fatigue at manageable levels. You have to make it clear to both the child and the teacher, that such requests are not just excuses and that you will ensure that any missed work is done later. Encourage your child to develop a positive outlook by emphasising ability and not disability.

In exceptional circumstances home tutoring may have to be arranged. Your child’s education is important – take steps to ensure that they can make the most of any support that is available.

Standing back

Your role is to teach the child to live successfully with this condition and to look after themselves. At the same time, you will have to watch that a younger child does not overdo physical activity and end up in bed for a week.

An older child should be allowed to judge what the physical costs are for their various activities. If staying up late, or going to a disco or football match causes more pain and fatigue, they will have to learn to budget their energy, so that they can make progress at school and still have some fun.

If you are the main carer, ask a friend or partner to take over while you spend time with other children in the family. You must avoid other children resenting the time you spend with their brother or sister.

Support

Many support groups exist around the country but, unfortunately, there is no group specifically for children and young people. There will be people in these groups that may have had fibromyalgia since they were children and can relate the strategies they used to cope.

Managing Fibromyalgia

The best way to cope with fibromyalgia is to use a number of techniques that ease the symptoms as much as possible.

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 Rehabilitation and 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. Dr Pellegrino is the author of several books on fibromyalgia including "Up Close and Personal" This excellent book is packed with information including: overcoming fatigue, exercise and pregnancy.

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.

In recent times it has become far more difficult to get DLA or for it to be accepted that you cannot work. You may know of people who do not seem to be as disabled as you are, who have been awarded one of these benefits whilst you are struggling to get anything. This unfortunately is not uncommon.

The Baby Challenge: A Handbook on Pregnancy for Women with Physical Disability, by MJ Campion

If you would like to discuss any personal issues about fibromyalgia and pregnancy,

FMA UK have a list of mothers with fibromyalgia who would be prepared to talk to you. Contact the FMA UK office for details.

If you are worried and would like to email a professional

midwife with experience of fibromyalgia you could contact Denyse at: wateralfe@hotmail.co.uk

CHILDREN AND YOUNG PEOPLE

The aim of this section is to provide basic information about fibromyalgia in children and suggest some management and coping skills. Parents and other care-givers can assist young people to manage a social life, continue with their education and plan for the future despite this troublesome condition. As with adults, fibromyalgia affects children in different degrees but is not life threatening.

Why Insist on a Diagnosis?

If an illness is not identified, a child may be suspected of laziness, school phobia or of faking an illness to get attention. As a parent you may be accused of keeping your child away from school without good reason. You know better than anyone else if your child is faking an illness. A child that is too tired to play with friends or eat their favourite food is not faking. With a diagnosis a parent or other care-giver can counter any such notions.

You may have a child who has displayed a confusing combination of symptoms for several months, and it may have been difficult to get a diagnosis. If the main symptoms have been pain, muscle stiffness and fatigue and standard laboratory tests have proved negative, then the diagnosis is likely to be fibromyalgia.

Diagnosing Fibromyalgia

It can be particularly difficult to diagnose fibromyalgia in a child. One reason is that symptoms may be overlooked

among the many changes that take place, both mentally and physically, as a child is growing up. Also, a child will often over-compensate when slowed down by an illness. A young child is unlikely to be able to explain how they feel and questions developed especially for the young may be used by the doctor to discover how badly a child is affected.

Teenagers are often easier to diagnose as they are older and more able to describe their symptoms. Fibromyalgia often occurs after a viral illness, but it can be triggered by other factors such as an accident or shock. The doctor will discuss the medical history of the child and will probably carry out a physical examination.

Fibromyalgia is diagnosed the same way as in adults, and has the same collection of associated symptoms as described on page 2.

As you can see, you are dealing with a very complex condition. Fibromyalgia is not the type of illness that will just run its course and fade away in a week or two. Unlike many childhood illnesses, fibromyalgia is a long lasting condition.

At present there is no cure, therefore it must be managed in a way that allows a child to live a full and productive life. With careful consideration of circumstances and team work, this can be achieved.

Treating the Symptoms

Obtaining a diagnosis is probably very welcome as it does provide some of the answers. However, it may also be very disturbing, because you will have learned that the child has to deal with this condition

for many years. So how do you help a child live with this condition?

Treatment will be carefully worked out for the individual child, as certain medication may be effective for one child but may make another feel worse. The dosage of medication for a child will be small and should be monitored carefully.

To ease pain and promote sleep, anti-depressant drugs are sometimes prescribed, but in doses that are much smaller than those used to treat depression. Where other health problems are evident, a combination of medication may be prescribed. Always discuss the success or failure of medication with a doctor.

Rest is also an effective treatment for chronic pain and fatigue and can help the body use its resources to fight illness. However, too much rest can mean that the body becomes de-conditioned, and even more pain and fatigue can result.

One of the most important aspects of rest is a good sleep pattern. This means establishing a bed-time routine with the same events at the same time each night. For a younger child this could mean a bath, snack, brushing their teeth; a story or a chat, and lights out in the same order every night. For older children the routine may be different, but it should still be the same every night.

Daily exercise is recommended at a level that does not aggravate the symptoms unduly, either at the time or the next day. As fitness improves, the exercise can be increased. Physiotherapy is

WELFARE BENEFITS

The two main welfare benefits that people with fibromyalgia may be able to claim are Incapacity Benefit and Disability Living Allowance.

Neither fibromyalgia or any other illness is an open door to any benefit. What matters is



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 breast-feeding. 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 nighttime 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:

www.disabledparents.net - this site provides many innovative ideas and useful resources.
Disability Parents Network (0870 2410450), information@disabledparentsnetwork.com

DLA

There are two components to DLA – mobility and care. Even if you only fill in details for one component the other will be looked at also. Therefore it is advisable to fill in both parts. The mobility component has a low and high rate. You cannot apply for one rate in particular, as it is up to the Adjudication Officer to decide which, if any, you qualify for. If you re-apply for DLA (either components) you could lose what you already have.

Mobility component

The main criterion here is whether you are unable or virtually unable to walk without severe discomfort. The problem for people with fibromyalgia is convincing someone of that severe discomfort and that it can prevent us walking very far. When assessing this for yourself, measure what is an average distance to walk for you and how long it takes to walk that distance (along the flat, not uphill or upstairs). This must be a very short distance and has been stated as being no more than 50 metres and probably less even on one of your better days. However any additional information that you give is very important.

Care component

One of the criteria for this part is whether or not you can cook a meal from raw meat and two raw vegetables for yourself on a regular basis, using a normal oven.

Other criteria concern your personal hands-on care requirements e.g. having a bath, washing your hair, getting out of a chair etc.. Housework needs and shopping are not considered for this benefit.

It is the amount of care you need that determines the rate at which you will qualify for the care component. Thus it is essential that you put down the amount of time that you need help for, even if it is only

sometimes two minutes; the minutes add up! If having read this you think you qualify for DLA, please do the following:

1. Keep a diary.
2. Contact your local Department for Works and Pension (formerly Benefits Agency) and ask for a claim pack.
3. Study the pack carefully, take measurements and make notes on a separate piece of paper.
4. Write down everything you suffer from e.g. Irritable Bowel, Raynaud's Disease. Do not assume that the adjudication officer or even the doctor knows that they can be part of the fibromyalgia syndrome.
5. Go to or contact your local Citizen's Advice Bureau, Welfare Rights office or disability agency such as DIAL and get help filling in the forms. **This is essential.**
6. Keep a copy.
7. If you are not successful you should ask for a review and failing that you can go to appeal. You have only one month in which to appeal.
8. Get help from the CAB or Welfare Rights for a review or appeal. Ask if someone from one of these organisations can represent you – if they can you have a considerably higher chance of winning your appeal (probably 30% higher). **Please note** it is now necessary to ask for an oral hearing if you wish to attend the hearing yourself.
9. If your appeal fails:
 - a) You can apply again after 1 month. Prior to this they will look at your previous form.
 - 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.

Incapacity benefit

The major concern with this benefit is the "All Work" test.

The aim of this questionnaire is to discover whether you are fit to do ANY work at all, not just the job you were doing. To pass it you must score 15 points. The questions deal with how far you can walk, how long you can sit down or stand up, climbing stairs, picking up objects, bowel and bladder control and mental problems. If you receive one of these forms, please do not panic but follow these steps:

1. Go through the form carefully and make notes on all the areas you have problems with. Remember that if you say, for example, that you could walk 200 metres, this means for 5 consecutive days. Then ask yourself if this is actually the truth. If not make a note as to why not.
2. Go to or contact your local CAB or Welfare Rights office and get help in filling in the form. **This is essential.**

It is also very helpful if your doctor supports you, because if you are turned down, particularly for Incapacity Benefit, 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. We have in writing that the government does recognise fibromyalgia and if you need this evidence please contact us. Fibromyalgia is also listed in a book that the Department for Works and

Pensions doctors use for Incapacity Benefit and possibly for DLA. The description is correct but in our opinion

inadequate. 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.

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.

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.

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. 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.



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 Association 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.

A Collection of 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). Fibromyalgia is called a syndrome because it is recognised as a collection of symptoms rather than by one specific symptom or malfunction. 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 syndrome 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 from 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 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

- 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,

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