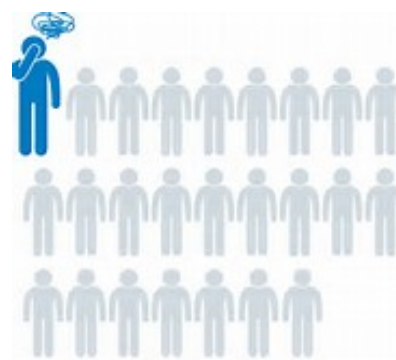


Fibromyalgia Syndrome (FMS)

Fibromyalgia Syndrome (FMS) is a common and complex condition. It affects up to 2-4% of the population – that's up to one in twenty-five people. Despite this, many people have not heard of it and there is still some way to go in building awareness and understanding of what FMS is and how it affects people. If you or someone you know has FMS, it may be really helpful to start to understand more about the condition.

This handout aims to tell you more about:

- What Fibromyalgia Syndrome is
- How Fibromyalgia can affect people
- How Fibromyalgia Syndrome is diagnosed
- Who gets Fibromyalgia
- What Causes Fibromyalgia?
- What is thought to be going on in the condition.
- What is the long-term outlook
- What treatments and therapies are most helpful
- How to get started with managing the condition
- What other help and support is available



What are the Symptoms of Fibromyalgia Syndrome (FMS) ?

People with Fibromyalgia Syndrome can experience a variety of symptoms. These vary from person to person.

- The main symptom is persistent (long term) pain throughout many areas of the body.

This comes along with:

- Fatigue
- Poor unrefreshing sleep
- Cognitive problems

Fibromyalgia is a 'syndrome' - this means a collection of symptoms that occur together without an obvious or identifiable cause. People with Fibromyalgia may often have struggled with lots of different difficulties for some time, sometimes seeing many different health professionals, before someone identifies that these difficulties all fit the pattern of Fibromyalgia Syndrome.



Widespread Pain is the key experience of having Fibromyalgia Syndrome. Pain occurs throughout many areas of the body, but might feel worse in some areas. Headaches and pelvic pain are common. Pains are generally in the muscles and ligaments rather than the joints. Sometimes pains are there all the time, sometimes they come and go or may even seem to move around. The experience of pain can vary and be felt in different ways. Common descriptions of pain include:



Fibromyalgia can make people extremely sensitive to pain. Sensations that would not normally be painful such as light touch and temperature changes can start to hurt. Pains that relate to other conditions or injuries can also feel worse. If you hurt yourself – for example, if you stub your toe – this may be more painful than you would expect and the pain may continue for longer than usual.

Fibromyalgia can also cause stiffness. This may be most severe when you have been in the same position for a long period of time – for example, when you first wake up in the morning.

Some people get spasms in their muscles when they contract (squeeze) tightly and painfully.

As well as pains, people can also experience altered and 'strange' sensations:



Some people find they become very sensitive to noise, temperature changes, smells, bright lights and busy places.

These changes in sensation and pain experiences make sense when we understand that in FMS there are thought to be changes in the nervous system that lead the system to be in a state of 'high alert'. These are very real changes.

Fatigue is a deep sense of tiredness or weariness. This is beyond normal tiredness. It can range from a mild, tired feeling to being really exhausted. Severe fatigue may come on suddenly. Some people say it's like the 'energy plug' has been pulled. Others say it feels like they are a bit fluey.

Sleep is often poor and people find that even when they do get to sleep they wake up feeling like they still need more. People with Fibromyalgia Syndrome do not get the deep sleep that normally helps you feel refreshed in mind, body and spirit. It's not uncommon for people with FMS to have other sleep related difficulties such as restless leg syndrome, teeth grinding, sleep apnoea and other sleep disturbances.

Cognitive Problems are difficulties with mental processes. This includes problems with memory, concentration, finding the words you want and ordering your thoughts. Some people describe this as 'fibro-fog'. It's common to find that too much information may leave you feeling overwhelmed. Some people find that busy situations where there is lots of sensory input, such as supermarkets or crowded places, with lots of noise and lights, can become difficult to tolerate.

Other symptoms can occur and may include some of the following:

- | | |
|-----------------------------------|------------------------|
| ▪ Muscle pain | ▪ Wheezing |
| ▪ Irritable bowel syndrome | ▪ Raynaud's |
| ▪ Thinking or remembering problem | ▪ Hives/welts |
| ▪ Muscle Weakness | ▪ Ringing in ears |
| ▪ Headache | ▪ Vomiting |
| ▪ Pain/cramps in abdomen | ▪ Heartburn |
| ▪ Numbness/tingling | ▪ Oral ulcers |
| ▪ Dizziness | ▪ Loss/change in taste |
| ▪ Insomnia | ▪ Seizures |
| ▪ Depression | ▪ Dry eyes |
| ▪ Constipation | ▪ Shortness of breath |
| ▪ Pain in upper abdomen | ▪ Loss of appetite |
| ▪ Nausea | ▪ Rash |
| ▪ Nervousness | ▪ Sun sensitivity |
| ▪ Chest pain | ▪ Hearing difficulties |
| ▪ Blurred vision | ▪ Easy bruising |
| ▪ Fever | ▪ Hair loss |
| ▪ Diarrhoea | ▪ Frequent urination |
| ▪ Dry mouth | ▪ Painful urination |
| ▪ Itching | ▪ Bladder spasms |

Whilst many symptoms and difficulties can be linked to FMS it doesn't at all mean that everyone will get all of these. Some symptoms will also come and go over time. It can be tricky to work out whether any new symptoms that you have are part of the FMS or relate to another condition. If you do have any concerns about new symptoms do discuss this with your GP.

Other Difficulties that can be related to Fibromyalgia Syndrome

Fibromyalgia can be related to and overlap with other conditions, including:

- Chronic fatigue syndrome CFS/ME
- Interstitial cystitis
- Migraine
- TMJ disorders
- Dizziness due to vestibular complaints.
- Neurally mediated hypotension
- Burning mouth syndrome
- Non-cardiac chest-pain

Diagnosis of Fibromyalgia Syndrome (FMS)

Many people find they have lived with the symptoms of Fibromyalgia Syndrome (FMS) for a number of years before they are eventually diagnosed. The difficulty is that there is no one test for Fibromyalgia. There are no scans or blood tests that show Fibromyalgia. The diagnosis is made by looking at the overall collection of symptoms that you have.

FMS used to be diagnosed according to the number of 'tender points' or spots of extreme tenderness in the body. You may find that this is mentioned in some of the older information that you read about FMS. Since 2010 the way that the condition is diagnosed changed. The diagnosis was updated again in 2016 and is now made according to the distribution, severity and length of time that you have had symptoms.

Because the symptoms of Fibromyalgia Syndrome can overlap with symptoms found in other conditions, your GP will also need to go through a number of investigations with you to check that any treatable causes or conditions that might account for your pain and other symptoms have been identified.

It is now accepted that people can have a diagnosis of Fibromyalgia Syndrome alongside other diagnoses. So, Fibromyalgia Syndrome might not be your only diagnosis or your main concern. If you do have a condition that causes pain then having Fibromyalgia Syndrome can amplify the pain from that condition.

Getting a diagnosis of Fibromyalgia may bring mixed feelings. Some people say it is a relief to eventually have an explanation for what they have been experiencing. Getting a diagnosis can give a sense of a way forward. For others it may take some time to come to terms with having a persistent pain condition.

How Fibromyalgia Syndrome (FMS) Can Affect People

It is important to recognise that everyone will be affected differently by the condition. There is some suggestion by leading researchers that there may be different kinds of Fibromyalgia Syndrome, but this is not yet clear. It may help to explain why some people with FMS have different experiences to others. Some people maintain fairly full and active lives, for others this can be more of a challenge.

Some people with Fibromyalgia Syndrome can find that it becomes more difficult to do the things that matter. In this situation it is understandable that you may have times when you feel low in mood, depressed, frustrated, anxious and worried about things.

What is the long-term outlook for Fibromyalgia Syndrome?

Fibromyalgia Syndrome is generally a long-term condition. While there is not a known 'cure', there is good evidence that many people can improve their quality of life by applying skills and strategies to manage life alongside their symptoms. Self-management techniques and other treatments and therapies really can help to improve life with Fibromyalgia Syndrome. Fibromyalgia is not life-threatening and it is not a condition that *has to* get worse over time.

People often find that symptoms may vary from one day to the next. Symptoms can also alter in severity over time. There may be periods when your symptoms get better or worse. This can depend on factors such as your stress levels and how physically active you are. Many people report that changes in the weather can affect how they are feeling. Times when you experience other illness or pain may also increase your Fibromyalgia symptoms. In women, times of hormone change around your period and at menopause may affect symptoms.

What Causes Fibromyalgia Syndrome?

It is not fully understood what causes Fibromyalgia Syndrome. It is most likely that it is caused by a number of different factors that come together to trigger the onset of the condition. Sometimes causes have been reported in the media which turn out to have little evidence behind them when further studies are carried out. What is known is that:

- Fibromyalgia is far more common in women than men: For every one man affected there are nine women who have it.
- It tends to run in families suggesting that some people may inherit the tendency to get Fibromyalgia. This doesn't mean that there is one gene for the condition – only that there may be some people more at risk of developing it.
- It often follows on from infection, injury, illness, childbirth, traumatic events (physical or emotional) or long periods of stress. Sometimes several of these things may have come together to trigger the onset – however, it's often not possible to say why any one person develops Fibromyalgia Syndrome (FMS). Sometimes Fibromyalgia comes on with no obvious trigger at all.

How can Fibromyalgia Syndrome be explained?

Lots of possible explanations have been put forward to try and explain what is going on in Fibromyalgia. The explanation or theory that has the most research behind it is the theory of 'Central Sensitization'. This does not mean that people with Fibromyalgia are 'just being over sensitive' or 'making a fuss about things'. Instead, it seems to be that there are very real changes in the nervous system of people with Fibromyalgia Syndrome. These are not changes in the structure of the nervous system, so they don't show up on scans. Instead, they are changes in the way that nerve messages are processed. It's a bit like there is a change in the software of the system. In Fibromyalgia Syndrome there are a number of changes in the processing of nerve messages:

- 1) Nerve messages get amplified and made BIGGER so you feel MORE PAIN.
- 2) Nerve messages take longer to die down so that pain sensations carry on for longer than usual.
- 3) Nerve messages get confused and altered – so sensations are changed.
- 4) The nervous system's normal ability to dampen down pain messages gets reduced.



Overall, it's a bit like the whole nervous system gets stuck in a state of HIGH ALERT. It's like having a threat detection system or an alarm that won't turn off.

There are known to be changes in the chemistry of the pain system including changes in chemicals such as Substance P, growth hormone, cortisol, serotonin and norepinephrine.

Is Fibromyalgia Syndrome 'All in the Mind?'

Fibromyalgia is a very real condition with very real changes underlying it. It is certainly not 'all in the mind'. FMS is often poorly understood by many people, including some health professionals. People with fibromyalgia can come across others who do not understand the condition and often feel 'not believed'. This can be a frustrating and upsetting experience. Hopefully as there is more education and understanding about the condition this will gradually improve.

Treatments & Therapies for Fibromyalgia Syndrome (FMS): A self-management approach.

When you have been diagnosed with a long-term condition it can be difficult to know what best to do. The internet is full of people offering 'cures' and treatments – often at a price. The information here is based on the latest and most trusted research and guidance about treatments that are recommended for FMS.

In 2016 the European League Against Rheumatism (EULAR) pulled together all the best scientific studies and experts on Fibromyalgia Syndrome to produce some guidelines comparing different treatment approaches.

These guidelines suggest that the best approaches to help people with Fibromyalgia are not those that involve the use of medication. Recommended approaches are aimed at helping people to find ways of managing and coping with symptoms to improve their quality of life. These are called 'self-management' approaches. Finding gradual ways into using self-management approaches can help you to feel better. This is not necessarily about making pain and other symptoms 'go away'. Self-management approaches are aimed at helping you to live life more fully alongside the symptoms of FMS. Some people find that these approaches do help to reduce pain and other symptoms. Finding ways to manage difficulties can mean that the pain and other symptoms also have less of an impact.

So, Which Treatments & Therapies are most helpful for Fibromyalgia Syndrome (FMS)?

The strongest evidence is for Exercise:

- Exercise comes out as the number one recommended approach for Fibromyalgia Syndrome. Aerobic and strengthening exercise is strongly recommended. It is understandable that some people can feel quite daunted or put off by this idea when it is first mentioned. So, it's important to remember that you should ease into this gradually in small steps, in a way that works for you. Getting started with exercise gently can be helpful. For more guidance on how to do this look at the Reconnect2Life website *'Improving health and fitness'*



Other approaches that help, which have weaker evidence, include:

- Meditative movement therapies (qigong, yoga, tai chi and mindfulness-based stress reduction).
- Defined physical therapies, acupuncture or hydrotherapy
- Cognitive behavioural therapies (CBT) – these are talking therapies helping you to manage your thoughts, actions and emotions in a helpful way. These are aimed at helping you reduce stress, anxiety and depression.
- Multicomponent therapies: These include both physical and psychological therapies together. They cover a range of different approaches such as skills to manage exercise, activity and emotions. These approaches, in combination, should be considered for people with severe disability.



Whilst medications are not the first line of treatment, there is some weak evidence that these medications are useful for some people:

- Amitriptyline (at low dose)
- Duloxetine
- Tramadol (in short courses for periods of worsened pains)
- Pregabalin

The research shows that some therapies and approaches are NOT recommended for Fibromyalgia:

There is weak evidence against the use of:

- Biofeedback,
- Hypnotherapy,
- Massage.



There is strong evidence against:

- Chiropractic,
- Guided imagery (used on its own)
- Homeopathy
- The use of strong opioids – these are not recommended for Fibromyalgia at all.



You may be surprised to see that there is only weak evidence for some treatments and actually evidence against other treatments. Other treatments are not mentioned in this list because there is not enough scientific research to comment on them at present. This is not to say that individuals do not sometimes report benefit from these, only that this is not supported by the available research. These guidelines are here to help you in your choices.

First Steps in Moving Forwards With Fibromyalgia

Now that you understand a bit more about Fibromyalgia Syndrome you might want to start thinking about what sort of self-management approaches might be helpful for you. The Reconnect2life website <https://www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/> has some information to help you get started:

- If your ability to move and exercise is affected you may find it helpful to look at 'Improving Health and Fitness'. Take small and gradual steps into improving your exercise and activity levels, gently building these up over time.
- Look at where and how you are spending your energies and efforts. If you would like to find about more about ways of managing your activities and getting back to activities that matter to you look at 'Reconnecting to your Values'.
- To find out more about managing your emotions go to 'Changing the Way You Think and Feel.'
- Reducing stress and learning to relax can be helpful. To learn about using Relaxation and Meditation to help with this go to 'Creating Skills for the Future'.

Further Support and Resources

- Fibromyalgia Action UK <http://www.fmauk.org/>
- European League Against Rheumatism (EULAR) Revised Guidelines for the Management of Fibromyalgia Syndrome (2016)
- Reconnect2Life – <https://www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/> a website with lots of information and guidance about managing persistent pain problems.
- A good self-help booklet to download about managing FMS is available through Arthritis Research UK <https://www.arthritisresearchuk.org/shop/products/publications/patient-information/conditions/fibromyalgia.aspx>