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INSIDE THIS MONTHS ISSUE:

The magazine that has something for everyone

Fibromyalgia – or is it?

Guilty or Not Guilty – The doctor who now has CFS

Aims of the Magazine

An aid to those who have been diagnosed with Fibromyalgia (FM) Chronic Fatigue Syndrome (CFS) and Myalgic Encephalopathy (ME) who need support and guidance to help them come to terms with their lifelong debilitating condition.

To help their families, friends, colleagues etc. to understand and be able to offer their own level of support.

As a tool to assist the medical profession when dealing with patients who have presented regularly over a 6 month period or more with unexplained pains which could be FM, or those who have already been diagnosed.

As an outlet for FMCFS/ME sufferers to share their experiences.

A way to raise awareness and educate the general public of the many symptoms and issues that make up these similar but different conditions.

To work toward fundraising for research, we all want the same thing:

A CURE!

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Thank You

Thank you to everyone who has contributed to this months magazine.

Contributors:

Elyse Runacre – Features Editor

Sara-Louise Williams – Graphic Design

Ailsa Bancroft – Arts & Crafts

Beverley Barnett – Copy Editor

Plus Guest contributions



To all our regular contributors, our wonderful readers and everyone who has done anything to raise awareness in whatever way they were able this month and especially to those who donated.

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Message from The Editor

Hi

This is the last issue of the magazine that I will be really involved with for the next 12 months. Health issues, trying to ensure all the paperwork and legal stuff required for the charity is in place. Aiming to get to parliament to get more support networks put in place for all fibromyalgia patients, plus a few other projects simply means I do not have enough time/energy for everything and something has to give. The good news is that Sara-Louise Williams (Trustee) who has worked with me since its inception working her magic has agreed to take over. Elyse Runacre who joined us just over 12 months ago has been doing a fabulous job as features editor and without her on board I would not have got through the last 12 months. I know I am leaving you in very safe hands and I would love it if you could help both Sara-Louise and Elyse by supporting them. Write in, get involved, share your thoughts on articles – let them know what you think.



Fibromyalgia – which has previously been known by other names and it would appear that it's about to undergo yet another name change – Central Sensitivity Syndrome. I wonder does it really matter the name and will it improve anything for the patients? To my mind it won't change the condition, it won't suddenly be understood. However it may be seen by the general public as a 'new condition', one they have never heard of before – that is of major concern to me personally, all the work that has gone before to raise awareness of fibromyalgia, do we have to start again?

Change isn't something that happens overnight (unless you get fibro or something similar). Raising awareness and getting more bio medical research will take many years of work, of campaigning, of fighting. Change is one, very slow, step at a time. The more people who join in, the more chance we have of reaching those goals – please ask yourself 'what can I do to help?' Talk to those who are already involved, never think you have nothing to offer. Join our awareness group - <https://www.facebook.com/groups/ffawareness/>

Read the article in this month's magazine of how Meg made the decision to become an awareness advocate. Be inspired.

Beth X

Fibro Petition

The Butterfly Effect: This effect grants the power to cause a hurricane in China to a butterfly flapping its wings in New Mexico. It may take a very long time, but the connection is real. If the butterfly had not flapped its wings at just the right point in space/time, the hurricane would not have happened.

The name 'The Butterfly Effect', coined by Edward Lorenz for the effect which had been known long before, is derived from the metaphorical example of the details of a tornado being influenced by minor perturbations such as the flapping of the wings of a distant butterfly several weeks earlier.

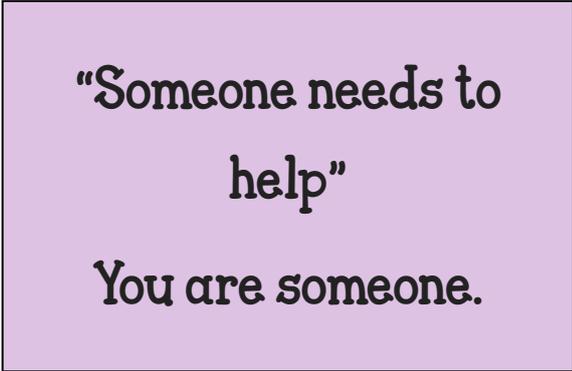
One butterfly started a petition, just one signature – 6 months later the petition has been signed by over 50,000 people!

The long-term plan is to reach 100,000 signatures and then to present it to parliament. There is a substantial cost involved in holding a drinks reception (£6,000) to be attended by MP's, where we (the trustees of Fibro Flare Awareness Group and other representatives) can ensure the voice of the whole fibromyalgia community can be heard.

So far we have received donations of £355.77 and have been applying for grants. We do have to show that we can match the amounts applied for – reality, we need £3,000 of donations.

We are happy to work on your behalf, but we need your help to raise enough funds to make this happen. That is why we are asking you to donate – if every person who signed the petition donated just 50p we would cover the cost and be able to add more to the future research fund.

Almost without fail every fibro patient I have spoken with agrees that more awareness and research is needed and that is what we are focused on.



**"Someone needs to
help"
You are someone.**

All monies from the sale of goods from July-December via our online shop will also be used towards this event. Take a look and share the link with family/friends.

<http://fibro-flare-shop.myshopwired.com/>

Be In to Win

By Sara-Louise Williams

Hello Everyone, I am a trustee for Fibro Flare Awareness Group and I also work on the magazines. We have created a page where we hope to raise funds for the annual running costs and also to raise money to attend parliament.

If you want a chance to win something, then check out our RAFFLE page and add family members/friends – help us to help you.

<https://www.facebook.com/groups/1248471085262812/>

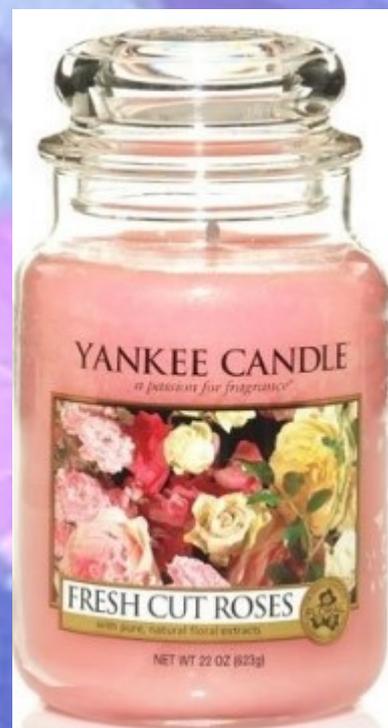
If there is something you'd like us to raffle, please ask and we'll try our best to accommodate it!

Remember, this is gambling, and only play with what you can afford to lose, when the fun stops, stop! <https://www.begambleaware.org>

Players must be over 18!

1. Find prize you would like to have the chance to win
2. Check available numbers in comments
3. Comment what number(s) you would like
4. Pay via paypal to Fibroflarerafle@outlook.com
5. When raffle is filled it will be drawn using a random number generator and the results posted online.

Prizes will be sent direct to winner and additional postage costs may apply if outside UK



6 Activities People Might Not Know Are Affected by Chronic Pain

By Sian Fiona Williams

courtesy of The Mighty (<https://themighty.com/2017/06/everyday-things-affected-by-chronic-pain/>)

Anyone else with the same/similar condition knows that each day is different, but at the moment I am struggling quite a bit. The main issue I have is a lack of knowledge regarding what I can and can't do. This isn't just by friends and family but also me. I do not know what my body is capable of and every day seems to be a struggle and dance to see what activities I am able to manage.

1. Cinema

Last night I went to the cinema to see a film I had been waiting to see with my husband for weeks! I had been sat on my rocking chair all day perfectly happy, in pain but happy, so assumed the cinema would be fine. This was a mistake! Within 20 minutes I was in agonizing pain. I was hugging the chair in front of me trying to stretch, I was breathing heavily, I had to leave the movie to try and stretch myself out in the bathroom! It was heart-breaking but a realization that I am not able to do activities that most think are perfect for someone with pain and joint issues.

2. Eating dinner in a restaurant

You would think, well you can eat dinner at home so you must be OK to eat dinner out too. I found out Monday this was a mistake, too. My body was in so much pain, I was so warm and then cold, I was shaking and eating a lot to get through the pain. The only comfortable position was when my legs were up on the bench with me. At first I had my legs up on the bench with my jacket over the top of them because I knew it wasn't appropriate to have my legs on the bench. When I felt too bad having my legs up I had them down and crossed, and this was when the heat came over me.

3. Putting on a sports bra

I normally wear sports bras because they are more comfortable. With the pain I can be in I try to be as comfortable as possible, so no wired bra/sports leggings/ anything that doesn't dig in or cause unnecessary discomfort. Unfortunately lately tight T-shirts and sports bras have become my nemesis! I have to contort my arms and shoulders to get them on and have taken to having to sit down because of the pain and dizziness once I have put them on!

4. Making a cup of tea

Now this one I know from my support groups is an issue for quite a few people. I have always been OK until now though so I didn't realize how debilitating it can be! I love my tea! I have a pot at least once a day and twice on my days off work. Unfortunately, lately I cannot lift the kettle properly or the teapot when it is filled. My hands shake, I feel weak, and I feel emotional. In all honesty it is one of the easiest activities to a non-ill-person and I do feel a lot of jealousy when my husband pours drinks for me and looks at me like I am mad for not having the strength!

5. Drying my hair

People always compliment me because I have long thick hair, but lately it has not been a blessing! I wash my hair in the bath because when it is wet in the shower it feels so heavy I feel like my neck could give way. I stay in the bath until my hair is part dry and then I go into the bedroom, sit on the floor and spend what feels like hours drying my hair. My arms ache, my head is heavy and I just want to sleep, but if I don't do it my hair goes uncontrollable which I cannot handle! This being said, the past two times I have dried my hair with my hairdryer I have had to have a nap and ended up half ruining my hair, leading to me pulling lots out lots of hair trying to comb it when it is so unruly!

6. Putting on shoes

This past week I have stopped wearing half my trainers and shoes. In all honesty I do not have the energy for tying shoes. It makes me dizzy, it makes me realize how useless my hands are becoming and really upsets me! It is upsetting that it takes me so long to try to wear shoes that I used to take for granted. When we are rushing out the house I feel guilty, when I get my shoes on before we need to leave and people feel I am rushing them, when really I just know that even putting on shoes I will probably need a rest!

There are so many other activities I have found difficult through this difficult time in my illness, but I wanted to share a few so people in the same position know they are not alone. We are strong!

The Great Debate

Last Month, I asked the question.... Do you think that Fibromyalgia is hereditary?

Even though I was only diagnosed with FM 6 years or so ago, I have had symptoms most of my life. Both my maternal grandmother and my mother both showed symptoms neither ever went to the doctor about it and unfortunately one of my daughters is having many fibromyalgia symptoms and has been for about a year. She has just started going to the GP, but at the moment they're not doing much.

A couple of years ago, another of my daughters was hospitalised after catching viral meningitis. Whilst there and for about 2 months afterwards she was showing symptoms. The hospital did start to investigate and ruled out multiple sclerosis, but once home she didn't follow it up. So far, the symptoms haven't returned. My sister has suffered with a variety of FM symptoms for years and is currently under investigation.

So, this question has always been at the forefront of my mind. I do think that there must be some kind of link and as usual more research is needed.

The result:

159 People responded to the question. Thank you.

98 Said **YES**,

31 Said **NO**,

30 Said **UNSURE**.

These are some of the comments that we received:

- ◆ 3 of my cousins have got it, all on my mum's side.
- ◆ I believe it to be hereditary. 4 cousins (2 of whom are sisters) have been diagnosed. All on my mother's side of the family.
- ◆ I know a couple of mothers and daughters who have it. One of the daughters was diagnosed when she was just 4 years old.
- ◆ No-one in my family has it
- ◆ I think that the "family" of conditions is linked. Not necessarily FM alone.
- ◆ I and my middle daughter both have it.
- ◆ No, I haven't got it from anyone. None of us had heard of it until I was diagnosed.
- ◆ My daughter, my sister and I have FM. My Fathers mum was bedridden in the 1950's with a mystery illness with symptoms that now sound like fibromyalgia.

By Elyse Runacre

Why I Became an Awareness Advocate

By Meg Day

I just wanted to share with you all that I decided to become an advocate to all those (myself included) living with chronic illness. I am so incredibly sick and tired of the lack of understanding surrounding this so I am making it my life's mission to raise awareness.

I figured I would start by telling you my story. I would like to start by taking you all back to August 2012. I was in my 1st month of pregnancy with my youngest. I was living in Manchester at the time but had travelled down to Essex to visit my dad for a few days with my then husband and our other 2 children. I remember when we got back to Manchester, I discovered a large bite mark on my right leg from some kind of insect. That bite took almost a year to disappear fully. It wasn't long after I noticed the bite that I started noticing I was becoming more tired more easily. This wasn't normal pregnancy fatigue. I should know as I already had 2 other children.

When I was around 8 months pregnant, I was walking down the stairs one morning when my left arm just seized up. It was so painful but only lasted for a few minutes. I went to the doctors but they just put everything down to stress and tennis elbow. I gave birth to my youngest in April 2013 and the day he was born he had to be admitted to hospital as he wasn't feeding and his body temperature was low. So I went with him. That night at the hospital, a nurse told me to rest and not to worry, she said someone would come in during the night to feed my son as I hadn't slept for over 50 hours. Ironic when I was so tired all the time. Well, I went

to sleep and must have been in a really deep sleep as apparently they tried and failed to wake me to feed my son.

A few days later I discovered they had contacted social services quoting concerns about my attitude towards my son. All because I couldn't be woken? A few months later we moved back to Essex and the social care team eventually closed the case. Just before they closed the case, however, I had received the results of my blood test which proved my new GP's theory. I had Chronic Fatigue Syndrome/ME and Fibromyalgia. I remember the day he told me. I walked out of his office sobbing my heart out, feeling as though I had just been handed a death sentence. Since receiving that diagnoses, a whole new world has opened up in front of me. I have discovered how severely misunderstood these types of illnesses are, not just by friends and family but also the medical profession.

As it is classed as an invisible illness, people have the arrogant attitude that if they can't see it, it doesn't exist. Well, you can't see diabetes or cancer but does that make it any less real? Does a person with ME have to be literally bed bound in order to gain recognition that they are in fact ill and not just faking it? I have been accused by the social care team of faking it just because they can't see it. Now before I get ahead of myself, let me tell you all the events leading up to the current day.

Myself, my (now ex) husband and our 3 children were given our first ever housing association place together. I was so excited. A fresh start for us all. Then a few weeks after moving in, I discovered my brother's best friend had been fatally stabbed. The funeral was overwhelming. So many people turned up to pay their respects. A few months after that, my nan was diagnosed with cancer. It quickly spread and she eventually lost her fight in November 2015. 1 month after I asked my husband for a divorce as his behaviour was becoming unbearable. The children couldn't run around making a noise without him shouting and swearing at them. We buried my nan in December and exactly 1 week after my nan's funeral, my husband committed a serious sexual assault on me. So I had to endure physical examinations and video statements whilst trying to adjust to life as a single mum of 3 and battling my own emotions at the same time. It all got too much for me and I ended up suffering from agoraphobia and I was making myself sick after meals too. It reached a critical point however when I attempted to take my own life as I could not deal with the emotional pain anymore. If it hadn't have been for my long-time friend Phil, I wouldn't be here today to tell my story.

I had to give my children up because of my health and the lack of understanding and support and because I needed to be able to focus on myself, to try to salvage what remained of my sanity so I asked for social care to get involved to help and I ended up signing a section 20 because they seemed more interested in making me out to be a bad mum than supporting me to be a better mum and all I wanted was what was best for my children. Giving my children up was the hardest decision I have ever had to make but I know it was the right decision as I couldn't give my children the care they deserved. Now, I am one of the lucky few because I actually had a family member come forward to have the children and they have settled in nicely with her, but I do not want others going through what I did. Hence why I have decided to become an advocate.



Is this living?

You say I should be grateful because I am alive
Is this really living or just learning to survive
Each day for me is torture each night is much the same
Feeling pretty useless I hang my head in shame

So difficult to communicate how living like this feels
I cannot find the right words to accurately appeal
You tell me that you understand when I describe my pain
You think you do, and try to, you nod as I explain

Understanding what it's like for us each and every day
Sometimes waxing sometimes waning but never going away
Always with me, always there, part of who I am
Lying to myself each day just because I can

Pretending to feel ok, saying I am fine
But sometimes giving glimpses of this life which is now mine
Lying to myself and lying to you too
Wearing my mask and smiling, is so much easier to do

Each day I fight against it, each day it will take more
Leaving me to mourn the life that I lived before
When I ask for understanding I am offered another pill
Often adding to the problems to those already ill

A visit to the priest perhaps part of my confession
A visit to the doctor or some other medical profession
Mental health, pain management, looking for the cure
No one has an answer none of them are sure

Take a bit more exercise, or perhaps a swim
Lose a bit of weight you say with time spent at the gym
Look for something natural something herbal in a cream
Shows a lack of understanding and makes me want to scream

If it was that easy by now I would be cured
Not living here in agony so often silently endured
No quick fix available and not a state of mind
So do not say you understand hoping to be kind

Fibromyalgia - What is it?

I like to read as much research as possible. But I still find myself struggling to fathom whether the research points more towards central nervous system or is it an auto immune disorder? I asked Dr Kim Lawson, Sheffield Hallam University if he would be prepared to answer some of my questions and he has kindly agreed to do so. I started with the one that has baffled me the longest.

Q. As research appears to be pointing strongly towards central nervous issue / auto immune disorder. Can one trigger the other?

A. The evidence is clear that there is an error in the central nervous system of people with FM, associated with central sensitization and dysautonomia etc. Although there is evidence that there are changes in the immune system (but no evidence of autoimmunity), it is not clear whether this is related to cause or consequence. The likelihood is that the changes in the central nervous system lead too much of the biology of someone with FM working inefficiently resulting in inflammation and a build-up of immune cells. So the immune component is probably a consequence of the central nervous system changes, however the severity is dependent on the person; hence some people get relief from anti-inflammatories and others do not. Dare I say that is the short/simple answer. Kim

I do have more questions but I don't want to monopolise Dr Lawson's time so I will only ask occasionally but if you have a question that keeps burning a hole in your brain please send it to me, just be prepared to be patient on awaiting answers.

fibroflaremag1@outlook.com – mark the Subject – Beth/KL

The influence of assistive mobility devices on wellbeing

I am emailing about the online survey that you kindly distributed to your members last summer as part of my master's research project into the experiences of mobility aid users, and because you expressed interest in hearing about the findings of the study.

I have now completed the research and have written up my findings as a report as part of my qualification. I have attached a document summarising the research and the key findings, which I hope you and your members find interesting.

I would like to take the opportunity to thank you again for your help and for expressing your interest in my research.

Best wishes,

Rachel Curtis

Background and why the project was needed

Assistive mobility devices are important tools for enabling individuals with mobility difficulties to improve independence and functioning. Yet, despite their ability to compensate for physical impairments, more than 30% of aids are abandoned within a year, by individuals who could benefit (Draffan, James, Cudd & Bentley, 2015; Scherer & Glueckauf, 2005). This risks damaging individuals' wellbeing, functioning and participation, potentially increases the demands of carers, and illustrates an ineffective use of health-care resources (Ripat & Woodgate, 2011).

Some researchers suggest that social stigma may partly explain why so many assistive devices are abandoned (Draffan, James, Cudd & Bentley, 2015). Yet, whilst research often highlights the enabling benefits of assistive mobility devices, their contradictory disabling impact, through stigmatisation, is typically overlooked (Krantz, 2009). Assistive mobility devices can draw attention to people's disabilities, which can encourage negative attitudes and treatment (Krantz, 2009). Therefore, the visibility of assistive devices may place users at risk of reduced wellbeing, and affect how positively they view themselves. Nevertheless, factors such as how well assistive mobility device-users incorporate disability into their identity (Bogart, 2014; Tajfel & Turner, 1979) and whether the assistive mobility device fulfils its purpose of improving independence (Shinohara & Wobbrock, 2011), may help protect users from the negative impact of the device's visibility. Thus, research was needed that explored the role of visibility and investigated potentially protective factors.

Additionally, despite findings that assistive devices can attract stigma and embarrassment, several studies demonstrate that individuals' mobility devices allow them to participate independently in their lives, which improves quality of life (May & Rugg, 2010).

Thus, this raises the question - what factors influence assistive mobility device users' wellbeing and whether they have positive or negative feelings about themselves? Limited research has explored factors affecting stigmatisation and wellbeing among assistive mobility device-users, as most research to-date has focused on physical, technical and service-delivery factors affecting assistive mobility device-users' experiences (Krantz, 2009). Moreover, there are many shortfalls with existing research. For example, many previous studies are small-scale, and wheelchairs are often the only devices included (e.g. Stenberg, Henje, Levi & Lindström, 2016; Carneiro, Rebelo, Filgueiras & Noriega, 2015), which overlooks individuals who use other common assistive mobility devices, such as mobility scooters and frames. Similarly, research examining experiences of assistive device users have been dominated by investigations of the elderly, which overlooks other groups who use these devices, such as younger people (McNeill & Coventry, 2015). Therefore, there was a clear need to tackle these limitations and explore factors that influence stigma and wellbeing among assistive mobility device-users. By developing research, hopefully service-providers will be better equipped to help meet the physical and psychosocial needs of individuals with mobility impairments who use assistive mobility devices.

Aims

Therefore, this project aimed to examine and compare factors that influence inwardly-directed stigmatisation and wellbeing among assistive mobility device-users. Specifically, we aimed to examine factors such as age, gender, experienced discrimination and how long participants had used their most frequently used device. Most crucially, however, we investigated the impact of the device's visibility, how well people incorporated disability into their identity, and perceived independence. We also aimed to identify factors that alter the strength of the relationship between mobility devices' visibility and inwardly-directed stigmatisation and satisfaction with life/wellbeing.

Data-collection

To achieve these aims, an online questionnaire was distributed through online support groups. We collected responses from 149 individuals over the age of 18 years, who had long-term mobility difficulties and used at least one assistive mobility device (i.e. a manual or powered wheelchair, a mobility scooter, crutches, a frame or a walking stick). The data gathered were analysed using statistical tests.

Key findings

The key findings were that:

- Assistive mobility devices' visibility did not influence satisfaction with life, or whether participants inwardly directed stigma.
- Participants who positively incorporated disability into their identity demonstrated less inwardly-directed stigmatisation and better satisfaction with life than participants who poorly incorporated disability into their identity.
- Participants with higher levels of perceived independence demonstrated less inwardly-directed stigma than participants with lower levels of perceived independence.
- As participants' reported inwardly-directed stigmatisation increased, satisfaction with life decreased.
- The visibility of assistive mobility devices only prompted more inwardly-directed stigma when participants had poorly incorporated disability into their identity.
- How well participants incorporated disability into their identity did not alter the impact of assistive mobility devices' visibility on satisfaction with life.
- Perceived independence did not alter the effect of assistive mobility devices' visibility on satisfaction with life or whether participants inwardly directed stigma.

Implications and recommendations

Although these findings are preliminary, and the study should be extended to explore differences between users of different mobility devices with a more representative sample, the findings have several implications and practical applications for providers of assistive mobility device services. Firstly, demonstrating that inwardly-directed stigmatisation is harmful to global wellbeing illustrates the importance of tackling inwardly-directed stigmatisation among service-users. Therefore, we recommend that rehabilitation providers assess this, in order to maximise outcomes.

Furthermore, the findings, which imply that assistive mobility devices' visibility does not impact wellbeing, reveal that merely altering devices' appearance may not be enough to influence wellbeing or maintain device-use. Rather, personal appraisals, and how well assistive mobility device-users incorporate disability into their identity, are pivotal to augmenting wellbeing and reducing inwardly-directed stigmatisation. Hence, whilst additional research is recommended to verify these findings, we recommend that, when providing assistive mobility devices, experts assess how well service-users incorporate disability into their identity. Indeed, these findings begin to identify factors which could protect or place assistive mobility device users at risk from poorer wellbeing and inwardly-directed stigmatisation. This could help to maximise the effectiveness of assistive mobility device provision, by providing additional support to those with the most need, and hopefully minimising device-abandonment. Individuals who have not positively incorporated disability into their identity, especially those who use highly visible assistive mobility devices may be at greater risk from inwardly-directed stigmatisation and its harmful consequences. Based on these findings, we recommend that assistive mobility device services integrate or recommend interventions such as disability support groups, Disability Affinitive Therapy, or Cognitive Behavioural-based Therapy, which enhance the incorporation of disability into individuals' identity, to maximise wellbeing and rehabilitation outcomes.

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Nature's Pharmacy



Headaches/Migraines:

As headaches and/or Migraines are a common symptom of Fibromyalgia, here are a few helpful remedies and tips to help you find some relief.

1. Relax- have a nice bath or just some quiet time.
2. Ask someone to give you a shoulder/neck massage. Locate a knot in the muscle, apply pressure whilst drawing a small circle in the knot. Breathe normally and try and relax. This does hurt (I get shooting pain from the knot, up my neck and into my head), but the pain and the tension headache should subside within 30 seconds.
3. If possible, roll your shoulders and neck to help relieve the tension.
4. Lay down in a cool room without any noise or light.
5. Gently, rub your temples in a circular motion.
6. Place a cool damp flannel on your forehead or over your eyes.
7. Apply ice to your temples.
8. Hold an ice-cube on the back of your neck, at the base of your skull for a few minutes.
9. Drink a cup of Ginger tea. Ginger is well known for having pain relieving properties.
10. Drink a cup of chamomile tea, to help you relax.
11. Drink some water- your headache maybe caused by dehydration.
12. Massage a couple of drops of Peppermint oil onto your temples.
13. Eat something that has Cayenne Pepper, Turmeric or Chillies in it. All of which are great pain relievers.
14. Watermelon is also good for relieving headaches as it rehydrates you.

Below are a few easy recipes for drinks that should help to relieve a headache/migraine;

The green one-

- Pineapple chunks
- 4 Kale leaves
- Cucumber
- Juice of ½ a Lemon
- ½ inch of root ginger
- 1 stick of celery

Place all the ingredients into a blender until smooth.

Mango and Turmeric Smoothie-

- Mango chunks
- ½ inch Ginger root
- 1 tablespoon honey
- ½ teaspoon ground Turmeric
- Some Oats
- 2 tablespoons of Greek yogurt
- Milk (cold)

Place the ingredients into a blender and blend until smooth.

The cooler-

- Cucumber, sliced
- Fresh lemon juice
- 4 mint leaves
- Cold water
- Ice-cubes

Place the cucumber and mint into a glass, add the lemon juice and then the ice-cubes. Pour in the water. Stir well.



By Elyse Runacre

Arts and Crafts

By Ailsa Bancroft

Children's September Craft – Awareness day

A Butterfly Mask

You will need:

Stiff cardboard;
String/elastic;
Different colours of purple felt tips/crayons;
Scissors.

- 1 Enlarge the mask to fit an A4 piece of paper
- 2 Cut the mask out from stiff cardboard
- 3 Colour in different shades of purple
- 4 Make holes in the sides to tie the elastic/string on
- 5 Make some for your friends as well

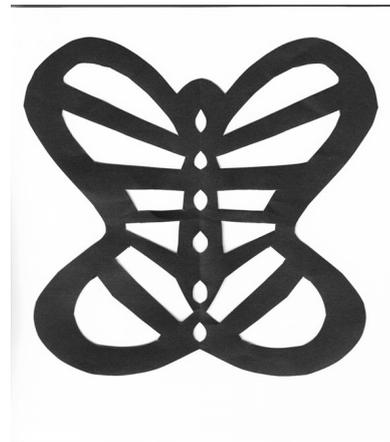


Stained Glass Butterfly

You will need;

Thick black paper/light weight card;
Different shades of purple tissue paper;
Glue (PVA);
Scissors.

- 1 Draw a butterfly shape onto the black paper/ card
- 2 Cut the butterfly out



3 Cut the purple tissue paper into strips of about 3cm by 2 cm

4 Lightly spread glue onto the back of the butterfly

5 Stick the tissue paper randomly onto the butterfly

6 Again lightly spread a little pva glue over the back of the butterfly and leave to dry#

7 Once dry trim the edges of the butterfly



8 Bluetac the butterflies to your windows for the stain glass effect.

Helping Ourselves - Alternative Therapies



Members are always looking for alternatives or something to supplement their medication to alleviate the pain of fibromyalgia. Below are the more common therapies used that have been found to help some. As always some work better than others, because as we have all learned – we are all different. Most of the following are not available on the NHS and have to be paid for privately but don't be put off looking and giving consideration to any/all of these.

Magnesium

A note from Dr. Briden on Magnesium (Mg), Thyroid and Hormones:

As my patients can tell you, I prescribe magnesium for almost every hormonal condition. I prescribe it for PCOS, thyroid, adrenal fatigue, hair loss, PMS and menopausal symptoms. I love magnesium because it makes people feel better almost immediately.

What is up with this mineral? Why are we all so deficient? We're deficient because our cells dump Mg during stress. We actively push the mineral out of our bodies as a way to rev up our nervous system and cope with daily life.

A revved up nervous system is what an average modern human needs to get through an average modern day. If you work, or commute, or drink coffee, or worry, then you are deficient in magnesium. If you live the meditative life of a monk on a mountainside, then you're probably Ok.

8 ways that Magnesium Rescues your Hormonal System

1. It regulates cortisol. Magnesium calms your nervous system and prevents excessive

cortisol. Your stress hormonal system (called HPA or hypothalamic-pituitary-adrenal axis) is your central hormonal system. When it is better regulated, then your other hormonal axes – thyroid and sex hormones – will function better.

2. Mag lowers blood sugar. Magnesium is so effective at sensitizing the insulin receptor that I refer to it as our 'natural metformin'. Better insulin control means fewer sugar cravings. Healthy insulin sensitivity is important for weight loss and PCOS, and it also prevents osteoporosis.

3. It supports thyroid. Magnesium is essential for the production of thyroid hormone. It is also anti-inflammatory, which helps to quiet the autoimmune inflammation that underlies most cases of thyroid disease. (Other ways to address thyroid autoimmunity include gluten-elimination and a selenium supplement.)

4. It aids sleep. As I've written here before, magnesium is the great sleep-promoter, and sleep is crucial for hormone production. Sleep is when we should have a surge in anabolic hormones like DHEA and growth hormone.

5. It fuels cellular energy. Magnesium is so intricately involved with glycolysis and the Krebs cycle (ATP energy production), that we can safely say: "There is no cellular energy without magnesium." Glandular tissue like thyroid, ovaries and testes is metabolically very active, so requires even more cellular energy and more magnesium than other tissue.

6. It makes hormones. Magnesium is involved in the manufacture of steroid hormones such as progesterone, oestrogen and testosterone. Magnesium has been shown to reduce hot flashes by 50%.

7. It activates vitamin D. Without enough magnesium, vitamin D cannot do its job. Conversely, too much vitamin D supplementation can cause magnesium deficiency.

8. It is anti-aging. The mineral has been shown to prevent telomere shortening, reduce oxidative stress, and enhance the production of glutathione.

Magnesium is powerful medicine.

Mg is a big player in emergency rooms, where it treats heart arrhythmias, heart attack, migraine and the toxemia of pregnancy. But why should magnesium be restricted to acute care emergency medicine? It is time – past time – for magnesium to take up its role in treating chronic conditions.

For more information on magnesium this video link is worth a watch.

<https://www.youtube.com/watch?v=d55y4yOnn3c&t=26s>

LDN (Naltrexone in low dosage). LDN is an opiate blocker and most definitely not an opiate. It is not illegal and is a licensed medication purchased via a pharmacy. For more information check out the charity website and Facebook page. There are thousands of video testimonials and they have a weekly radio show.

Facebook: (18,000+ members) - https://www.facebook.com/groups/LDNRT/?ref=br_tf

Website: <http://www.ldnresearchtrust.org/>

CBD Oil (Cannabinoid Oil). CBD is not illegal in the UK but is in some other countries. For more information check out what the users say.

Facebook: (10,000+ members) - <https://www.facebook.com/groups/CBDusersUK/>



Hyperbaric Oxygen Therapy (HBOT) – This is proving to be extremely beneficial to some fibro patients and has good research results in many countries. It's not as expensive as you may think. For more information and to find a centre near you check out –

<https://www.hyperbaricoxygentherapy.org.uk/fag>

<https://www.hyperbaricoxygentherapy.org.uk/find-chamber>

Golden Paste (GP, made at home with organic turmeric, coconut oil and black pepper). Great for inflammation. Works for humans and animals so if you have a pet this is definitely worth looking into. For more information and user comments.

Facebook: (220,000+ members) - <https://www.facebook.com/groups/415313751866609/>



Symptom Shout Out!

By Elyse Runacre

Restless Leg Syndrome

Restless leg syndrome is also called `Willis-Ekbom disease` and is a common condition of the central nervous system. Which causes an overwhelming, irresistible urge to move your legs? This syndrome also causes an awful crawling sensation in the feet and legs. Despite the syndromes name it can also affect your arms, although this is less common. Normally it is much worse at night. 1 in 10 people will experience Willis-Ekbom disease at some point in their lives. Women are twice as likely to get it then men.

Some neurologists believe that it is caused by the way that our body handle`s a chemical called `Dopamine`, which is involved in controlling muscle movement and may then be responsible for the involuntary leg movements associated with the syndrome. Restless Leg Syndrome can also be caused by the Iron deficiency – Anaemia. Pregnant women can also suffer with it as well.

This syndrome has plagued my life for 2 decades. Not only is it a daily symptom but it is also (for me) one of my worst. It used to drive me insane.

Restless leg syndrome was one of the first things which, once I had my FM diagnosis I spoke to my GP about. Luckily for me, Pregabalin helped. My GP recently changed my medication from Pregabalin to Gabapentin (200mg 3 times a day) and thankfully this works as well.

Before my diagnosis (and medication), I tried a variety of things in trying to rid myself of a symptom that kept me awake longer and more frequently than my pain did. So, I decided to run a poll via our Facebook page, to find out how many of us suffer with this symptom and what they do to help keep this symptom under control.

Here are the results of the poll:

144 people responded to the poll. Thank you.

118/123 have suffered or still suffer from it.

Listed below are the medications and other ways that fellow sufferers have said worked for them in treating restless leg syndrome-

- Place a bar of soap at the bottom of your bed (under the sheet).
- Tonic water
- Gentle leg exercises
- Fluoxetine
- Gabapentin
- Quinine tablets
- Distraction
- Walking on a cold floor
- Clonazepam
- Amitriptyline
- Magnesium spray
- Cooling spray
- Epsom salt baths
- Aspirin
- Cannabis
- Coconut water
- Pramipexole
- Tens machine
- Listening to music

I also ran a separate poll asking how many sufferers also had the same symptoms in their arms and hands. Here are the results; 46 people responded. Thank you.

36/46 said yes, they did get it in their arms and hands.

Fibro Links

By Elyse Runacre

Introduction

For over a year now I have been lucky enough to have the role as Features Editor with this wonderful magazine and 2 years ago I set up and still run one of the many fibromyalgia support groups on Facebook. I am also a member of several other FM support groups and chronic pain groups. As a result, I speak to a lot people with FM/M.E/CFS on a daily basis. The vast majority of us have other medical conditions alongside FM/M.E/CFS. When such things are discussed the same conditions/illnesses keep cropping up repeatedly.

Which led me to have **2** thoughts?

The first, Is there a **link** between FM/CFS/M.E and some of these other conditions?

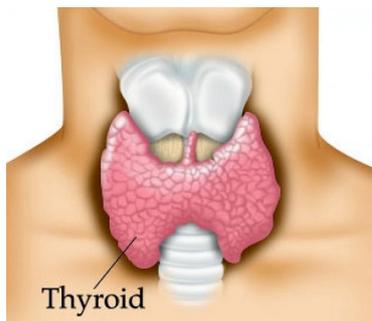
Well sorry folks but I can't answer that one, but it is possibly a BIG coincidence if they aren't.

My second thought, do we know what these conditions actually are? I promise you I am not being condescending. Some of these are very common and things that we hear about, such as underactive thyroid, type 2 Diabetes, iron deficiency, vitamin B12 deficiency etc... and even though I thought I did it turns out that whilst I knew a bit about some of them I still didn't really know.

In each issue of the magazine a different condition/illness will be covered.

Starting with –

Underactive Thyroid



Also known as Hypothyroidism.

The thyroid is a small butterfly-shaped gland which is found in your neck, in front of your windpipe.

One of its main functions is to produce hormones that help regulate the body's metabolism (the process that turns food into energy).

These hormones are **Triiodothyronine (T3)** and **Thyroxin (T4)**.

When the thyroid gland doesn't produce enough of these hormones it causes many of the bodies functions to slow down.

Both men and women can have hypothyroidism however it is more common in women. In the UK it affects 15 in every 1,000 women and 1 in every 1,000 men.

Causes

- Immune System. Most cases of hypothyroidism are caused by the immune system (which usually fights infection) attacking the Thyroid gland. Damage caused by this means that the thyroid cannot produce enough of the hormone Thyroxin. A condition called Hashimoto Disease. This is the most common type of autoimmune reaction. Other autoimmune conditions such as, type 1 diabetes and vitiligo, can also be causes.
- Previous thyroid treatment such as surgery or a treatment called radioactive iodine therapy. These treatments are sometimes used to treat Thyroid Cancer or Overactive thyroid.
- Viral Infections.
- Some medications used to treat other conditions- Lithium, Amiodarone and interferons.
- Problems with the Pituitary Gland.

Symptoms

- Dry, coarse hair
- Loss of eyebrow hair
- Puffy face
- Slow heartbeat
- Fatigue
- Depression
- Dry skin
- Forgetfulness
- Heavy menstrual periods
- Muscle aches
- Weight gain
- Constipation
- Brittle nails
- Being sensitive to the cold

These symptoms are similar to those of other conditions and tend to develop slowly so you may not notice them for years.

To find out if you have an underactive thyroid speak to your GP about having a blood test to test your thyroid levels.

Treatment

You will be prescribed a hormone replacement tablet called Levothyroxine. This hormone replacement tablet will raise your Thyroxin levels. Treatment will usually need to be taken daily for the rest of your life.

Self-help

The following foods will aid your thyroid gland function.

- Kelp
- Radish
- Parsley
- Strawberries
- Bananas
- Mustard greens
- Spinach
- Coconut oil

IF LEFT UNTREATED THIS CONDITION CAN CAUSE VERY SERIOUS PROBLEMS WITHIN YOUR BODY. IF YOU THINK THAT YOU MAY HAVE SOME OF THE SYMPTOMS LISTED ABOVE, SPEAK TO YOUR GP.

Symptom Shout Out!

By Elyse Runacre

Headaches

One of the most common symptoms that patients with fibromyalgia get are headaches. Almost everyone will have headaches at some time or other but FM patients who get headaches as one of their symptoms found that with the onset of FM the frequency with which they get headaches greatly increased. The aching or throbbing pain in your head, behind your eyes or in your temples can hit anyone without warning. Headaches can be caused by fatigue, illness, stress or hunger and often they can be easily dealt with over the counter painkillers. But for FM patients dealing with constant headaches may not be that simple. Patients with FM tend to suffer from three different types of headaches – muscle tension headaches, migraines and combination headaches.

Muscle Tension Headaches

This type of headache is caused by muscle contractions that in the back of the neck, head, jaw, upper back and shoulders. These spasms start at the base of the neck working the way upwards eventually spreading to the temples. They are often described as feeling like a band tightening around the entire head. The pain of this headache can range from moderate to severe and normally last a few hours.

Migraine Headache

Also, known as vascular headaches, migraines are caused by constrictions of your blood vessels and arteries. Due to stress, illness or fatigue, blood vessels in your head and neck begin to constrict and dilate. This causes severe pain, nausea, eye pain and dizziness. A migraine headache can also move around your head, shifting from side to side.

The most common type of migraine is called “common” migraine and affects about 70% of migraine sufferers. Usually preceded by episodes of anxiety, depression and fatigue. The less common type is called the “classic” migraine and is always preceded by visual symptoms including double vision, flashing dots, bright lights, blurry vision or distorted vision. Often called migraine aura. These visual symptoms may be experienced for 15 to 60 minutes immediately before the migraine. Typically, the migraine will last about 4 hours, though they can plague you for as long as a week. Migraines can develop into chronic headaches.

Combination Headaches

People with FM can suffer from a combination of both headache types (tension and migraine).

Headache Triggers

No one is exactly sure of the triggers that cause headaches in FM patients. Sleeping problems and fatigue are probably related to the increased number of headaches suffered. Muscle spasms and pain caused by fibromyalgia may also increase the frequency of headaches.

Migraine triggers include light, weather and sound. Stress also triggers frequent tension headaches.

Causes of Headaches in Fibromyalgia

Headaches are extremely common symptoms of FM. Over half of all FM patients suffer from constant headaches or migraines.

There are several theories as to why FM patients suffer from so many headaches. Many of these rest on the idea that the same dysfunction that causes Fibromyalgia also causes migraines.

- **Sleep Disorders:** Patients with FM may suffer from these headaches because of the disordered sleep that FM often causes. There have been several studies on migraine sufferers that showed that their sleep patterns were significantly disturbed, particularly by Sleep Apnoea and other sleep-related disorders. As many FM patients suffer with sleep disorders this may be the reason why so many suffer with these headaches. Furthermore, sleep disorders also make the severity and frequency of these headaches worse.
- **Temporomandibular Joint Disorder (TMJD):** A large percentage of people with FM also suffer from another disorder known as TMJD. This disorder causes muscle and joint pain in face, jaw and neck and often causes severe migraines. TMJD also causes Bruxism (teeth grinding) in many FM sufferers, which also contributes to headaches.
- **Low Levels of Serotonin:** One of the most widely held theories suggests that migraine headaches are actually caused by the same factors that cause FM. This would mean that migraine headaches aren't a symptom of FM, but are actually a concurrent illness. Studies performed recently on people with migraines show low-levels of SEROTONIN in their brains. Serotonin is a neurotransmitter that helps to communicate pain signals to different parts of the brain. Those who don't have enough serotonin don't seem to be able to communicate pain signals effectively, resulting in increased, and even severe pain. Fibromyalgia has also been linked to low levels of serotonin in the brain.
- **Low Levels of Magnesium:** Magnesium is a mineral that is also found in low levels in both migraine sufferers and patients with FM. Studies support that these low magnesium levels may actually be a cause for migraine headaches and Fibromyalgia.



Headaches can make Fibromyalgia pain much more intense. Headaches, especially migraines, tend to increase your fatigue, making pain much more difficult to tolerate. 36% of FM patients with chronic migraines experience greater levels of depression and pain in their illness.

If you suffer from any of these chronic headaches speak to your healthcare provider to find a treatment that is suitable for you.

Check out our Online Store

www.fibro-flare-shop.myshopwired.com/



Fibro Flare Magazine Shop sells many products to help raise some much needed funds for research and awareness.

Plus much more

Did You Know?

Our leaflets have been taken by The Royal Bath Hospital and the University Hospital, Southend.

Q. Where does your money go?

A. Every item bought contributes to our awareness/research funds enabling us to do even more to help the fibromyalgia community.

Donations are always welcome and can be sent via our online shop also.

T-shirts and Hoodies can be found at: <https://teespring.com/stores/fibro-flare-clothing-store>



Various sizes and colours available.

Help Raise M.E Awareness

[A plea from a fallen doctor on Chronic Fatigue Syndrome \(ME/CFS\)](https://www.reddit.com/r/cfs/comments/6sneul/a_plea_from_a_fallen_doctor_on_chronic_fatigue_syndrome_(ME/CFS))

https://www.reddit.com/r/cfs/comments/6sneul/a_plea_from_a_fallen_doctor_on_chronic_fatigue/



I was educated at Baylor and practiced medicine for 30 years. I had a thriving practice, a rich social life, and excellent physical and mental health. I loved what I did and loved my life. I ran marathons, spoke at conferences, and chaired non-profits.

I am now completely bedridden from post viral CFS.

I am writing this to beg my fellow colleagues to take this disease seriously, understand that it is 100% organic in origin, and that it can happen to anyone.

I used to see CFS patients fairly often in my practice. Some of them were quite debilitated and some semi-functional. I always tried to be sympathetic and did what I could to help, but truth be told there was always a voice in my head questioning if their symptoms were psychosomatic. At times I delayed a diagnosis because the literature told me to wait 6 months. I recommended exercise, antidepressants, and psychotherapy because that had always been the conventional wisdom. And when patients didn't come back, I subconsciously assumed they had gotten better, and that I was justified in my approach. I feel tremendous guilt about this now.

When I got the flu that started this, I thought I would be out of work for 10 days. 10 days turned into 10 weeks, and then 10 months. The virus was gone, my labs were clean, and yet I still felt horribly ill.

My symptoms:

- I could barely stand up in the shower due to orthostatic intolerance. Later my wife would have to install a shower chair
- I could not read or write due to cognitive dysfunction
- I could not walk more than 45 steps without extreme lactic build up in my muscles
- Any minor exertion would produce an intensifying of symptoms for several days
- Add on insomnia, sensitivity to noise and light, and uncharacteristic emotional liability and you understand the hell my life became

Every type of conventional medical test came back negative or could not explain symptoms. My own family thought I was crazy (not to mention my friends, cohort, and colleagues).

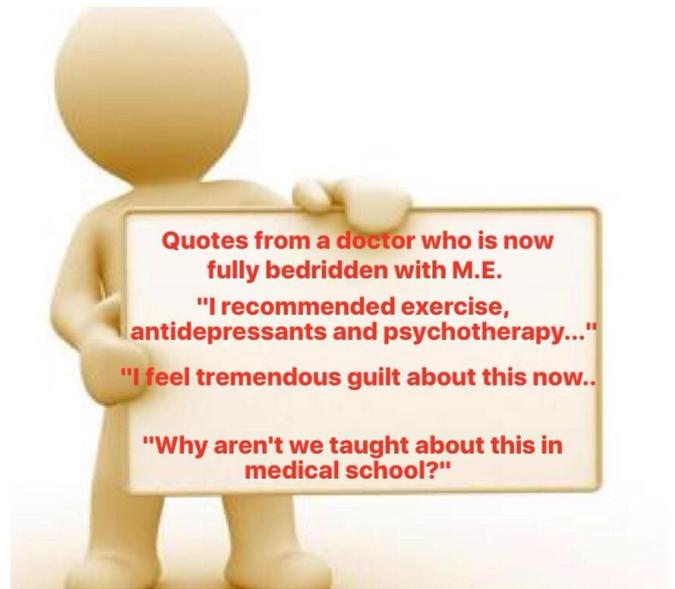
Of course I tried the standard things I told my patients to do. Antidepressants were hit or miss as they so often are and did not touch the core symptoms. Psychotherapy was helpful for coping. Exercise of any kind was a complete unmitigated disaster that severely and permanently worsened my state.

Finally I did find lab abnormalities. Cytokines. Krebs cycle metabolites. Near zero ADH. As I lay bed-bound I slowly regained the ability to process complex data, and I poured through the research and discovered that yes this is a very real illness with organic abnormalities documented as early as 1932. Why aren't we taught this in medical school?

I tried antivirals, antibiotics, hormone replacement, and yes I'll admit, even some more questionable alternative medicine protocols. Nothing worked.

Finally I went into remission using a combination of monoclonal antibodies (Rituxan, Cosyntex, Enbrel). Remission was glorious. I took my wife to Costa Rica, played with my grandchildren, and learned how to sail. And then I relapsed for no good reason and hell returned. As of yet I have been unable to reproduce the first remission.

I beg other doctors to take this to heart. CFS is a real disease, as bad as end stage AIDS or cancer. It is also treatable, but only through trial and error, and even then nothing is guaranteed.



Researchers Find Evidence Chronic Fatigue Syndrome Is an Inflammatory Disease

By Erin Migdol

(Courtesy of The Mighty <https://themighty.com/2017/08/stanford-chronic-fatigue-syndrome-real/>)7

A new study has found a link between [chronic fatigue syndrome/myalgic encephalomyelitis](#) (ME/CFS) and 17 markers of inflammation found in the blood — indicating that not only does the often-doubted condition have a real, biological basis, it may be diagnosable with a blood test.

What the Research Says

Using [blood samples](#) from 192 patients with ME/CFS and 392 people without the condition, researchers from the Stanford School of Medicine found significant differences in cytokine levels — immune-system signalling proteins found in your blood — between those with and without the condition.

After analysing 51 cytokines, the study, which was published in the “Proceedings of the National Academy of Sciences,” discovered that the levels of two different cytokines were markedly different in those with ME/CFS. Among those with the condition, levels of 17 cytokines varied based on the severity of their symptoms.

Of those 17 cytokines, 13 were found to be “pro-inflammatory,” suggesting that inflam-

mation drives ME/CFS. This connection to the immune system may explain many of the symptoms people with ME/CFS experience, which are often described as “flulike.”

Interestingly, some cytokine levels were lower in patients with mild ME/CFS than in the healthy control subjects, but higher in patients with severe ME/CFS. Lead author Dr. Jose Montoya, who oversees the Stanford ME/CFS Initiative, said he believes this may reflect varying genetic predispositions among patients, which could help explain why some people have a more severe form of ME/CFS. The study also shed light on a possible reason why more women have ME/CFS than men — as women tend to have more leptin, one of the cytokines associated with disease severity, in their blood.

What It Means For You

With measurable differences between the blood of those with and without ME/CFS, researchers say their findings could lead to a diagnostic blood test as well as pave the way for future treatments.

“There’s been a great deal of controversy and confusion surrounding ME/CFS — even whether it is an actual disease,” said Dr. Mark Davis, the director of Stanford’s Institute for Immunity, Transplantation and Infection and the study’s senior author. “Our findings show clearly that it’s an inflammatory disease and provide a solid basis for a diagnostic blood test.”

More research is needed to establish any cause and effect between the inflammatory cytokines and ME/CFS, but Montoya told [Stat News](#) that the research gives an idea about the type of inflammation patients are experiencing, validating the disease.

“I have seen the horrors of this disease, multiplied by hundreds of patients,” he said. “It’s been observed and talked about for 35 years now, sometimes with the onus of being described as a psychological condition. But chronic fatigue syndrome is by no means a figment of the imagination. This is real.”



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sleep system

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FIBROFLARE

Information on the N:rem Mattress



- 3 different densities of deep reflex foam tablets in firm, medium and soft.
- Ideal for chronic pain sufferers to provide comfort for painful areas and support where needed
- 40mm Viscoool foam comfort layer with an open pored structure to regulate body temperature
- Each reflex foam tablet is easily interchanged in the comfort of your own home

- Personally tailored options on each side of the bed allows you and your partner to have individual set ups
- 2,000 springs for added comfort and bounce
- Natural cotton cover aiding a cool night's sleep
- Both the quilted cover, viscoool layer and foam tablets can be easily removed for cleaning



[Find out more information
on the N:rem Mattress](#)

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Easy Fundraiser

Do You Shop Online?

Did you know that whenever you buy anything online - from your weekly shop to your annual holiday - you could be raising a free donation for Fibro Flare Awareness Group?

There are nearly 3,000 retailers on board ready to make a donation, including Amazon, John Lewis, Aviva, Thetrainline and Sainsbury's – it doesn't cost you a penny extra!

It's really simple, all you have to do is:

1. Join
Head to <https://www.easyfundraising.org.uk/causes/fibroflareawarenessgroup/> and sign up for free.

2. Shop
Every time you shop online, go to easyfundraising first, pick the retailer you want and start shopping.

3. Raise
After you've checked out, that retailer will make a donation to your good cause for no extra cost whatsoever!

There are no catches or hidden charges and Fibro Flare Awareness Group will be really grateful for your donations.

Thank you for your support.



Think
shopping,
think **easyfundraising**





Fibro Community

The link below is to a world map of others who have fibromyalgia. Add your name and location, find others near you. Local support can go a long way to alleviating isolation. It gives more chance of a meet up, if only occasionally and a local fibro friend who will understand.

There are several local groups listed at the back of the magazine, but there is a need for many more to be set up. If you would like to form a local support group – and this could be just for a coffee and a chat then contact Beth Urmston, fibroflaremag1@outlook.com.

It's a great way to help yourself whilst helping others and can give extra meaning to your life. Why not make a New Year's resolution to at least give it a try.

<https://www.diseasemaps.org/en/fibromyalgia/join-the-map/>

Fibromyalgia Map | Join

Map Satellite

Enter your location:

Example: **Park Ave, 10028 NY**

Find

Step 1/3: Select your location

By Beth Urmston

Making a Complaint

If you think you have been treated unfairly, or been disrespected there are a few avenues open to making a complaint. The following is taken from the NHS website:

There is a simple two-stage process for complaints about NHS services.

Your NHS complaint: what to do first

Every NHS organisation has a [complaints procedure](#). If you want to complain about an NHS service – such as a hospital, GP or dentist – ask the service for a copy of their complaints procedure, which will explain what you need to do.

You may choose to make a complaint in writing, by email or by speaking to them. If you speak to them, they may be able to resolve your concerns without you having to go through the formal complaints process.

This is called a local resolution. It aims to resolve complaints quickly, and most cases are resolved at this stage. However, if you don't feel comfortable raising your concerns directly (or your problem wasn't resolved) and you would still like to make a formal complaint, follow the [NHS complaints process](#).

You may make a complaint to either the organisation that provided your healthcare or the organisation that commissioned that NHS service. The commissioning body will be either the local [clinical commissioning group \(CCG\)](#) for hospital care, or NHS England for GP, dental, pharmacy and optical services.

Time limit for NHS complaints

You should make your complaint as soon as possible. The time limit for a complaint is normally:

- 12 months from the date the event happened, or
- 12 months from the date you first became aware of it

Patient Advice and Liaison Services (PALS)

You can get help and advice from Patient Advice and Liaison Services (PALS), whose officers are available in most hospitals. They offer confidential advice, support and information on health-related matters to patients, their families and their carers.

NHS Complaints Independent Advocacy Service

Individual local authorities have a legal duty to organise independent advocacy services to provide support for people who are making, or thinking of making, a complaint about their NHS care or treatment. Find details for [your local council](#) on the GOV.UK website

Contact your local [PALS](#), complaints manager or local authority for information about how this service is provided in your area.

Citizens Advice Bureau

You can also get advice and support from your local Citizens Advice Bureau if you want to complain about the NHS, social services or local authorities. See their website for information on [how to get advice from the Citizens Advice Bureau](#).

Other options for making a complaint

If you feel too uncomfortable to complain to the service provider directly, you can make a complaint to the commissioner of the services instead. NHS services are commissioned, planned and paid for by either NHS England or clinical commissioning groups (CCGs).

If you're unhappy with the response to your complaint after trying a local resolution, another option is to complain to the [Parliamentary and Health Service Ombudsman](#). The ombudsman carries out independent investigations into complaints about government departments, their agencies and the NHS. You can call the ombudsman's complaints helpline on 0345 015 4033 or see their website for more information about [contacting the ombudsman](#).

You can also raise your concerns by contacting regulatory bodies, such as the [Care Quality Commission](#).

For more information, see [about NHS complaints](#).

<http://www.nhs.uk/chq/pages/1084.aspx?categoryid=68>



disabledviewuk@yahoo.com

@disabledviewuk

DisabledViewUk was set up out of a group discussion between Caregiver's and Disabled People who were and still are concerned about the many systemic failings in our Society to date.

There are far too many Issues that are affecting the wellbeing of Disabled People and Caregivers, with a proper consultation in place, a lot of safeguards could be reached and established to prevent the many of the Issues being experienced currently.

3 major key factors have come to light and this was the grounds for the foundation of DisabledViewUk.

- Independent Disability Commission
- Positive Pathway Programme
- National Support group for Disabled People, Caregivers and Advocates

DisabledViewUk provides: Crisis support, member enquiry support, welfare advice support, we also contact Government departments, Agency and Charities when required. We have supported members in highlighting their cases, raising them when required too parliamentary level. To date we have had 100% positive outcome on every case we have supported.

We have consulted on Government consultation at local and national level.

As National Group DisabledViewUk is growing in membership every day.

We are speaking out against the reforms as they stand, due to the systemic, on-going and fundamental failings. We are requesting a reconsideration of policies involved.

Our main objective for 2016 is the foundation of The Independent Disability Commission, we are preparing draft document and calling for a National a consultation and discussion. We are non-political group looking to encompass the views of Disabled People, Caregivers, Charities, National Government, Local Government Bodies, all Political Parties, Employment Sectors, Health Sector, NHS, wellbeing and Social Care Agencies within the UK.

To provide a Positive National Platform in Addressing, Establishing and Supporting the Rights of Disabled People and Caregivers.

Warm Home Discount Scheme

Extra help with gas and electricity bills during the winter months for pensioners and other vulnerable people from the Warm Home Discount Scheme.

<https://www.citizensadvice.org.uk/consumer/energy-supply/help-if-you-re-older-disabled-or-on-a-low-income/warm-home-discount-scheme/>

It has been confirmed the Warm Home Discount has been extended until 2021, with a yearly review. Applications for the core group should begin in July, the broader group in October.

Also, the discount is applied to your electricity account, not gas. If you have a pre-payment meter, you will be sent a voucher to use to top up. Occasionally, the shop will put £70 on each but they aren't supposed to.

Core Group = Pensioners. They are automatically getting paid each year, they check the data with DWP. Only when they have been paid, do applications open for the broader.

Broader Group = low income, DLA, PIP, children). Broader group funding is limited so it's first come, first served - and each energy supplier will have their own criteria.

Each energy supplier has its own criteria for the broader group. Anyone needing clarification should contact their own energy (electricity) supplier.

Help for people on a low income - the Social Fund and other welfare schemes

Information on community care grants, budgeting loans and crisis loans, and maternity grants, funeral payments and cold weather payments.

<https://www.citizensadvice.org.uk/benefits/help-if-on-a-low-income/help-for-people-on-a-low-income-the-social-fund-and-other-welfare-schemes/>

Groups

Groups we are affiliated to who help and support us:

Dubbo Fibromyalgia Support Group -
<https://www.facebook.com/DubboFibromyalgiaSupportGroup/?fref=ts>

Fibro Family – You’re Not Alone –
<https://www.facebook.com/groups/1645989475667771/>

Fibro Social Club UK –
<https://www.facebook.com/groups/760266097417614/?fref=ts>

Fibro Support UK –
<https://www.facebook.com/groups/818013851580139/>

Fibromyalgia Awareness and Advocacy, Ireland -<https://www.facebook.com/groups/fmawarenessadvocacy/>

Fibromyalgia Meet Up and Support, Leicester
<https://www.facebook.com/Fibromyalgia-Meet-Ups-and-Support-Leicestershire-907503995937440/?fref=ts>

Folly Pogs Fibromyalgia Research
<http://www.fibromyaliasoutheast.org.uk/index.html>
<https://www.facebook.com/FollyPogsFibroResearchUk/?fref=ts>

Hope 4 ME and Fibro, N. Ireland –
<https://www.facebook.com/groups/newryandmourne.me.fms/>

Juvenile Fibromyalgia Group –
<https://www.facebook.com/groups/JuvenileFibromyalgiaUKSupport/>

Sophie’s ME Awareness Campaign –
<https://www.facebook.com/groups/851991271478504/>

FIBRO FLARE MEET UP GROUP
Don’t forget to check out our new group – putting you in touch with others in your area. <https://www.facebook.com/fibromeetup>

Blogs

Donna Gregory Burch - <http://fedupwithfatigue.com>

Sally K Burch - <http://sallyjustme.blogspot.co.uk>

Important Notice

By Beth Urmston

We have a bank account where you can transfer funds using online banking. This means you do not have to use PayPal and will net us more of your donations as we will not have to pay their fees.

Donate or pay for goods direct to the bank – when you pay £5 we will receive £5.

Donate or pay for goods via PayPal – when you pay £5 we receive an average of £4.63.

Our accounts are handled by Kate Lis who is a volunteer.

For bank account details please contact Beth Urmston

When making payments please add your initial and surname (e.g. B Urmston) in the reference.

NB: This only applies to UK donations and payments. Overseas members should continue to use PayPal as bank charges for transfers from overseas cost approximately £25 per transaction.

To ensure we remain safe and legal we will in future request that all PayPal payments for Goods/Services are dealt with as such.

We will have to forego approximately 5% of contributions but we hope to still be able to make the most of every penny we do receive.

If you would like more information or help when making payments please contact Beth and she will be happy to guide you through the process.

Our PayPal account is fibroflaremag1@outlook.com

Remember to use Goods/Services when making payments.

The PayPal logo is displayed in a large, blue, italicized font with a trademark symbol.



To all our regular contributors, our wonderful readers and everyone who has done anything to raise awareness in whatever way they were able this month and especially to those who donated.

Disclaimer

The information provided within the magazine is for information and should not be used as an alternative to seeking the advice of a medical professional.

In case of emergency call:

UK: 999. For out of hours advice, ring 111.

USA: 911.

EUROPE: 112. This emergency number applies to all European countries.

Links to other sites are provided for information only and do not constitute endorsements of those sites or any of the content or opinions provided therein.

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Readers should always consult with their medical practitioner regarding their own specific health issues.

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