

**Fibromyalgia  
Action UK**

# Fundamentals of Fibromyalgia



**Fibromyalgia Action UK**  
Fighting for Freedom from Fibromyalgia

[www.fmauk.org/publications](http://www.fmauk.org/publications)  
[www.fmauk.org/resources](http://www.fmauk.org/resources)

# Fibromyalgia - What

## What is fibromyalgia?

Fibromyalgia is a debilitating condition which can bring unpleasant and life changing symptoms. Common symptoms include:

- Fatigue and exhaustion
- Widespread body pain
- Non refreshing sleep
- Cognitive disturbances and confusion

People who suffer from fibromyalgia can find that it has a huge impact on their lives, and they may not be able to do things that they once did before developing fibromyalgia. This can lead to people changing jobs as it can become too challenging, and many find simple tasks to become incredibly more difficult.



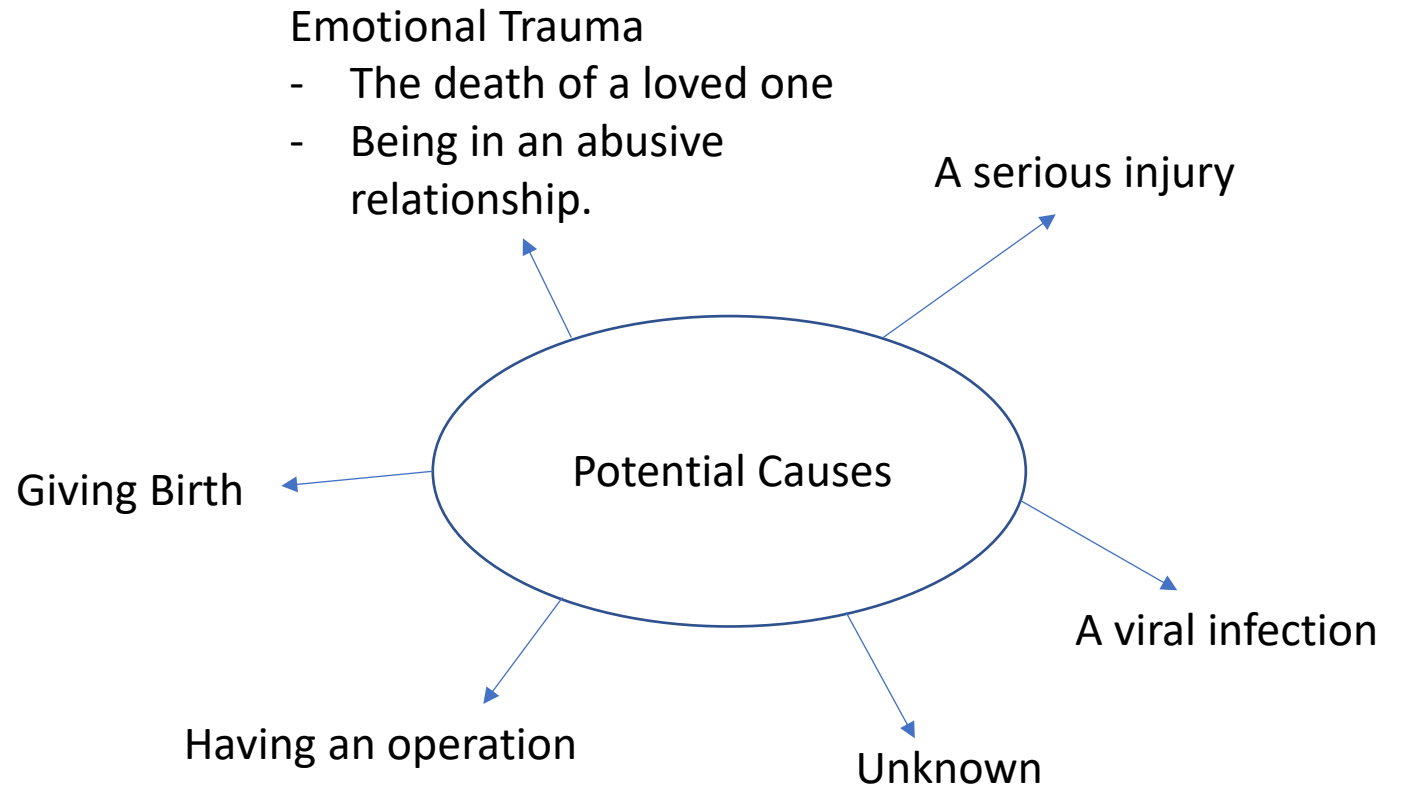
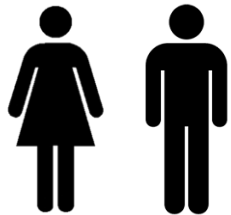
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# Fibromyalgia – Who/Why

## Who is affected and what causes fibromyalgia?

Fibromyalgia is thought to impact around **1 in 20** people in the UK, and for unknown reasons impacts women more than it does men. The women/men ratio is around **7:1**



# Fibromyalgia – The journey

## Diagnosis of fibromyalgia

- Complex condition
- Symptom overlap with other conditions
- Can take years + several doctors
- Royal College of Physicians website has diagnostic guidelines

## Treating Fibromyalgia

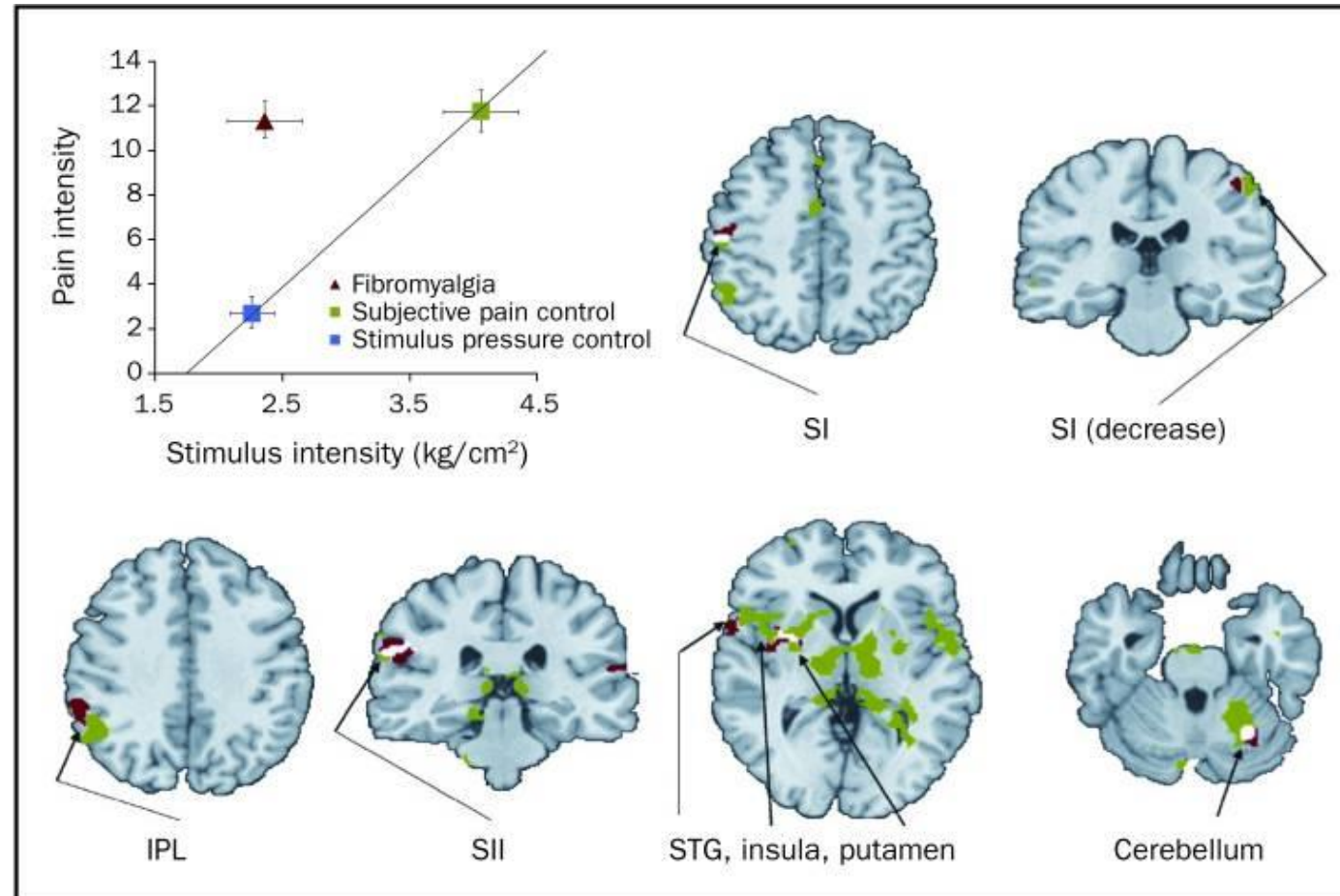
- No cure
- Treatment is focussed on managing the symptoms of the condition
- Combination of pain killers, anti depressants and anti epileptic medications are often used. NICE guidelines 2021 only recommend anti-depressants.
- Cognitive Behaviour Therapy and counselling – doesn't reduce the pain but can put people in a better place to deal with it.
- Activity – Simple, gradual and gentle exercises can be beneficial. Examples include Tai Chi, Yoga etc.



# Fibromyalgia – The Science

## Its in your head after all

- 2002 - Functional magnetic resonance imaging evidence of augmented pain processing in fibromyalgia - Richard H Gracely 1, Frank Petzke, Julie M Wolf, Daniel J Clauw
- 2013 - Science of Fibromyalgia - Daniel J. Clauw, MD, Lesley M. Arnold, MD, and Bill H. McCarberg, MD
- **Extra** Substance P, nerve growth factor, and glutamate
- **Less** serotonin, norepinephrine, and dopamine
- Central Amplification / CSS – Turned up to 11!
- Other factors – SFN, Autoimmune



# Case Studies

## Rachel, 20

“Fibromyalgia really impacts on my ability to study - the difficulties processing information, the sensitivities to different things, brain fog, and the pains which make me nauseous. But my university are being so supportive, which is so helpful and reassuring!”



## Kayleigh, 22

“Fibromyalgia has completely changed mine and my family’s lives. I was working to my dream career and about to achieve it, but that’s now been taken away from me as I’m in too ill health to carry out the role. It’s gave us financial problems as I now can’t work as much as I did. It’s gave us all a different outlook.”



# Our Mission

**Mission Statement** – To improve the lives of people with fibromyalgia by increasing awareness of the condition throughout the UK and elsewhere, and improve the awareness of, and access to treatments for fibromyalgia.

We are a registered charity working to improve the lives of people living with fibromyalgia, by:

- **Increasing awareness of fibromyalgia**
- **Improving access to treatment**
- **Providing support to those living with fibromyalgia**

# Our Staff and Volunteers

**Board of Trustees** – Des Quinn (Chair), Janet Horton, Helen Watts, and Tracy Wheeler  
They are responsible for overseeing direction of the charity.

**Staff** – Small team, which makes up the equivalent of 2.5 FTE's (Full Time Employees)

Hazel Borland - Administrator

Lynda Warden – Fundraising Assistant

Sarah Dean – Social Media & Admin Support

**Volunteers**

- Regional Co-ordinators
- National & Benefits Helpline Volunteers
- Office Volunteers
- Forum /Facebook Admin Volunteers
- Newsletter Editor & Volunteer Writers
- General / Advocacy Volunteers
- Medical Advisory Board



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# Our Activities

## Fibromyalgia Action UK provides

Medical information for professionals

National information and benefits helpline

Information for people living with fibromyalgia – info packs & newsletter

Links with 100+ local support groups

An online support forum through HealthUnlocked and social media pages

Awareness-raising campaigns



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# Fundraising



Charity Skydive



Falkland Island Trek



Charles River Bake Sale



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# Social media campaigns

GOING FOR A FEW PINTS WITH YOUR FRIENDS TONIGHT?



Imagine for a second you couldn't make it. Because you are in constant pain. And are experiencing severe fatigue. And more unpleasant symptoms.

This is often the case for those with fibromyalgia.

Become aware, get informed.  
Visit [www.fmauk.org](http://www.fmauk.org)



## FIBROMYALGIA QUICK GUIDE #BecomeFibroAware Not All Conditions Are Visible.

It is thought to impact around **1 IN 20** people in the UK.

### Symptoms of the condition can include:

- Widespread body pain
- Extreme fatigue levels
- Cognitive dysfunction
- Dizziness
- Sensitivity to environments
- Headaches

The condition can have a **severe impact** on the quality of life for those living with it. It is an extremely challenging condition to live with, but there is **not enough awareness** of it.

Help us to raise more awareness today



[www.fmauk.org](http://www.fmauk.org)



Men get fibromyalgia too.

Visit [www.fmauk.org](http://www.fmauk.org) for more information on fibromyalgia.



#BecomeFibroAware

If only we could see fibromyalgia, then people would realise how common it is.

Become aware, get informed. Find out more.  
Visit [www.fmauk.org](http://www.fmauk.org)

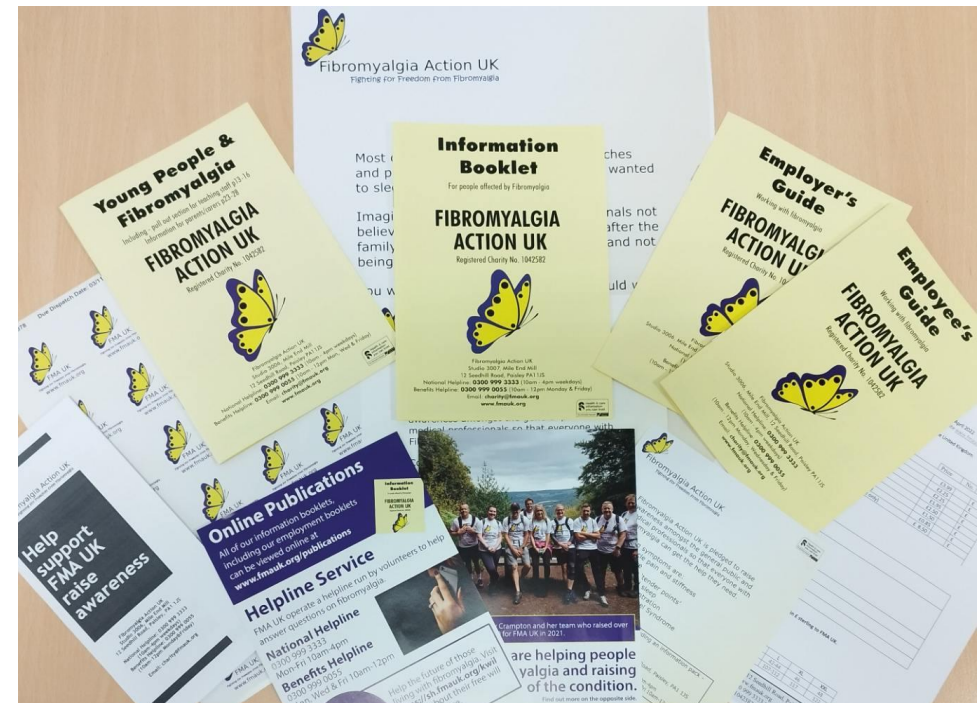


# Information Pack

Information packs are an important part of what we do – we send out thousands across the UK each year. They are often a source of information to those who are newly diagnosed or struggling to understand what has happened to them.

[www.fmauk.org/resources](http://www.fmauk.org/resources)

[www.fmauk.org/publications](http://www.fmauk.org/publications)



# Thank you for your supporting us

**If you have any questions, please feel free to ask us!**

## Further Resources:

[www.fmauk.org](http://www.fmauk.org)

[www.fmauk.org/history](http://www.fmauk.org/history)

[www.fmauk.org/resources](http://www.fmauk.org/resources)

[www.fmauk.org/publications](http://www.fmauk.org/publications)

[www.fmauk.org/groups](http://www.fmauk.org/groups)

[www.facebook.com/groups/fibroaction](https://www.facebook.com/groups/fibroaction)

[www.nhs.uk/conditions/fibromyalgia](http://www.nhs.uk/conditions/fibromyalgia)

## Support / Contact

National helpline - 0300 999 3333

(10 to 4 Mon - Fri)

Benefits helpline - 0300 999 0055

(10 to 12 Mon, Wed, Fri)

[charity@fmauk.org](mailto:charity@fmauk.org)

[benefits.advice@fmauk.org](mailto:benefits.advice@fmauk.org)

[head.office@fmauk.org](mailto:head.office@fmauk.org)



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