

Fibromyalgia Information Booklet



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This handout aims to tell you more about:

- What is Fibromyalgia?
- Common symptoms of Fibromyalgia
- Diagnosis of Fibromyalgia
- What causes Fibromyalgia
- Treatments/Therapies that are most useful
- Understanding Fibromyalgia pain
- How to support a loved one with Fibromyalgia
- Diet and Fibromyalgia
- Grief Cycle
- Tips on coping with Fibromyalgia
- Sex & relationships with Fibromyalgia
- Pregnancy and Fibromyalgia
- Further support and resources



*What is
Fibromyalgia?*

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.



Common Symptoms of Fibromyalgia

The main symptom of fibromyalgia is widespread pain throughout the body. Other symptoms of the condition include but not limited to are:

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

- Muscle pain
- Irritable bowel syndrome
- Thinking or remembering problem
- Muscle Weakness
- Headache
- Pain/cramps in abdomen
- Numbness/tingling
- Dizziness
- Insomnia
- Depression
- Constipation
- Pain in upper abdomen
- Nausea
- Nervousness
- Chest pain
- Blurred vision
- Fever
- Diarrhoea
- Dry mouth
- Itching
- Wheezing
- Raynaud's
- Hives/welts
- Ringing in ears



- Vomiting
- Heartburn
- Oral ulcers
- Loss/change in taste
- Seizures
- Dry eyes
- Shortness of breath
- Loss of appetite
- Rash
- Sun sensitivity
- Hearing difficulties
- Easy bruising
- Hair loss
- Frequent urination
- Painful urination
- 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

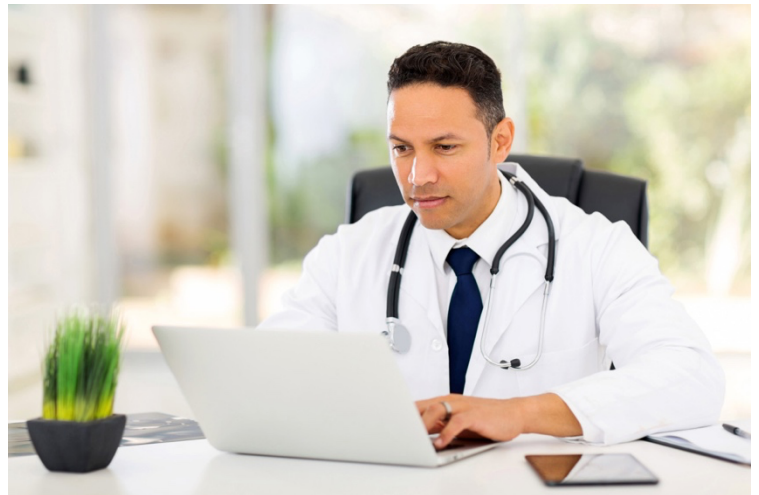
Fibromyalgia can be related to and overlap with other conditions, including:

- 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

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 test 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.

For fibromyalgia to be diagnosed, certain criteria usually have to be met.

The most widely used criteria for diagnosis are:

- you either have severe pain in 3 to 6 different areas of your body, or you have milder pain in 7 or more different areas
- your symptoms have stayed at a similar level for at least 3 months
- no other reason for your symptoms has been found



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.



What Causes Fibromyalgia?

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.



*Treatment/Therapies that are most helpful for those
with Fibromyalgia*

**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.



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.



Understanding Fibromyalgia Pain

Imagine you're planning a party and expecting about 20 guests. Three or four friends told you they'd come early to help you out. But they don't show, and instead of 20 guests, you get 100. You're overwhelmed.



That's what's happening with our pain signals. The cells send too many pain messages (party guests), up to five times as many as in a healthy person. That can turn simple things like mild pressure or even an itch into pain.

When those pain signals reach the brain, they're processed by something called serotonin. However, we don't have enough serotonin (the friends who didn't show up to help), leaving the brain overwhelmed.

This is why we have pain in tissues that show no sign of damage. It's not imagined pain; it's misinterpreted sensation that the nerves and brain turn into actual pain. Because when your brain says something hurts, it hurts.



Other substances in the patient's brain amplify a host of other signals—essentially, "turning up the volume" of everything your senses detect. That can include light, noise, and odour on top of pain, and it leads to sensory overload. This can cause confusion, fear, anxiety, and panic attacks.

It can be tough coming to terms with a chronic illness diagnosis and when you do get that diagnosis, it's important to get the right professional support. But perhaps even more importantly, the support from friend and family is vital to manage day-to-day.



Does diet help in Fibromyalgia

Many people with fibromyalgia feel they have sensitivities to particular foods, particularly if they also have irritable bowel syndrome (IBS). If you think that foods may aggravate your symptoms, try keeping a daily food journal. You could also try an elimination challenge diet, in which you stop eating a certain food for a few weeks, then add it back to your diet to see how you feel.

Make sure you don't miss out on essential nutrients when you do this. Try to eat a well-balanced diet high in fruits, vegetables, whole grains, and lean protein.

If you're struggling with pain and exhaustion, it's hard to cook nutritious meals. Try eating small meals frequently throughout the day - and always eat breakfast, which should include some protein and slow-release carbohydrate, which will give you the right kind of energy to get you going through the morning, even if your body is aching and you're feeling tired.



How to support a loved one with Fibromyalgia

Here are some of the ways you can support someone who suffers from fibromyalgia too;

1. Learn about fibromyalgia

Most people don't know anything about the condition so get googling. Some good sources include NHS and or own website. This can help you and the person that you are supporting gain an understanding of what happens and equip you both to manage the pain and be survivors.

2. Help them find a regime that helps

A number of treatments need to come together to manage Fibromyalgia. Medication helps but other things include massage, paced exercise and keeping warm. It can take time to find the regime that works so it can help to discuss the options and adjust over time.

3. Remind them that it's OK to stop

Remember to remind your loved one that stopping is not failing.

4. Support them to them keep going

It can be very hard to get the balance right. When the pain and fatigue hit, it can take every ounce of determination to keep



going. A vital part of management is regular exercise so remember to support your loved one to keep it up regularly.

5. Do the little things

It's surprising how touching it is when someone else simply runs a bath or heats up a wheat bag.

6. Take time for yourself

Supporting someone with any chronic illness can take its toll on you. It's OK to take a break for yourself and when you come back, you can support them with renewed energy.

7. Stay positive

Yes, Fibromyalgia is a chronic, debilitating condition but it's not the end of the world and everyone involved needs to stay focused on the fact that it can be managed



7 Stages of Grief

Denial: This stage is more like *'shock'* and *'disbelief'* that turns into *'denial'*. This stage is characterised by *'We wonder how our life is going to change and how we are going to live with those changes'*. Denial and shock help us to cope and make survival possible. This stage can be dangerous for people with chronic pain and illness because if they are in denial about their condition, they may not take the necessary steps to get themselves the treatment they need.

Pleading, Bargaining & Desperation: This stage is characterised by pleading and bargaining in order to keep or live the way it was in order to not have to make the necessary changes and to continue living as though nothing is wrong. Sometimes we plunge ourselves into working out, eating healthier, etc in order to attempt to *'cure'* ourselves. You might feel guilt thinking *'did I do this to myself?'* or *'Could I have done anything to prevent this?'* You might also start to wonder what your purpose in life is or questioning your identity.



Anger: Once we realise that no amount of pleading or desperation will change our diagnosis, we start to get angry. Angry at having the illness, angry at the lack of a cure or treatment options, angry at the limitations it imposes on you, the list goes on. It's important that we allow ourselves to feel and express these feelings. We need to really work through this stage in order to start healing and move on to the next ones.



Anxiety & Depression: Anxiety and depression is an *'appropriate response to a loss or life altering situation'*, this stage can *'feel as though it will last forever'*. This stage can come and go with the repetitive cycle of worsening and then improvement of symptoms, like the flow of the tides. It's important to recognise that we are grieving the loss of a life that we once had, loss of abilities and wellness as well as experiencing anxiety about what our future holds. All of this is normal and it's ok.

Loss of Self & Confusion: This stage is where we really start questioning who we are and where we fit in. We undergo a sort of *'identity crisis'* where we *'may question what your purpose in life is now'*. This can come on the heels of anxiety and depression or happen alongside it, but again, this stage is necessary for healing and is completely normal.

Re-evaluation of Life, Roles and Goals: Once we start questioning who we are now and where we fit in, we are inevitably forced to rewrite our life narrative by exploring new roles and goals for ourselves. We explore ways to incorporate aspects of who we used to be into our *'new normal'* and start to mold our new purpose out of the *'clay'* we are given to work with. For some, it's exploring new career options that allow us to have flexibility and work from home, for others it's finding small ways to do things we enjoy but not *'overdo it'*.

Acceptance: This stage is where we have fully integrated our illness into our lives and have come to the realisation that while it may have to be a normal part of life for us, we can still grow and experience joy in our lives. This is not simply being *'ok'* with being sick – but it is coming to terms with and finding ways to integrate the illness without making it the *'driver'* or the *'main character'* in our life story. We find ways to properly manage the illness and care for our mind and bodies when we need to, but also find ways to be happy, experience new things and surround ourselves with people who understand our needs and help us achieve our goals.

It's important to remember that these stages do not always come in this order, nor do they *'end'*. Sometimes we can experience them and not return to



earlier stages, but it is normal to experience '*acceptance*' and then head back to '*anger*' or '*depression*' here and there depending on how our condition behave and as life throws us curve balls. There is no '*one size fits all*' way to grieve life changes, we do the best we can with what we have.



Tips on Coping with Fibromyalgia

De-Stress

Stress may trigger fibromyalgia symptoms. Minimizing stress can improve your quality of life. Some proven stress busters are yoga, exercise, sleep, and meditation. Breathing deeply and exhaling slowly can also help. Or keep in mind activities that you enjoy or that make you feel better.



Jot It Down

If "fibro fog" is hurting your focus or memory, keep a pen and paper handy. Make to-do and even "to say" lists -- to help you remember topics you want to talk to your spouse or family about. Keep shopping lists, friends' names, and important phone numbers and addresses in a notebook to carry with you.

Exercise Regularly

Regular, low-intensity exercise, such as walking or warm-water exercise, is one of the best treatments for fibromyalgia. It helps decrease pain and stiffness, reduce stress, and may increase your sense of control over fibromyalgia. You may also sleep better.

Do Some Serious Soaking

Soaking in a warm bath or hot tub can relax tense muscles, reduce pain, and help you move more easily. If it's difficult for you to get in and out of the tub, try a sauna or put a stool in the shower so you can sit and let the water do its work. Moist heat may increase endorphins, which block pain signals, and help you sleep more soundly.



Reach for Decaf

Caffeine may compound stress, both physically and psychologically. It stimulates the heart and central nervous system, and can increase nervousness, anxiety, and insomnia. So, decaffeinate to de-stress. For better sleep at night, avoid caffeine from the late afternoon on.

Take Some 'Me Time' Every Day

Fibromyalgia can pose unique health challenges and make life complicated. So, make time for yourself every day as a part of your treatment. Lose yourself in a hobby, put on some music, rest -- whatever makes you feel good. It may bring more balance to your life, help you fight stress, and boost your energy for the things you need to do.

Make Work Life Better

Is work leaving you exhausted and in pain? Design a flexible plan that works for you and your boss. Ask about working from home part-time or setting your hours for earlier or later in the day so you can be more productive. At the office, rearrange your workspace for comfort and easy accessibility.

Talk About It

Fibromyalgia puts stress on you and those around you. Communication is critical. Don't try to always put on a happy face. Your loved ones need to know what makes symptoms worse. Plan talks for your best time of day. Try focusing on one issue and look for solutions. And don't be afraid to ask for help.

Just Say No

Fibromyalgia is sometimes called an "invisible illness" -- you can look fine but feel bad. People may forget that you need to prioritize and pace yourself. When weighing activities, favours, or invitations consider if they will keep you from the rest, exercise, or relaxation you need to feel well. It's OK to simply say "no."



Make Your Bedroom a Sleep Sanctuary

If you're not getting enough rest, set the mood in your bedroom for sleep. Reserve the bed for sleeping, and keep the room dark, quiet, cool, and distraction-free. Keep regular sleep hours and ban the computer and late-night TV watching. Instead, wind down with relaxing music or a warm bath.

Keep a Daily Journal

Keeping track of events, activities, symptoms, and mood changes can help you take charge of fibromyalgia. It may make you aware of when symptoms start and, over time, what may be triggering them. Then you can work to eliminate triggers or learn coping strategies to lessen their impact.

Join a Support Group

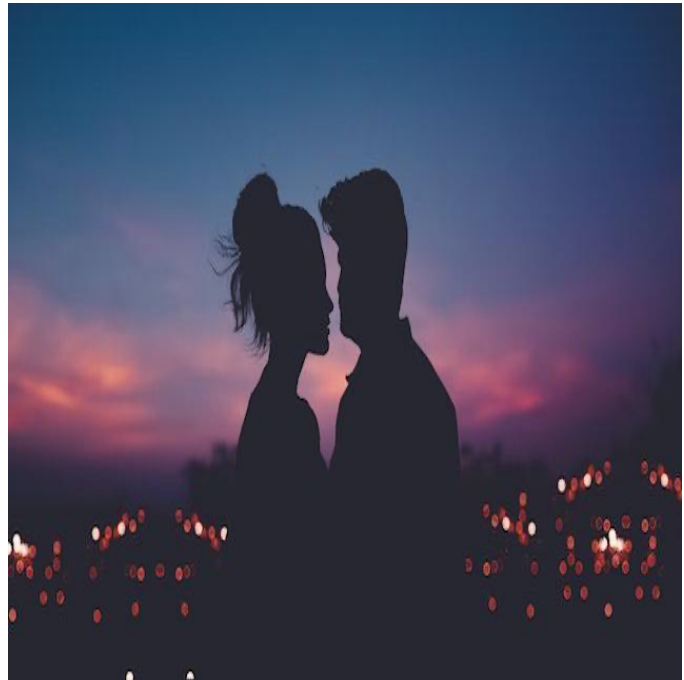
Support groups can play an important part in the lives of people with a chronic illness. Whether in person or online, they offer a safe place to talk with others who may share your frustrations and concerns. Support groups provide emotional support, information, and tips for coping.



Sex & Relationships with Fibromyalgia

Sex can be an important part of a relationship, but all too often people with disabilities such as Fibromyalgia (FMS) and chronic fatigue syndrome believe they have to severely limit their sexual activity, or even give it up altogether.

Either pain or fatigue may be enough to make someone fear or avoid sexual activity. When you have the Fibromyalgia symptom of allodynia (pain from gentle touch) or the ME/CFS symptom of post-exertional malaise (exhaustion from moderate activity), sex can seem impossible.



However, with open communication, experimentation, and forethought, you may be able to reclaim your sex life.

Obstacles to Sexual Activity

Pain and fatigue may be serious obstacles, but they're certainly not the only ones we face with Fibromyalgia.



Self-Image

It can be difficult to feel sexy when you don't feel good about yourself. Chronic illness can take a big toll on your self-esteem. You may feel flawed, broken and inadequate as if you no longer have anything to offer. You may also be feeling guilty about the things you can no longer do.

Illness can cause weight gain as well, which may compound the problem. Being unable to put a lot of effort into your appearance doesn't help either.

Strained Relationships

It's often difficult for our significant others to come to terms with our illness and the changes it inflicts upon our lives. Sadly, some of them have trouble believing that we truly are sick and not just "being lazy" or "trying to get attention."

This is a factor that can work in a couple of different ways. A drop in sexual activity may strain the relationship, or strain on a relationship can cause a drop in sexual activity.

Brain Chemistry

The neurotransmitter dysregulation of FMS may sap your motivation and interest in a multitude of things, including sex.

Depression

Depression is common in chronic illness, and even more so for these conditions. It can lower your sex drive, as can many of the medications for it.



Sexual Dysfunction

Antidepressants such as SSRIs and SNRIs can cause sexual dysfunction. These drugs are frequently prescribed for Fibromyalgia even if depression isn't present because they work on neurotransmitters that are believed to be dysregulated in these illnesses.

Sexual dysfunction may also result from Fibromyalgia, according to research. However, we don't yet know much about it other than that it exists, so further research is needed into why.

Overlapping Conditions

Other illnesses including vulvodynia (pain in the vulva) or interstitial cystitis (pain in the bladder) can make sexual intercourse extremely painful, on top of the pain you already have.

Fear

You may be afraid of sex exacerbating your symptoms, which could make you unable to relax and enjoy the experience. And you may not be the only one held back by fear -- your partner may also be concerned about hurting you or triggering symptoms.



Overcoming the Obstacles

Solutions to these problems start with communication - you need to communicate with both your partner and your doctor.

Open communication with your partner may be difficult if you're not accustomed to talking about sex. However, it's important for him/her to know where you have pain, the limits of your endurance, and what activity you're comfortable with.

If you're having other relationship problems, you'll need to work on those as well. A couple's counsellor may be able to help.

You may also want to see a counsellor for problems with self-esteem and depression.

Your doctor can help you diagnose and treat any overlapping conditions, such as vulvodynia or interstitial cystitis, that may be getting in your way.

Talking about sex can be difficult, whether it's at home or in a clinical setting.

The Right Positions

You may find that certain sexual activities or positions sap less of your energy and therefore are less likely to trigger a symptom flare.



Pregnancy and Fibromyalgia

Pregnancy is a journey for any woman, truly miraculous and filled with incomparable excitement and anxiety. For a woman who suffers with FM, there can be additional challenges along the way. Starting with tips for your own nine-month journey can help this be a time to enjoy that beautiful glow.

Medication, exercise, pacing, and naturopathic remedies can help a lot. If you're planning to become pregnant, be in the best shape possible.

Tip 1- Educate yourself before becoming pregnant. FM itself should not harm an unborn child; but discussing medications during pregnancy is important. Consider discontinuing naturopathic treatments due to a lack of solid information on effects to the unborn child. Perhaps a medication will have a safer alternative and a decrease in them all to a level where symptoms are still manageable will be recommended.



Tip 2- Be at your best mentally and physically at the start of a pregnancy. It takes a toll on your body to support the growth of another little being, so start out ahead. Exercise throughout the pregnancy with your obstetrician's approval. Think about switching things around. If walking your dog becomes difficult because of back pain, start walking in a pool, with the water at chest level. The water takes the weight off your body and provides a relief. Be sure to talk with your doctor before undertaking any exercise program during pregnancy.



Tip 3- Try to educate your family and friends about FM. The fatigue of pregnancy hits harder than for most women because of FM. It helps to have friends and family who understand why you are sleeping most of the day, need encouragement, and help to continue things like home-cooked meals.

Tip 4- Manage the pain and fatigue like you always do, but make sure to approve what you do with your OB. Long, hot baths early in the pregnancy are not recommended. Medical pressure stockings can decrease calf pain, as well as a maternity belt to decrease hip and back pain (until the later stages of pregnancy). (Be sure that the constriction is never tight enough to cut off your circulation.)

At times, fatigue and faintness are overwhelming, and what you can accomplish can be minimal, especially in the first and last trimesters.

Tip 5- Get some help lined up for the postpartum stage. You will most likely need it. There will be two patients coming home from the hospital—you and the baby. This is too much for your significant other to handle, even if he takes time off from work.

Tip 6- Breastfeeding is a topic in itself. Be flexible and realistic. Sometimes FM pain and sleeplessness flare up a few weeks postpartum, and there is a need for more meds to just be able to function as a new mom. Some women stop breastfeeding because of the effects the meds would have on the baby.

Tip 7- Have no expectations. Pregnancy and parenthood can be likened to holding onto your partner's hand and jumping off a cliff together into the great unknown. You just really do not know what is to come. Some women do well, and others recognize the benefits of only-childhood. Being mommy for one can prove to be plenty of a challenge for a woman with FM.



No research confirms concerns for women to be afraid of pregnancy. Educate yourself. You are the responsible party, not the docs. Women with FM usually learn, the hard way, how to prioritize and what is really important in life.

If bringing a child into the world is important to you, take care of yourself, surround yourself with understanding and help, and enjoy the journey!

Further Support and Resources

- **FibroSupport-Wales:** www.fswales.org
- **NHS:** <https://www.nhs.uk/conditions/fibromyalgia/diagnosis/>
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