“Did you know?”

Lets talk about

Fibromyalgia

Young Carers
Bedford Borough

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What I think Fibromyalgia (FMS) is and how it feels to have it.

Write or draw your ideas below

What is Fibromyalgia?

Fibromyalgia (FMS) is a long term condition which causes pain all over the body. The exact cause of fibromyalgia is not known, but it is related to unusual levels of certain chemicals in the brain. This changes the way a persons' brain, spinal cord and nerves react to pain messages around the body.

For some it may feel like

- Increased sensitivity to pain
- Muscle stiffness
- Increased body temperature
- Difficulty getting to sleep or staying asleep
- Brain fog such as difficulty concentrating or remembering things
- Headaches
- Stomach pain and bloating
- Feelings of frustration, worry or low mood

The symptoms of this condition can sometimes become better or worse depending on how someone manages their health habits.

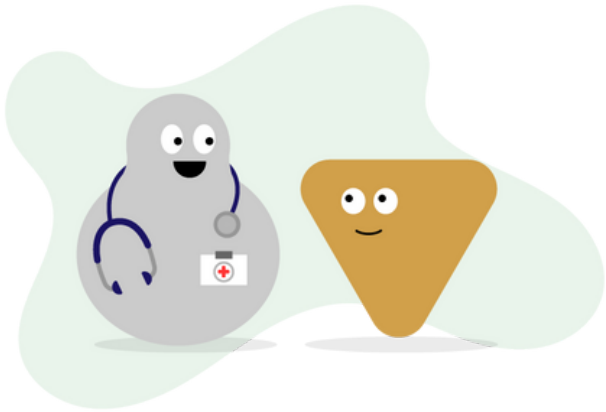
Fibromyalgia tends to affect women more than men, but it is possible that this condition can be passed down through genetics.

There are 3 main treatments recommended for someone with Fibromyalgia:

Exercise

Talking therapies

Medicines



Exercise

It’s really important to be physically active when someone has Fibromyalgia. This can be difficult if they are in a lot of pain, but regular exercise does help reduce pain and improve overall quality of life.

Walking is the easiest, and you don't need any special tools other than a good pair of shoes. Swimming and biking are also good options. The trick is to find something and start with 10 minutes each day and work your way up.

Next time you go for a walk, make sure to do some gentle stretches so you can keep going for longer!

Talking Therapy

Talking about fibromyalgia and how it is affecting a person daily life is the first step to managing it. Talking can help a person learn to accept what is out of their control and commit to making changes that will improve their life, one step at a time.

Think of some words to describe your feelings and write them below

Medicine

There is some medication that doctors can give which can help ease the pain when it gets too much. Everyone may cope with Fibromyalgia differently, so it is best to discuss all options

Getting enough sleep is one of the most effective ways to treat Fibromyalgia, it can also helps to go to bed and get up at the same time each day and limit napping during the daytime.

Sometimes it can be hard to understand and cope

We can't go out as much as I would like because mum is in too much pain to leave the house

I am too shy to invite friends over to my house as it gets so messy if we haven't tidied up

I have to wake up really early to make sure mum has everything she needs before I leave for school

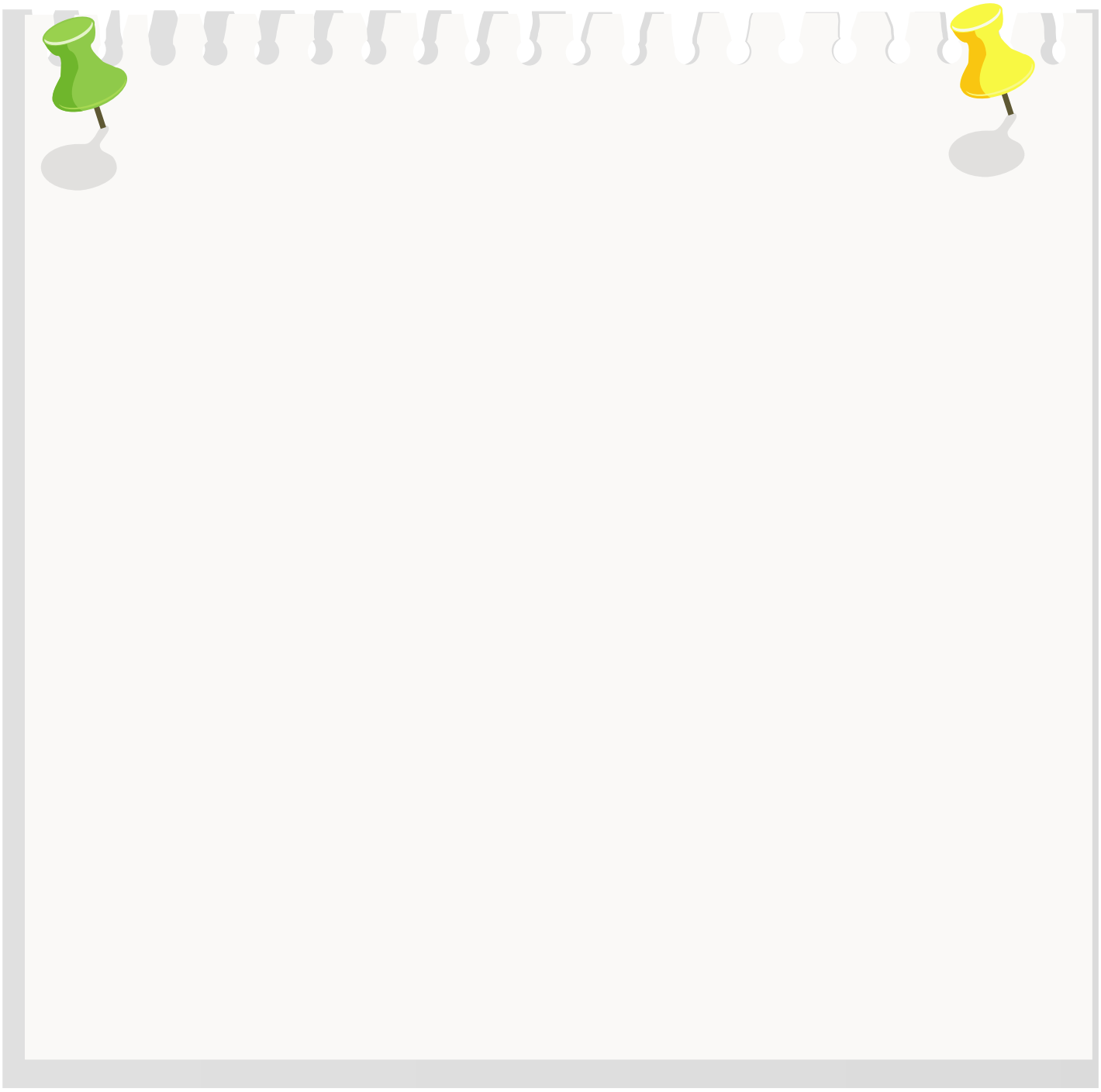
"I feel sad that mum can no longer do things she used to enjoy, but I guess we can have new hobbies"

Top Tips

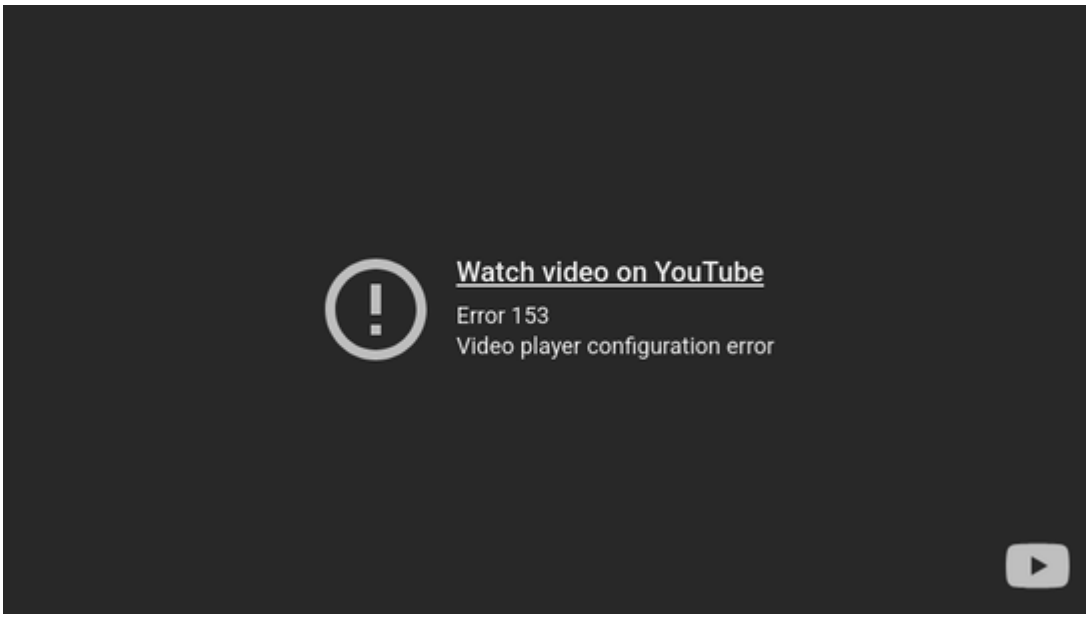
For someone living with fibromyalgia, it is important for them to know there is always someone there for them. And those who live with the condition may also need support too...

- **Write a list of questions for your mum or dad. They may not be able to give you all the answers but finding things out a bit at a time may help you understand better.**
- **Talk to your teacher if the care you are doing is stopping you from doing your homework**
- **Make sure you give yourself time to do things you enjoy, it is ok to want some time alone**
- **It is always important to speak to a trusted adult or friend if you feel overwhelmed**

Now you have completed this workshop, take a moment to think about your thoughts and anything you have found useful.



Internet support Links



https://www.youtube.com/watch?v=RWJ0W761hes

Support services

- **FIBROMYALGIA ACTION UK**: is a charity that offers information and support to people with fibromyalgia. If you have any questions about fibromyalgia, call the charity's helpline on 0300 999 3333.

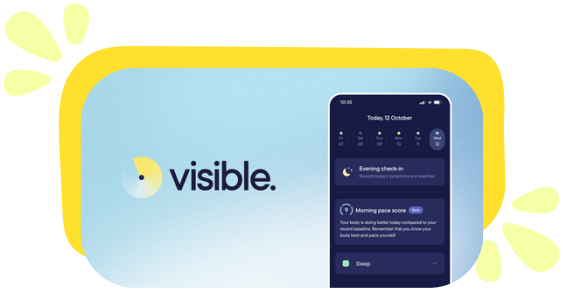
- **UK FIBROMYALGIA:** Another organisation that could be useful with lots of information and support services - www.ukfibromyalgia.com

- **THE DISABILITY RESOURCE CENTRE:** They run regular network and support group with occasional guest speakers for people with Fibromyalgia - for more information go onto www.yourwellbeingbedfordshire.org.uk

- **FIBROMYALGIA ACTION:** Is an charity of volunteers majority of whom also have FMS, which means your cared for can get support from people who really know what it's like to live with this condition. Find out what they do here - www.painuk.org/members/charities/fibromyalgia-action/

Apps

- **VISIBLE.** is an app and wearable made to help manage energy-limiting illnesses like Fibromyalgia. It helps pace and manage your energy better, saving it for the things that matter to you.



Use the app to:

📊 Measure your energy

📅 Plan your day around physical activities

🔔 Get real-time alerts when you're over-exerting

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This booklet is for you to have a better understand of Fibromyalgia, how this condition affects a person, and tips on how you can support them

We are an experienced charity supporting unpaid carers, of all ages, across Bedfordshire.

BEDFORD BOROUGH COUNCIL

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