

LOCAL SUPPORT

Functional Fitness

<https://www.functionalfitnessrx.co.uk/>

(We've had Leon come in to talk to us in the past.)

NATIONAL SUPPORT

NHS

www.nhs.uk/conditions/fibromyalgia/

Fibromyalgia Action UK

www.fmuk.org

UK Fibromyalgia

www.ukfibromyalgia.com

Fibromyalgia Awareness UK

www.fibroawarenessuk.org

For more local and national support check out our website.

FIBRO INFORMATION BOOKLET


For people with Fibromyalgia



The following booklet information can also be found on our website.



Scan me for our website

Find us online & on Facebook 

www.dawnofthenightingales.com

www.facebook.com/groups/dawnofthenightingales

dawnofthenightingales@hotmail.com

WHAT IS FIBRO

Fibromyalgia, sometimes known just as Fibro or FMS. Is a long-term, chronic condition that impacts the central nervous system. Researchers believe that fibromyalgia amplifies painful sensations by affecting the way your brain and spinal cord process painful and nonpainful signals.

As an invisible illness, many with this condition can appear totally fine and it affects approximately three million people across the UK. Fibro is an incredibly debilitating and life-altering condition. But with the right support people can sometimes lead a relatively normal life with long periods of remission.

Fibro is a common condition and is, in fact, more common than rheumatoid arthritis and unfortunately even more painful. The name is made up from 'fibro' for fibrous tissues such as tendons and ligaments, 'my' indicating muscles, and 'algia' meaning pain.

May 12 is Fibromyalgia International Awareness Day. This day coincides with the birthday of Florence Nightingale, British nurse, statistician, and founder of modern nursing. She became chronically ill from a bacterial infection and was often bedridden later in life.

Dawn Of The Nightingales takes its name of 'Nightingales' from Florence. The lantern in our logo is a folded Turkish lantern, or fanoos which is what Nightingale relied on to illuminate her patients.

ADDITIONAL HELP

OTHER MOBILITY AIDS

If you get PIP, Motability scheme (www.motability.co.uk) can exchange your qualifying mobility allowance for a brand-new car, wheelchair-accessible vehicle, scooter or powered wheelchair.

Better Mobility has a list of charities that can help you with funding your mobility equipment. There are many charities that specialise in providing funding for children, and while it can be more difficult to find funding for adults, it is available. (www.bettermobility.co.uk/charity_funding_options.php)

CARER/HOME HELP

It can be difficult to take care of yourself and your home with a chronic condition, so you might need help from a carer at some point. Getting loved ones to help out is ideal if they are willing to come over to give your home a quick Hoover or change your bedsheets but sometimes we don't have someone who can help us.

If you want to get help from a paid carer your local council can arrange homecare for you if you're eligible for it or you can arrange your own.

Home help is slightly different and means day-to-day domestic tasks you might need help with. Great if you are able to care for yourself but struggle with your home. You can contact a charity such as the Royal Voluntary Service, the British Red Cross, or a local Age UK to see whether they can help (it may not be free).

<https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/homecare/>

(above link is all one line or search 'help at home from a paid carer NHS' and it should be the first NHS link in the search results)

www.royalvoluntaryservice.org.uk/our-services/supporting-people/

www.redcross.org.uk/get-help/get-support-at-home

www.ageuk.org.uk/services/in-your-area/home-help/

www.gov.uk/apply-needs-assessment-social-services

ADDITIONAL HELP

Apart from Nightingales, there are many resources out there that can help you. From benefits, travel, websites and other resources. We have many of these listed on our website or/and forum. Below and on the next page are just some of the resources that could help you.

BENEFITS

Whether you can work or not, you could be entitled to one or more benefits. The most common one is PIP (Personal Independence Payment), which took over from (DLA) Disability Living Allowance.

Another is ESA (Employment and Support Allowance) or even a benefit/s to help if you're on a low income. This can help with heating, housing and other living costs.

For more information, visit : www.gov.uk/browse/benefits

TRAVEL

If you are unable to drive, getting around can be difficult. Especially if you struggle to get to bus stops or can not afford a taxi. Door-2-Door is a great alternative. Phone up to book, it's cheaper than a taxi and comes straight to your door. It's fully accessible and allows you to get out and about without having to rely on friends and family.

Barnsley - 01226 732096 | Doncaster - 01302 342400
Rotherham - 01709 517100 | Sheffield - 0114 285 9906

NHS MOBILITY AIDS

The NHS will let you borrow aids (walking sticks, walking frames, wheelchairs) and you can ask your GP for help in getting an NHS wheelchair. They will refer you to your local wheelchair service for an assessment and they will decide if you need a wheelchair and, if so, what type. You might be able to get a voucher, helping you pay towards the cost of a different type of wheelchair.

CAUSES OF FIBRO

The actual cause of fibro has not yet been found and is still being studied, but it's thought to be related to abnormal levels of certain chemicals in the brain and changes in the way the central nervous system (the brain, spinal cord and nerves) processes pain messages carried around the body. What has been discovered is that people with the disorder have an increased sensitivity to pain, so they feel pain when others do not.

Genetics. Fibro tends to run in families but little is known for sure about the specific genes involved.

Infections. Some illnesses appear to trigger or aggravate fibromyalgia.

Trauma. This can act as a trigger, a car accident, childbirth, an operation or emotional event.

DIAGNOSIS

Fibro is a difficult condition to diagnose due to there being no specific test for the condition. Usually your GP rules out other conditions that could be causing the symptoms first. This can be time consuming.

A doctor will likely take down your medical history, asking about the location, severity and duration of your pain plus any other symptoms you have experienced. They may also ask about other conditions as it can be common for people to have others with fibromyalgia.

A physical exam will also be done to examine your joints. Tests that could be done include urine and blood tests. You may also have X-rays and other scans. If you are found to have another condition this does not rule out fibro as you could still have this as well.

SYMPTOMS

Fibromyalgia has many different symptoms that can vary from person to person. During your time with this condition your symptoms could improve or get worse depending on factors such as your stress levels, changes in weather and how physically active you are. The pain symptoms are that of pain, fatigue, sleep and cognitive problems.

Widespread Pain - This may be felt throughout your body but could be worse in particular areas. It is likely to be continuous, improving or getting more severe at different times. The pain could feel like a burning sensation, an ache, a sharp, stabbing pain or even a mixture of these.

Fatigue - You might find yourself often waking up tired even though you have slept for long periods. The fatigue can range from feeling it mildly to a deep exhaustion often felt during a flu-like illness.

Sleep Problems - Your night's sleep can often be disrupted by pain and many people with the condition also have other sleep disorders.

Cognitive Problems - These are issues related to mental processes such as thinking. You may have trouble with your memory, learning new things, paying attention and concentrating. Have brain fog (or fibro-fog) making you confused or different to speak.

Other Symptoms - Sensitivity, stiffness, headaches, irritable bowel syndrome (IBS), dizziness, abnormal temperature sensations, anxiety, numbness, digestive issues and more.

TREATMENT

There is no cure for this condition but there are treatments which aims to ease your symptoms, making it easier to live with and improve your quality of life. The main three treatments recommended for fibro are, exercise, talking therapies and medicines.

Traditional treatments like pain medication aren't always helpful. A doctor can help you explore your options and help you decide the best treatment for you. Depending on what you prefer and what is available in your area.

Due to this condition affecting people different, remember that something that works for one person may not work for you.

Exercise, movement and activity - It is important to be physically active with fibro, it can be difficult if you're in pain but it can be a useful way to manage and reduce pain. Try to find something you enjoy and can continue doing long-term. Also keep in mind your lifestyle, health needs and physical ability when choosing.

Talking Therapies - There are two talking therapies that could help reduce pain cause by fibro. One, acceptance and commitment therapy (ACT). Where you learn to accept what is out of your control and commit to making changes that will improve your life. Two, cognitive behavioural therapy (CBT). A talking therapy that can help you manage your problems by changing the way you think and behave.

ACT has been shown to improve sleep, reduce pain and help deal with negative thoughts and feelings. Whilst CBT can also help improve the quality of life for people living with long-term pain.

Medicine - Antidepressants are sometimes used to help relieve the pain of this condition. They can also help improve your sleep, emotional health and overall quality of life. There are many different types and you may find one works better for you than others or even have to change to another over time if one stops being effective.