

The

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Fibromyalgia Magazine

Support for the FM FaMily

*A Merry Christmas
to all our readers*



*Hoping you keep your Fibromyalgia Gremelin
well tied up until the New Year*



Temperature Sensitivity In Fibromyalgia

by Sue Vickers

Temperature sensitivity affects many women with fibromyalgia, myself included. You can be cold all the time or hot all the time or alternate between being hot or cold. For over twenty-five years I had hot flashes and night sweats. I can't tell you how many times I was totally embarrassed because I could not stop sweating. My hair and clothes would be drenched regardless of the outside temperature. Now I am freezing all the time.

Research shows that people with fibromyalgia have an inability to adapt to changes in temperature along with a lower pain threshold to both hot and cold stimuli. Julie at Counting My Spoons wrote about a study that examined the temperature thresholds for heat and cold in women with fibromyalgia compared to healthy women.

What Causes Temperature Sensitivity

Body temperature is regulated by the hypothalamus. The hypothalamus is a section of the brain responsible for hormone production. It is considered the link between the nervous system and the endocrine system.

The hypothalamus not only controls body temperature. It controls energy levels, the sleep cycle, muscular function, circulation, the gut and defense against infection.

Most fibromyalgia symptoms seem to be due to imbalances in the hypothalamus-pituitary-adrenal axis (HPA axis). These three glands work together to control hormone levels. Disruptions in the HPA axis seem to be at the core of fibromyalgia.

Thyroid hormones also play a role in regulating body temperature. An overactive thyroid (hyperthyroidism) can cause a person to feel too hot, while an underactive thyroid (hypothyroidism) can cause a person to feel too cold.

The thyroid gland is under the control of the pituitary gland. The pituitary gland itself is regulated by the hypothalamus. Anything that disrupts the HPA axis will also suppress thyroid function.

Certain medications interfere with the regulation of body temperature. Some drugs make you sensitive to heat, increasing the risk of heat stroke and some can lower body temperature.

Heat Sensitivity

Some heat sensitive people feel all-over heat sensations that seem to come from within their own body. Along with hot flashes, some people have problems with excessive sweating. Others may only have problems in their hands and feet, including puffiness and aching. Warm or hot weather can be unbearable with heat sensitivity.



To avoid getting overheated:

- Keep your environment cool.
- Wear soft, lightweight clothing that fits loosely. Stick to light colors in warm weather because dark colors absorb heat.
- Stay hydrated. Make sure you always have a cold drink (water is best) to sip on.
- Take a cool bath or shower. Sometimes just soaking your feet in cool water can help cool your body down.
- Use cooling products such as a cold pack or fan. Carry a small, hand-held, battery operated fan with you when you go out.

When the weather gets warm, heat sensitive people with fibromyalgia often experience symptom flare-ups. Research has found that people with fibromyalgia exposed to hot temperatures report increases in: pain, headaches, fatigue, anxiety and depression. They are also more likely to have heat rashes and heat exhaustion or heat stroke.

Heat stroke is a medical emergency. Signs of heat stroke and immediate action to cool the overheated person while waiting for emergency treatment can be found on the Mayo Clinic website.

Cold Sensitivity

People who are cold sensitive often feel chilled to the bone and have a hard time warming up. The cold can be all over or just in your hands and feet. This symptom is usually worse during cold weather, but can occur at any time.



To prevent problems with cold:

- Keep your environment warm.
- Dress warmly, especially in cold weather. Keep your feet covered, wear socks and slippers.
- Drink hot liquids and eat hot meals like soup and oatmeal.
- Take warm baths or showers.
- Keep a blanket handy or use a heating pad or similar microwave products.

An unusual sensitivity to cold in the hands and feet with color changes in the skin sometimes occur in people with fibromyalgia. This condition is called Raynaud's syndrome, also known as Raynaud's phenomenon.

Sensitive To Both, Heat and Cold

Some people fluctuate between being hot and being cold. One minute you can be sweating with hot flashes and freezing the next. This can be very challenging. You have to be prepared for either scenario.

- Dress in layers or have extra layers available.
- For night sweats, wear moisture wicking sleepwear or use temperature regulating sheets.

Fluctuations in temperature can make your fibromyalgia feel worse. It's important to plan ahead. You may have to spend most of your time indoors where you can better control the conditions.

Conclusion

Temperature sensitivity is a common fibromyalgia symptom. Most women with fibromyalgia report being extremely sensitive to cold and/or heat. Essentially, temperature sensitivity may be due to hormonal

imbalances in the hypothalamus-pituitary-adrenal axis. Medications can also interfere with the regulation of body temperature.

For many years, I was hot all the time. The warm and hot weather was unbearable so I preferred cold weather. Now it seems as if the switch has been flipped and I am always cold. The hot flashes stopped when I stopped taking antidepressants and Lyrica. So either it was the medications or I made it through menopause. Now, if I could just get warm.

Sue Vickers is the author and creator of the Fibrodaze blog.

<https://www.fibrodaze.com>

She is on a mission to help others with fibromyalgia learn ways to manage their symptoms and improve their quality of life.

You can also find Sue on Twitter @fibrodaze

Facebook <https://www.facebook.com/fibrodaze>

Are you interested in contributing to research into fibromyalgia?

Zoe Gotts and Morag Ritchie, Clinical Psychology Doctorate students at Newcastle University would welcome your participation. There is some understanding in psychology of the factors that can influence peoples' experience of pain in fibromyalgia, but we think our understanding could be much better. This study is for anyone over the age of 18, and if you have a partner, they can also participate. We are looking at how relationship styles affect the pain associated with fibromyalgia, the emotional impact of fibromyalgia, and some of the earlier life experiences that may be more common in those with fibromyalgia. This is an online questionnaire based study that should take no more than 30 minutes to complete. There is the option to enter a prize draw to win a £25 Amazon voucher on completion.

For more information and to take part, please click on the link: http://nclpsych.eu.qualtrics.com/jfe/form/SV_08GMGkeTb4C8PkN



Migraines: A Light Bulb Moment

By Madeleine Sara

While not every Fibromyalgia sufferer will experience tension headaches and migraines; approximately 59% regularly endure them. If you're a sufferer, you'll recognise that the symptoms include: tinnitus, nausea/vomiting, photo-sensitivity, tightness / static buzzing sensations across the forehead, neck pain. Some also include blind-spot and zig-zag visual auras. Their causes may include stress/ anxiety, fatigue, noise, sinus infections, food sensitivities/ bowel issues, strong aromatic scent, nicotine, LED screens, high contrast patterns, flickering light and piercing white spectrum light. Severity and type will also, partly, depend on how prolonged the exposure to these triggers continues.

I've been a migraine sufferer for a number of years now. 'Gloom and glare' are two of my enemies. Keeping food and daily activity diaries, to monitor my triggers, has enabled me to reduce their occurrence quite considerably. However the result has been quite significant on my life-style.



It was only when we engaged an electrician, to do some work in the house, that I finally discovered what type of light bulb is more migraine-friendly. He advised me that piercing white LED lights are worst, plus the flickering fluorescent tubes, but I had no idea that energy saver light-bulbs, are also a no-no!

Of course, it is always best to use natural light, which will also help boost your mood, but this may not always be possible. It is, therefore, best to use LED warm white (yellow) bulbs that are kinder to your eyes. Although these type of bulbs do still emit a small amount of UV rays, the amount is much lower than traditional bulbs. Don't be put off by the upfront cost of LED lights, as they will last a good length of time and ultimately reduce

your energy bills more effectively than equivalent energy saver bulbs.

So to be clear:

- ✓ LED WARM WHITE (yellow) bulbs are more relaxing for the eyes.
- ✗ LED Cool White, that gives a bluish hue, are not recommended for migraine sufferers.
- ✗ CFL (Compact Fluorescent Light) Energy saver bulbs produce the same flickering as fluorescent tubes, resulting in more headaches and migraines and should also be avoided.

As soon as we changed our bulbs, in just a couple of the rooms, to the yellow/warm-white ones, the relief it provided was quite remarkable. Of course, I still have to be aware of my other migraine triggers, but this small change is, nonetheless, a very welcome one.

Madeleine Sara is a freelance writer with a degree in Psychology and a postgraduate RCSLT qualification. As a retired, Paediatric Therapist, she likes to apply her experience and knowledge to every challenge she encounters.

RECOMMENDED READING/ REFERENCES:

Living with Fibromyalgia by Christine Craggs-Hinton (2000) Sheldon Press.

<https://www.which.co.uk/reviews/light-bulbs/article/five-tips-for-choosing-the-right-light-bulb> - Which?

<https://www.thejoint.com/texas/houston/meyerland-28030/choosing-the-right-light-bulbs-for-optimal-eye-hea>

Fibromyalgia Worsens Depression and Migraine Symptoms, Study Shows

Patients with fibromyalgia are more likely to develop worse symptoms of depression, migraine intensity and migraine-related disability.

The study with that finding, "Fibromyalgia in migraine: a retrospective cohort study," was published in *The Journal of Headache and Pain*.

Migraine is a common debilitating disorder in patients with fibromyalgia, affecting about 18 to 35 percent of patients. When both fibromyalgia and migraine are present, it can intensify patients' disability and affect their quality of life.

(MIDAS), and depression using the patient healthcare questionnaire-9(PHQ-9).

Patients with both fibromyalgia and migraine had higher PHQ-9 scores, meaning more days with depressive symptoms, and were more likely to score in a higher severity category of those same symptoms than the patients without fibromyalgia.

This group also demonstrated higher chances of developing more intense migraines than their counterparts.



Researchers already had found that patients with high frequency of chronic migraine had worse fibromyalgia symptoms and were more likely to have this condition than those with tension headaches.

Building on these findings, a team from the Mayo Clinic Rochester in Minnesota investigated if patients with both fibromyalgia and migraines experience more depressive symptoms, headache-related disability, or higher headache intensity, than patients with migraine only.

A total of 157 individuals with both comorbidities and 471 controls with just migraine were enrolled in the study, between 2012 and 2017.

Using data prospectively collected from a headache database, both groups were analysed in terms of participants' body mass index, average duration of migraine, number of headache days per month before the initial visit, age of first headache, and number of individuals with 15 or more headache days in the past month.

Researchers saw no differences regarding these characteristics among patients of either group.

The team also analysed patients in terms of migraine disability using the migraine disability assessment scale

Regarding the MIDAS questionnaire, which inquired about days a participant missed or had reduced productivity in its daily tasks, total scores among the two groups had no differences.

However, a more detailed analysis on disability severity showed that more patients with both comorbidities scored a higher grade of migraine-related disability.

The findings of this study help researchers understand the close relationship between fibromyalgia and migraine.

"The presence of fibromyalgia has been correlated with lower quality of life in patients with migraine, making it important to know when to screen for symptoms of fibromyalgia in the migraine population," the team said.

"Our findings suggest that it is important to inquire about comorbid fibromyalgia as this needs to be taken into consideration with regards to creating an optimal individualized treatment plan."

Based on this study, the team recommends screening for symptoms of fibromyalgia in migraine patients when they report a number of depressive symptoms, severe headache intensity or severe headache-related disability.

<https://fibromyalgianewstoday.com>



Ask The Doctor at The Fibro Clinic

Question. I suffer with fibromyalgia. Should I get pregnant?

Answer.

Research into pregnancy and sufferers of fibromyalgia is limited. Although the amount of studies into fibromyalgia are generally increasing, pregnancy is an area where much more research and investigation is required.

Although specialists and consultants are able to advise you, they are not in a position to say whether you should or should not get pregnant. As doctors we are able to highlight the risks involved and difficulties that you may face, but this is a decision that is ultimately yours.

A study by Wiger (1997) used a sample of 44 women with fibromyalgia. The group was split into two: one group that was already suffering with fibromyalgia before pregnancy and another that had children before the onset of their symptoms. Of the group that already had the symptoms, only one person claimed the symptoms didn't get worse during pregnancy. The study did, however, highlight that despite having fibromyalgia, the women gave birth to healthy, full term babies.

If you decide to get pregnant there are steps that you can take in order to encourage the most comfortable pregnancy possible:



Consult a specialist

Before you get pregnant, where possible, talk through your plans with a specialist who can advise you on all aspects of planning your pregnancy with fibromyalgia. Here at The Fibro Clinic, we combine the latest research and developments to provide you with the right combination of treatments to suit you.

Take care of yourself

Before bringing another person into the world it's important that you're taking care of yourself. That means

taking it easy and listening to your body – when it needs to rest, do so. Growing a little one inside you can take its toll on your body. By ensuring you're doing everything possible to ensure you are healthy, you'll increase your chances of enjoying a comfortable pregnancy. This means ensuring you get plenty of sleep, reducing alcohol intake, stopping smoking and adopting a healthy lifestyle that includes regular exercise and a healthy diet.

Prepare

There are techniques and treatments you can put into practise to help prepare yourself, both mentally and physically, for fibromyalgia symptoms to worsen. These include various types of Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET), medical treatments and trigger point injections. But preparation should go beyond the actual pregnancy. The first few months after birth can take it out of you. To make it easier to recover from birth, consider hiring help for once your baby is born and negotiating with your workplace for extended maternity leave to give your body the best chance at recovering.

Be prepared to be flexible

Breastfeeding can be a sensitive subject, but mothers who want to breastfeed may need to be open to alternative options as some of the pain medication for fibromyalgia can have an effect on the baby.

Educate yourself

Read about others' experiences to prepare yourself. There are some networks for fibromyalgia sufferers that may be able to provide you with support in a social capacity. Make your friends and family aware of your situation and how you might need their help during your pregnancy so they are able to support you when needed.

At The Fibro Clinic our considerable experience in the field means that we are able to offer safe, effective treatment that combines both medical and holistic approaches.

The Fibro Clinic is London's leading Fibromyalgia clinic. Based in Harley Street, our Consultants have a wealth of expertise in the diagnosis and treatment of Fibromyalgia and can offer a comprehensive and multidisciplinary approach to this condition. Dr Jenner and Dr Singh look forward to welcoming you to our clinic soon.

020 7118 0250

info@londonpainclinic.com

The Activity Trap: Disabled people's fear of being active

Disabled people count for one in five of Britain's population, almost 14 million people, but they are currently the least active group in society.

The benefits system and other forms of government and NHS financial assistance are designed to enable disabled people to be active in all aspects of their lives. However, evidence suggests that disabled people fear losing such support as a result of being seen to be active.

This study focused primarily on participants with physical impairments and sought to determine the prevalence and extent of this fear, with a particular emphasis on the processes of Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Employment and Support Allowance (ESA).

Disabled people deserve the same right to be active as everybody else, no matter whether they want to make use of their local gym or become an elite athlete. But the reality is that disabled people are still twice as likely to be inactive as non-disabled people.

The Activity Trap opens the debate into how disability discrimination impacts physical activity.



It is rigorous, well evidenced and has an important role to play in changing the reality of disability, inclusion and sport. It is the first time that the sport and activity sector has delved knowingly into the wider systemic barriers that affect disabled people's ability to be active.

Being active and reaping the benefits from activity does not happen in isolation. We cannot continue to assume that becoming active is a simple process of moving from inactive to active. There are many stages and considerations in between that we may not even associate with taking part in sport and active recreation.

To many disabled people, finding appropriate transport, getting personal support or even having the confidence to leave the house can affect our motivations to be

more active. We need to understand the challenges and barriers that disabled people face on a daily basis, including how we are represented in the media. It is not simply because we do not want to take part or cannot be bothered.

The numbers within the report, although shocking, give us a starting point for change. Undeniably, they show that unless we provide robust, effective support to disabled people in all aspects of their lives, we are not going to see a meaningful increase in the number of people being active.

It will take work with and across government to make active lives possible and we hope this report helps to widen the discussion beyond sport and health. Whilst some actions are long-term and will not happen overnight, there are things we can fix within the system at local and national level.

These changes will make society better for everyone, including disabled people.

Key findings from the study include:

Being active is important to disabled people.

Disability benefits are critical in enabling disabled people to be active.

A fear of losing benefits is preventing disabled people from being more active.

Fears of being active are driven by perceptions of government agencies as well as personal experience and knowledge of benefits not being awarded or being removed.

The research also highlighted the challenges that disabled people face through the benefits application system.

A clearer understanding may enable more disabled people to use their benefit payments to be active.

Four key recommendations and four significant discussion points emerged from the study to address some of the fears, ambiguity and difficulty involved in being physically active when receiving benefits and financial assistance, especially with regard to PIP.

Read the full report here:

<http://www.activityalliance.org.uk/how-we-help/research/4404-the-activity-trap-benefits-or-being-fit>



Supporting the Support

Fibromyalgia Question asked in Parliament



Wera Hobhouse Liberal Democrat Spokesperson (Housing, Communities and Local Government). Wera Benedicta Hobhouse is a British Liberal Democrat politician. She is the Member of Parliament for Bath

Question

To ask the Secretary of State for Health and Social Care, if his Department will review the clinical guidelines on the treatment of fibromyalgia syndrome to ensure clearer treatment pathways for people with that syndrome and what steps his Department will take to raise awareness of the condition of fibromyalgia syndrome?



Answer

Steve Brine the Parliamentary Under-Secretary for Health and Social Care

The Department is not directly responsible for developing or reviewing clinical guidance for identification and management of diseases and disorders. The National Institute for Health and Care Excellence was established by the Government to develop evidence based best practice for the National Health Service. Other organisations, such as the clinical Royal Colleges, and charitable organisations also convene expert groups to develop guidance for health professionals.

A range of support exists to help general practitioners (GPs) identify and manage fibromyalgia in primary care. This includes an e-learning course developed by the Royal College of GPs and Arthritis Research UK on musculoskeletal care, including fibromyalgia, and a medical guide developed by the Fibromyalgia Association UK (FMUK) for health professionals.

People with fibromyalgia can usually be managed through routine access to primary or second care provide via a GP or consultant. Treatment will depend on the severity of a patient's condition, but may include pain relieving medication; physiotherapy; dietary and exercise advice; counselling or cognitive behavioural therapy. For patients whose pain cannot be adequately controlled by routine access to NHS services, a referral may be made to a specialist pain service or specialist fibromyalgia clinic, such the Royal National Hospital for Rheumatic Diseases in Bath, subject to their having met certain criteria.

Information for the public can be found on the NHS website and is also available in a patient's information guide produced by FMUK. The medical guide, patient information booklet and NHS choice webpage on fibromyalgia can be found at the following links:

www.fmauk.org/dmdocuments/Medical%20Pack.pdf

www.fmauk.org/information-packs-mainmenu-58/booklet-mainmenu-135/490-patient-booklet

www.nhs.uk/conditions/fibromyalgia/



Mrs Jackie Lewis has a question for our readers

Hi, I have just been told I have Fibromyalgia, I am in a lot of pain most of the time and I have heard that a hot tub can help symptoms,, so we recently went and stayed somewhere that had a hot tub ,before I was diagnosed, and found it did help in the long term as it will get worse, do you think they would help?

Thank you in advance

jacquibob2@hotmail.co.uk

Hello

Having had very painful eyes for over 30 years continuously (diagnosed with fibro at last, in 2001), I was really excited on reading the article by Karen Crosby "Vision Changes with Fibro",

I took my fibro mag with me to my optician and was over the moon to be sold Hyco San Extra Drop at £11. The relief is amazing, so I wouldn't have thought it possible!

At least I only feel so tired, instead of looking it. Please try it. Much appreciation to Karen Crosby.

Christine Mallinson, Cleveland

NEW FM SUPPORT GROUPS

Seahaven Fibromyalgia / M.E. & C.F.S Support Group

Phone number: 07747305666

Email: valerie-harvey@sky.com

We meet on the 2nd & 4th Tuesday monthly 12pm-2pm in the Anzac Room at the Meridian Centre Peacehaven and also every Wednesday between 12pm-4pm at the Rendezvous on the South Coast Road behind The House Project Peacehaven. Please contact Cherie on 07850 252082 or Val on 07747 305666 for more details

Darlington for FM Group

Catherine Duguid - 07827681728

First Wednesday of each month at the Dolphin Centre, Darlington - 12-2.00

Hastings Fibromyalgia Warriors

07886 225110

taniacharman@live.co.uk

We meet every Saturday 10.30-12.30 at His Place Cafe in Robertson street, Hastings.

We are a group of people offering each other moral support and looking for ways to make friends and have fun.

Our principle is that everyone is affected differently, and we will operate in a non-judgemental way. We want to share solutions and to care when things don't work out. We aim to motivate each other and look for ways to help ourselves. This group is a collective affair, where everyone helps to make things happen. We welcome all ideas, however individually we all have to make things happen.

If your group is not listed at:

http://ukfibromyalgia.com/pages/support/support_map.php

please submit your details to be included.

Fibromyalgia and body weight

by Dr D. Mantle FRSC FRCPath Medical Adviser, Pharma Nord (UK) Ltd

Being overweight or obese may affect the severity of symptoms in fibromyalgia patients, or increase the risk of developing fibromyalgia (Mork et al, 2010).

Obesity is defined by having a body mass index (BMI) of more than 30 kg/m², and being overweight as having a BMI of more than 25 kg/m².

What effect does being overweight have on fibromyalgia?

Two recent clinical studies (Kocyigit & Okyay, 2018; Cakit et al, 2018) found obese fibromyalgia patients had higher levels of pain, tender point count and depression, and reduced quality of life.

Clinical studies have reported that up to 70% of fibromyalgia patients may be overweight or obese.

There are a number of possible reasons for the link between fibromyalgia and obesity, including psychological factors, sleep problems and dysfunction of insulin metabolism, but in particular a reduction in physical activity due to fatigue and muscle pain.

In addition, fat cells can release chemical substances that promote inflammation, and obese fibromyalgia patients may have increased levels of inflammation and oxidative stress (Feinberg et al, 2017).

Furthermore, as the BMI increases, the levels of the growth hormone ILGF-1 (insulin-like growth hormone-1), which is thought to reduce fibromyalgia associated fatigue, are decreased.

Some types of medicines prescribed for fibromyalgia, particularly certain types of antidepressants, may also cause weight gain. Obesity is widely accepted as an obstacle to pain management (Okifuji & Hare, 2015).

Can losing weight help fibromyalgia sufferers?

Weight loss programmes in fibromyalgia patients reportedly improve clinical symptoms (Shapiro et al, 2005).

In addition, bariatric surgery has been shown to improve fibromyalgia symptoms (Hooper et al, 2007).

Can supplements help with weight control?

In addition to physical exercise and modification of the general diet, a number of dietary supplements may help to control body weight; these may act via different mechanisms including reducing hunger or increasing satiety, reducing fat absorption, increasing fat metabolism, and reducing glucose absorption.

Conjugated linoleic acid (CLA) is an example of a supplement that can increase fat metabolism and reduce the proportion of body fat.

A number of randomised controlled clinical trials have

provided evidence for the efficacy and safety of CLA (typically 3-4g/day for 1-3 months) in reducing body fat mass and waist circumference (Gaulhier et al, 2007; Raff et al, 2009). Delphinol is an example of a supplement that inhibits the absorption of glucose from the digestive tract. Delphinol is a standardised extract of berries from the maqui tree (*Aristotelia chilensis*), a Chilean medicinal plant.

Clinical studies have shown delphinol significantly slows glucose absorption and reduces blood glucose levels in patients with moderate glucose intolerance (Hidalgo et al, 2014).

Finally, chromium is a supplement that helps to maintain normal blood levels of glucose, once the latter has been absorbed from the digestive tract. Chromium is an important component of the complex chromodulin, which plays a key role within the body in insulin signalling, effectively amplifying the effect of insulin in removing glucose from the bloodstream.

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BRENDAN KEELEY

Ethan Lowry is a PhD research from Ulster uniaversity in Northern Ireland. He is investigating any possible links between dietary intake and chronic pain, with a specific interest in fibromyalgia. The first step of this research is an online survey which will focus on this very topic. The survey is quite long, with an average time of completion being 20 minutes. But it is providing incredibly valuable data to help with some very much needed research. There are a few rules to be eligible to complete this survey.

1. Individuals must have had an official diagnosis from a health professional.
2. Individuals must be 18 years or older
3. Individuals must live in the UK or Ireland.

At the end of the survey you can register for the next stage in our research which is a series of focus groups. However these are only for individuals who live on the Island of Ireland (North or South).

If you have any questions regarding the survey you can email Ethan at lowry-e3@ulster.ac.uk

You can take the survey by clicking on the following link:

<https://www.surveymonkey.co.uk/r/RHB39M9>

Why talking therapies don't help many with Fibromyalgia. Part One By Katie Knight

The link between fibromyalgia and trauma is becoming more and more evident[1][2], and the theory is becoming more generally known.

As such one would think that psychology would be an essential tool for healing.

Yet the psychology of today – the talking therapies and CBT don't always help and can do more harm.

Research has discovered that talking about trauma and diving back into the past means it is relived.

As the event is being described by the patient, it's as if the event is happening for them, *in the very moment*. This has been well described by Psychiatrist Bessel Van Der Kolk in his book, 'The Body Keeps the Score.'

In his book he describes a lady suffering from PTSD. She is hooked up to brain imagining equipment and describes the specific trauma she went through. As she does this, her brain lights up as if the trauma was happening *in the moment*.

Her brain could not tell the difference.

This implies that those of us with a history of trauma, not only do we re-live it, but we are more wired to live in the sympathetic nervous system, (the fight or flight response) because trauma is never far away. Every time we think about it, we re-live it, and as such must be on constant alert for it.

If the trauma is relived again and again, without a resolution, the trauma remains, and the constant re-living puts a stress on the entire body.

Plus, the trauma needs a place to reside. The body needs to store the memory somewhere, and this brings us to the theory of cell memory.

Our brain is not the only repository of memory.

Cell memory is a thing [3] [4]. It is where we store emotional memory -in the cells. We think of our memory as simply in the brain, but it's all over our body. We store the good and the bad in our flesh. For me the trauma has been stored in my legs, and this is where I suffer with fibromyalgia.

So why doesn't talking about trauma always work?

As already mentioned, talking about the trauma means we re-live it. We can rationalise it, we can see it for what it was at the time, and we can recognise that we need to change a negative feeling around it to something more positive yet doing this is treating the symptoms not the cause. We are changing emotions without healing them.

What is needed is a healing of the hidden and stored away emotions, not simply changing them when noticed.

One way of achieving this is by healing what Freud would call the Superego.

The Superego [5], in a healthy person is there as moral guidance, to help us differentiate between right and wrong.

In an unhealthy person, (one that has undergone much trauma) the Superego becomes a monster that is the constant voice in our heads that we are not good enough, are unworthy, nothing we do is right and so we must strive, strive in order to achieve love. Only nothing ever comes of that striving. We never feel enough.

Instead we live in an unconscious soup of negativity, triggering emotional responses to events that happened years ago, that is stored in our cells.

This stresses the body, and one result is chronic pain.

We can often remember the emotions, without necessarily remembering the actual trauma, and this is enough to keep us in fight or flight. A noise, a word, a smell can trigger an emotional flashback, and we will be standing there feeling angry/stressed with no idea why.

In this state of being, we have several things going on at once.

- emotional trauma stored in the cells,
- with a monster in our heads reminding us we are not good enough,
- that triggers emotional flashbacks to events our conscious mind has buried in our bodies
- Keeping us constantly in the fight or flight response
- Leaving our bodies burnt out, in lack and in pain.

So, what can we do?

We need to change the Superego into a nice guy, essentially into a loving guardian. Doing this change everything. We stop thinking we are useless, unworthy. We reduce the emotional flashbacks, we release the trapped memories, we massively reduce the fight and flight response and we reduce the physical pain.

1. <https://www.sciencedirect.com/science/article/pii/S030645300500185X>

2. <https://fibromyalgianewstoday.com/2017/09/11/fibromyalgia-patients-should-be-evaluated-for-ptsd-researchers-say/>

3. <https://www.sciencedaily.com/releases/2008/05/080509152307.htm>

4. <https://www.psychologytoday.com/us/blog/looking-back/201107/nostalgia-trumps-cellular-memories-every-time-0>

5. <https://www.verywellmind.com/the-id-ego-and-superego-2795951>

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Marie-Louise Olsson
Chairperson at

 Fibromyalgia Association Sweden



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Nordic Wellbeing Ltd

Christine's Recipe

Here are two more great Christmas recipes, to get you in the spirit of things. The traditional plum pudding can be made in advance and stored or frozen until required.

The festive salad is a tasty, low-calorie option that will be a welcome relief to many an abused digestive system over the celebrations. It will keep for several days if stored in an air-tight container and placed in the fridge.

Plum Pudding - Makes 2 x 1.5 lb. (675g) puddings

8 oz. (225g) figs, roughly chopped
8 oz. (225g) prunes, stoned and chopped
2 oz. (50g) mixed peel
6 oz. (150g) sultanas
2 oz. (50g) blanched almonds, chopped
1 dessert apple, peeled, cored and coarsely grated
3 pieces of stem ginger, chopped
3 oz. (75g) self-raising flour
6 oz. (150g) browned breadcrumbs
4 oz. (100g) shredded suet
6 oz. soft brown sugar
3 tablespoons of clear honey
half a teaspoon of mixed spice
1 teaspoon of grated nutmeg
3 eggs, beaten
pinch of salt
quarter of a pint (140ml.) of barley wine



Grease two 1.5 lb. (675g) pudding basins with lard. Place all the fruit and dry ingredients in a large bowl and mix well. Beat together the eggs, honey and wine then add to the fruit mixture and stir well. Share the mixture between the two pudding basins. Cover the basins with a double layer of greaseproof paper, then a piece of pleated foil and tie securely with string. Place in a steamer over a pan of boiling water or in a pan of boiling water that comes two thirds of the way up the sides of the basins. Steam the puddings for 4 hours, topping up with boiling water as necessary. If the pudding is to be stored, replace the wrappings with fresh greaseproof paper, foil and string as before. Seal, label and place in a freezer or cool, dry cupboard for up to 12 months. To re-heat, thaw the frozen pudding overnight, unwrap and steam for 20 minutes. Turn the pudding out onto a serving plate, dust with icing sugar and decorate with a sprig of holly.

Festive Salad

2 carrots, peeled and grated
2 stalks of celery, chopped
2 oz.(50g) sultanas
4 oz. (125g) walnuts, chopped
2 oranges, peeled and segmented
5 oz. (150g) red cabbage, washed and shredded
2 dessert apples, cored and chopped
4oz. (125g) Stilton cheese, chopped
quarter pint (150ml) low calorie salad dressing
salt and ground black pepper, to taste



Place all the ingredients in a large salad bowl and mix well. Season to taste and serve cold. To store, put the salad into an air-tight container and keep in the refrigerator for up to 3 days

Christine Craggs-Hinton is the author of 'Living with Fibromyalgia', 'The Fibromyalgia Healing Diet' and 'The Chronic Fatigue Healing Diet', from Sheldon Press. They are available from the www.FibromyalgiaShop.co.uk website and from all good book shops.

THE FIBROMYALGIA EXERCISE COLUMN



Keeping active at Christmas

by David Jenkins

OK, so it's winter, Christmas is approaching and for most of you, exercising is probably not at the top of your to-do list. This would be even more marked if you have visitors staying with you for prolonged periods, after all – the true meaning of Christmas for a lot of people is spending quality time with family and friends. So what to do? Well this month's column examines ways to make the best of the time you have, and to address the delicate balance between ongoing exercise rehabilitation and family time.

First things first, and most obviously, take advantage of fine days. Just because it is winter does not mean to say it will always be raining, windy or cold. If a clement day presents itself to you during winter, get a coat on, grab your house keys and go for a walk. It is quite conceivable that if you have visitors then they would also appreciate the opportunity for fresh air as well and will no doubt wish to join you. Head out in the evenings and check out what your neighbours have all done to decorate the vista of their houses is my tip!



Let's now look at days that aren't so good. Not many people would choose to go out in the wind and rain, myself included. What I do instead may seem daft, but it works – I march on the spot while watching TV or something. Half an hour of brisk marching can generate around 2000-3500 steps depending on your speed and it WILL raise your heart rate to an exercising level. It might not be as interesting as walking outside but it does the job and it will keep you dry!

Other things you can do involve home exercises for stamina and strengthening (see self-help exercise guide), using a treadmill or exercise bike if you have one, using an exercise DVD if you have one, or simply just keeping moderately active in other, more useful ways e.g. housework. You will probably find that exercising in the morning after breakfast is a great time, as generally family time begins in the evening, and can therefore start in the afternoon

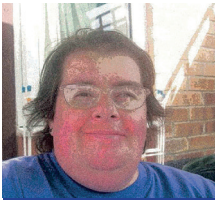
Finally, may I take this chance to wish you all a very peaceful Christmas and a successful, and of course healthy New Year!!!

Martin Westby (your magazine editor) and I have recently co-authored a Self-Help Exercise Guide that includes a whole section on how to do establish this consistency effectively. To order a copy please follow the following web link:

<http://ukfibromyalgia.com/pages/exercise.php>

Or alternatively you can email the magazine at office@UKFibromyalgia.com or myself on davidjenkin@hotmail.com and we can assist you in purchasing your copy. Maybe somebody could order you a copy for Christmas! To contact me directly, or enquire about 1:1 training prices please check out my website www.davidjenkinfitness.co.uk or email me directly on davidjenkin@hotmail.com

David Jenkin



A WEIGHTY ISSUE

By Helen Watts

So often we are told by our GP's that all we need to do is lose weight and our pain and symptoms will be less. I wondered whether there was actually any truth in this so asked the Facebook group this question.

'MM' "I started showing signs and symptoms of Fibromyalgia years ago, I was not overweight then. I began to put on weight as the symptoms of Fibromyalgia made me less active and the medication I've been subsequently prescribed for fibro. I find it very frustrating to have to put this point across to the patronising know all I've encountered in health care".

'DS' "I lost three stone and it hurt more. Weight pain on knees improved but actual Fibro pain increased ten fold".

'BB' "I have lost weight hoping to help my fibromyalgia but it seems to have had the opposite effect, I feel worse now than I have in a long time".

'NM' "I'm 15 stone. I was diagnosed as pre-diabetic a few months ago. My surgery has a weight clinic that is supposedly brilliant. So far I've found them to be condescending. They obviously don't believe my diet sheets, as they've put me on a diet eating a lot more carbs, after lecturing me on cutting down on them. I've stuck to the diet plan. No sugar, half my breakfast size, no fizzy drinks (sugar free or with sugar), and their bizarre portion sizes for dinner. I've been feeling down, depressed, fatigued, and my sleep is all messed up again. I didn't put two and two together until I broke the diet at the weekend - cookies and Pepsi max = caffeine and sugar. Suddenly I felt "better". As if the horridness had been sucked from me. I've returned to the diet though, and feel so bad I've taken the week off work. I'm not sure whether to tell the dietician of this discovery or not. I suspect I'll be told I imagined it. But my personal answer to your question is that whilst I feel heavy and gross, and have problems doing my shoelaces because my stomach is in the way - before I was put on this diet I was actually the happiest I've ever been in my life, and functioning better than I have done since I first became ill in 2002".

'SM' "This is very interesting, I wouldn't say I'm massively overweight for my height. I am holding a little more extra at the moment but I'm concerned about being on Gabapentin which puts weight on for some. For me I don't think weight is always a factor. I've had back issues on and off since my 20's and I'm now in my 40's. I went privately to see a consultant years ago and he was incredibly patronising, he straight away said up the exercise and lose weight. At that point I walked every day, had a young family, went to exercise classes, I was

doing more than enough to stay active and it made no difference".

'JM' "I was a size 10/12 when I was diagnosed with fibro and very active, over the 7/8 years of this robber taking over my life, I am a 12/14 and less active but the pains are still as bad as they were in the beginning, so for me, no weight does not affect me".

'GY' "I've lost 3 1/2 stone this year, and it hurts just as much".

'KH' "My whole life I was underweight. I'm 5'6 and was 7-8 stone when I developed fibro, diagnosed in 2010, now I'm 13 stone thanks to high dose steroids and my pain and symptoms are actually better than they were when smaller so I don't think weight has any input".

DLR' "Lady Gaga is not over weight and she still has her pain. Pain is pain whatever your size".

'LC' "No, I've lost 4 stone since april and the pain has got steadily worse, especially in my legs! You'd think that my legs would feel better, not carrying the extra weight".

'ED' "No in my opinion - I had fibro in my teens and I was skinny as anything back then".

'CM' "I went from a size 16 to a size 10, healthy bmi, it didn't help the pain, it did enable me to get a bit more exercise which I think can help a bit both physically and mentally".

'KH' "I lost 2 stone and felt better for a short while then it goes back on then back to feeling rubbish, so yes I would say it does help but not for long".

There are far more comments on the Facebook group than I have room for so we will be returning to the 'weighty' matter in the next edition of the magazine. Check out these and other discussions on the Facebook groups.

Helen Watts!

This month's contributions came from our closed Facebook Page - why not try it yourself?
<https://www.facebook.com/groups/UKFibromyalgiaPrivate/>

FM Survey- What would you say are the best tips for surviving the Christmas period?

As Christmas is fast approaching and following on from the article by Karen Lee Richards about Surviving the Christmas Holidays in November's magazine - as it fills as many of us with dread as much as it fill us with joy - we decided to ask our Facebook group " What would you say are the best tips for surviving the Christmas period?", this month we decided to let members add their own options to be voted on too. These are the results of our survey:

Only have a small Christmas with immediate family	137 votes
Shop online or in catalogues	98 votes
Don't try to make a perfect Christmas, make a Christmas that works for you.	83 votes
It is just one day, don't let it take over	46 votes
Prepare as much as you can in advance, make lists and plan ahead	39 votes
Work out what Christmas traditions are important to your family and only do those	24 votes
Start planning and stocking up early in the year (member added option)	23 votes
Use Gift bags rather than wrapping paper	22 votes
Remember it is just a roast dinner with extras	20 votes
Let go of the guilt	17 votes
Look after you, Make sure you have some time for you	15 votes
Don't worry about upsetting anyone if you need to take a break/rest take it. (member added option)	7 votes
Practice mindfulness to help with the stress	7 votes
If visiting relatives try to make sure you have a space to retreat to	5 votes
Ask guests (if you have them) to bring a dish	4 votes
Go away and spend it on a nice hot beach (member added option)	3 votes
Pretend it's not happening and treat it just like any other day. (member added option)	3 votes
Ask visiting family to bring what they need	3 votes
hibernate for 3 months (member added option)	2 votes
I go to yearly Christmas lunch that is arranged by local churches for people that would be on their own or are homeless (member added option)	1 votes

We also ask our members to share their opinions on the survey and these are some of their comments:

JD said "The pressure on us to have an amazing time based on what the media and big business want us to believe it's about. Whether you are religious or not the true spirit of Christmas has been lost along the way. It's about family and friends and not spend, spend, spend and eat, eat, eat. Just enjoy rather than work yourself up into a frenzy of shopping. Hugs xx "

MAH said "I don't make a big thing out of it anymore. I have some decorations and a small tree and the dinner is all ready to be put in the oven. I buy everything pre-chopped. Usually it's just me and a friend and we don't spend lots on gifts. For us it's about spending some time together.

I think if I had kids I'd get gifts online to avoid overcrowded shops and I'd make cookies and cake with them which they could decorate."

HD said "We are having buffet this year and eating out Boxing Day when it's cheaper. All our family are coming but will bring food. A big meal knocks us out anyway.x "

EL said "I have to say I'm lucky in that I love Christmas Eve/

Day even though it wipes me out. X "

PH said "I have 2 Christmas's every year. One in Wales with my husband's family, then one in England with my family.. 4 hours on the road with a car full of presents and 7 granddaughters to buy for.. thank goodness for the internet. The last few years we have eaten Christmas dinner in a restaurant with my lovely mother-in-law and wonderful step-son. No preparing, cooking or clearing up, and no food waste as we are not at home to eat it. "

MW said "We have a small family christmas just the 3 of us and the animals :) Decoration wise it is just a fibre optic 4 ft tree, with baubles, if i can muster the energy then theres window stickers, Hubby does christmas dinner he does lamb and duck and we have leftovers boxing day with Jacket potatoes. I try to get as much online gift wise as possible. Later this week i can book my delivery slot for the christmas food shop yay. "

Join us on our Facebook group to join in future surveys or just to receive support www.facebook.com/groups/UKFibromyalgiaPrivate



Hyperbaric Oxygen Therapy (HBOT) – My Results by Karen Crosby

Six weeks ago I embarked on a four week Hyperbaric Oxygen Therapy, and as promised in the October article, I am now sharing my results with you all!

I kept a chart diary every day for a week before treatment, during treatment, and for a week post-treatment.

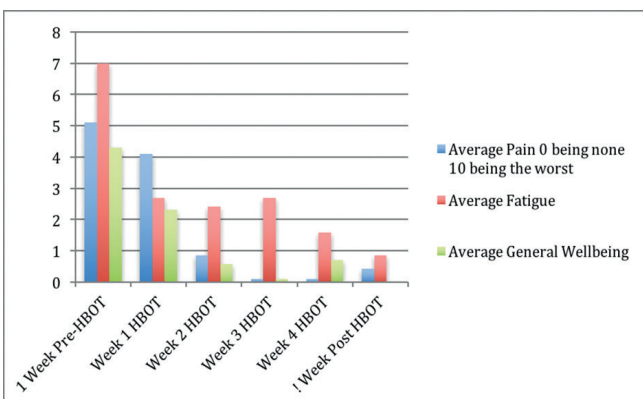
I thought it would be easier to put it in graph style (see below) so that I could measure my average pain over each week (0 being no pain and 10 being the worst pain). I did the same with fatigue and general wellbeing (emotions, mood, fear, levels of calm and so on).

During the second week of the HBOT I missed the first 2 days as I had my ears syringed and was told not to go the next day.

During the third week of HBOT I missed the last session because of a meeting, which meant in total out of 20 sessions I attended 17.

I need to report a few other areas needing mentioning but for the chart I stuck to the three main categories.

1. I had been suffering at least 4 days a week leading up to the therapy with IBS for about two months, that cleared up totally within a few days of starting the HBOT.
2. Within the first week of the therapy I began to notice improved sleep levels and now this is much improved (see average fatigue). Bear in mind also I can feel fatigue if I have a busy day, and in the week post-treatment I had my sister staying so I was out and about a lot and did a lot of walking so the fatigue was because of this. I sleep much better now, and I sleep in when I can which was unheard of for myself for years!
3. In general, I have noticed that my hips feel much more loose when I am walking, and I only noticed this because I didn't realise how stiff they were until the big improvement during therapy! This is great since I love walking!
4. I am quite an anxious person with fibro, and I have noticed I am calmer, more positive and less depressed than I was before HBOT. This can be seen on the chart in the general wellbeing, as it is now much lower and even unseen on the chart – great results.



Whilst in the Oxygen Chamber I met another lady who also is a Fibro sufferer called Mhairi (pronounced Vari), and Mhairi has kindly agreed to give me her feelings and results thus: -

Mhairi

The fatigue side of fibro stole three years of my life, my husband's life and the lives of my children. The oxygen chamber has literally put a full stop at the end of these statements. I am not sure if this is temporary or long-term, but only time will tell.

I can however say that my 20 sessions has changed my life.

The pressure is set to the same as being 8ft, 17ft, 24ft and 33ft under water, and the 17ft had no effect.

The 24ft gave me some energy, although I have had good energy times before.

The 33ft did not suit my body so I went back to 24ft, my new normality resumed and I feel great!

I still have pain, fibro fog and a number of other issues but Rome was not built in a day and my fatigue has lightened by 90% so I am happy to keep going back for top up sessions.

Back to Karen

I had the same sessions as Mhairi and I went back to 24ft as I found the 33ft was too tiring.

Top Tips

If you are thinking of trying some sessions: -

1. Have your ears checked out by your GP before your sessions, as it was painful for my ears but after syringing the pain was gone.
2. Take earplugs if you are sensitive when you fly on a plane as this helps.
3. Wear layered clothing as it is sometimes cold or warm in the tank and you can stay comfortable.
4. Go to the toilet before the session as you are in there over an hour (some sessions are 45 minutes some 60 minutes).
5. Take something to read or puzzles to keep the mind occupied (tablets, mobile phones and other devices work in the tanks).
6. The oxygen masks feel strange at first but you do get used to it after a few sessions.

Finally, I would like to say I have found it of so much help and I will see how the future unfolds, but for me it was well worth doing, and I will be going back for top-up sessions as soon as I can!

Far infrared saunas for health

Published studies in recent years have highlighted the benefits of taking regular saunas. A study from Loughborough University showed how exposing the body to heat for 60 min periods, burns calories and helps regulate blood sugar levels. Finnish studies highlighted benefits to the cardiovascular system and blood pressure. Australian studies showed benefits to the immune system and prevention of colds. Canadian research pinpointed sweating as an effective means of detoxing cells. American studies endorsed heat in pain management.

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The far infrared saunas are also popular with sufferers of fibromyalgia and ME, who benefit from the deep thermal energy which is similar to sunlight but without the UV rays. Lady Gaga recently posted how a FIR sauna was helping her to manage fibro symptoms.

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Apply for FM Support Group funding

The moneys that UK Fibromyalgia receive in donations is available to all UK Fibromyalgia support groups in the form of small grants.

Our aim is to provide a transparent system where as many support groups as possible can quickly source small items that are essential to the running of their local support groups, such as printers, books, train tickets, speakers' fees, PR materials, hall rental costs, photocopying, etc.

All grants paid out will be publicised in Fibromyalgia magazine.

There is no minimum amount but the maximum is £100.00. Funds are finite and the philosophy is to give a little, but often, so your bid is more likely to be successful if you apply for a small amount funding for indispensable items that will be key to the running of your group.

If your group has not received a grant yet then complete the form at:

<http://ukfibromyalgia.com/pages/support/grants.php>



How to set up and run Fibromyalgia Support Group - Fundraising and outreach season debrief

By Julie Barker - Chairperson

In this article, I am going to give feedback on our fundraising and outreach season, including our inaugural event the 'Fibro 5 Challenge', debrief and discuss starting plans for the next outdoor season.

It's important to debrief and feedback on all events, no matter how big or small. It gives you a record that you can refer to. You can analyse the key factors and decide whether it is worth pursuing again, or how you can do things better next time. It gives you a benchmark for the following year.

For example, last year was our first year out and about fundraising. We had a stall in the market place on Awareness Day, we borrowed a gazebo, tables and chairs and set up a tombola, but it rained all day. We raised around £87 and we were happy with that. However, this year we had our own branded gazebo, our own tables and chairs, it was brilliant sunshine and we raised £160.

We can compare the two years and know we have done better, and we have a new benchmark of £160.



Analyse and compare

We were able to look back at last year's events and identify what worked and what didn't go so well and why. Then we could choose which events we would return to. As Fibromites, our time and energy is precious and I don't want volunteers becoming despondent over a poor day. Identifying the reasons why we are attending these events will help our volunteers understand the aims and expectations.

Use awareness events to launch

Spring into Action was an awareness event during 'Falls Prevention Week', we organised the event in partnership

with Age UK - Strictly no Falling. We also used it as a launch for the 'Tai Chi for Arthritis with Falls Prevention' course and for our new website. We hosted the event with coffee and cake to help boost funds.



Community events to raise funds and awareness

The Awareness day stand, and carnival stall were jointly, outreach, Fibro 5 Challenge, awareness and fundraising. At the carnival last year it was glorious with a huge turnout but we weren't given a very good spot. This year the weather was overcast with showers and there weren't as many people there. We were in a better spot, but we took £20 less than last year. After speaking to other stallholders they were disappointed too, so that helped to put things into perspective.

Identify which events work

We learned from attending school fairs that the parents and children are loyal to the school stalls who are fundraising for their school, so after last year, I decided not to attend school fairs. However, my cousin was having a stall to raise money for the MS Society at her son's school and I needed to offload a tub of lollipops that were approaching their sell by date. I took along our lollipop game and shared a table, there was no planning or set up effort, I used it as an impromptu awareness opportunity for the Fibro 5 Challenge.

Making a closed audience work for you

The Ged Walker Dog Show was purely raising awareness of the upcoming Fibro 5 Challenge, we knew there would be a closed audience and we weren't expecting any income, so the donations we received were a pleasant surprise.

The Wilne 10K was a major game changer for us last year. I was on the organising team and I pushed for Fibro Active to be the chosen local cause. Leading up to the event gave us an amazing awareness platform on social media. We gained over 40 new Facebook members.

The day itself was purely fundraising and knowing the event well, I knew that flapjacks and cake would go well after the race. However, we were disappointed with the raffle and tombola income, especially after gaining some really great prizes. The Wilne 10K has a different cause each year so sadly we didn't return this year.

Putting your group on the map

The Fibro 5 Challenge was our inaugural event to put Fibro Active on the events calendar. Everyone enjoyed taking part and they embraced the challenges by visiting every base. The weather was very cold with light rain, which had a detrimental affect on the turn out. For a first event we raised a lot of awareness throughout the summer, not just for Fibro Active, but also for the organisations that sponsored the event and supported us on the day. There were no expectations for the first event, however from the feedback forms and from the enthusiasm of the participants we are planning our next challenge as a treasure hunt.



Keep it simple at Christmas

The Christmas Light Switch On is our staple fundraiser. We keep our fingers crossed for good weather, having said that last year it snowed when we were setting up. We just have to turn up to the market place, which has stalls in situ and sell tombola tickets. The hardest bit is lighting the stall as it is dark, there is no electricity and keeping warm can sometimes be difficult. The application for this event, along with our PLI Certificate went to the Rotary Club in August. As I am writing this article in October we haven't been to this year's event yet, but one thing I can say is that we already have a good selection of prizes!

Success can be measured by growth

It is important to analyse what impact outreach has on our membership. We know our Facebook membership increases after each event we attend; we know this is the hub of the group and that not everyone is going to attend group meetings. We also know how necessary connection with the Facebook membership is, as we have received feedback from members who sit in the background and now and again let us know how

important we are to them. Our Facebook membership fluctuates, we add a couple, we lose a couple and after the Special General Meeting in January we lost about 9 members, which was to be expected, so we were down to 271. Today we have 344 mainly local members. In 6 months, we have gained 73 members. This may not sound much compared to national or global pages. However, our aim is to support our local community - then world domination!! Well you have to have a goal!

Keeping our outreach local gives our members the opportunity of tangible support in a familiar environment; with 1 in 25 of us estimated to have fibro, there is a high probability that we all know someone who has it.

Planning ahead

There really is no down time from organising the group! I have had to really be careful, as until now, the challenge has flared up my fibro quite badly. It's only been 2 weeks since the Fibro 5 Challenge and we have analysed all the feedback, submitted the application form, risk assessment and PLI Certificate, to enable us to rent the park space on May 12th. The rest of the team are in the same boat, they sacrificed their time at the challenge, in return for a flare, and now we are all playing catch up. A big thank you to the team: Jane, Peter, Margaret, Penny, Yvonne, Kay and my mum.

Earlier in the year, I wrote an article about planning your event and mentioned a spread sheet which is essential for planning what is needed to be done leading up to your key dates. This spread sheet is called a Gant Chart. It's almost like a calendar, but you mark your deadline for each task that needs to be accomplished.

As an example of this, I have included the Publicity Gant Chart for the Fibro 5 Challenge. I put in the event first and then add the deadlines that need to be met in time for the event.

Jan	Feb	March	April	May 1 st	May 12th
Launch FB campaign. Send info to organisations, Website updated	Leaflets designed, printed, circulated	Permission for banners, Sponsors, Contact radio station	Banners up, Posters up, More leaflets	Printing submitted, Local radio	Fibro 5 Challenge

We have come full circle in the events calendar and we have already inserted next year's events. It's good to look forward about 6 months so that you can book your stall, prepare your stock and plan your promotion, so reducing last-minute stress.

From all of us at Fibro Active I would like to wish everyone good health through the festive season. Don't forget to pace yourselves especially with the sherry! Thank you for reading my articles. Please get in touch and tell me how your group is doing or if you would like a specific topic covering. You can email me at: julie@fibroactive.co.uk.

In the next article we are going to start 2019 off with the AGM and explore ideas on how to bring people to your meetings.



ASK BRIAN

Brian Barr is a solicitor at Brian Barr Solicitors who specialises in representing fibromyalgia sufferers with accident and insurance claims.

Dear Brian,

I have been badly affected by an accident and my solicitor says that I am entitled to 'general' and 'special' damages. What does he mean by this?

Alfred

Dear Alfred,,

General damages will include items like pain, suffering and loss of amenity, but also loss of the enjoyment of a job or loss of the use of a vehicle. Special damages are items of loss that have an exact monetary value. They are divided into pre-trial losses and future losses.

Past losses will include earnings on which you have already missed out, travel and medical expenses that you may have incurred, money that you have spent on aids and equipment, accommodation and care received purely because of your accident.

Future expenses will be loss of earnings, loss of earning capacity, loss of pension, care costs, medical and travel expenses into the future and other expenses that you will encounter. Often an expert will be instructed in a bigger case to work out in particular what the future expenses are going to be. There are technical rules as to how these are calculated.

To the whole will be added interest on both the general damages and the past losses, but not on the future expenses.

Brian Barr

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MIND FULL

by
Kayleigh Roberts
& Christine Harris



Spice up Your Life! Starting Easy with Anti-Inflammatory Foods

in·flame

/in'flām/

verb

past tense: **inflamed**; past participle: **inflamed**

1. provoke or intensify (strong feelings, especially anger) in someone.
2. cause inflammation in (a part of the body).

Closely tied to Fibromyalgia, Arthritis, Chronic Fatigue, Food Sensitivities, and other Inflammatory Diseases, inflammation heavily exacerbates pain and symptoms.

How does inflammation work? When your body recognises an infection or foreign object, it sends white blood cells to fight for you. White blood cells rush to warm up and treat the area. The white blood cells and chemicals released during this process can cause warmth, swelling, pain and discomfort; they may also inhibit movement, forcing that area to rest and heal. Think of it as similar to what happens with a sprained ankle. However, unlike with a sprained ankle, with inflammatory diseases the body often misidentifies something non-threatening as a foreign object and attacks it. This misdirected attack that was intended to save the body, may instead send the body into a fight against itself.

Food Sensitivities are Common with Fibro. If you and your healthcare provider think you may have a Food Sensitivity, starting an Elimination Diet to discover what is causing the problem and how to stop it is paramount - provided you have consulted with your healthcare practitioner that this is a good way to proceed. An Elimination Diet involves cutting out certain foods that commonly cause inflammation, food allergies, or sensitivities, and then recording results.

Luckily with Food Sensitivities, after stopping the offensive food for a while, people can sometimes slowly reintroduce the food in small amounts without experiencing the same inflammatory response. Just like us, our body needs a break in order to refresh and work better.

Pain is an evolutionary response to discourage damaging behavior. Inflammation makes pain receptors more sensitive. Fighting Fibromyalgia is difficult enough without a heightened pain sensitivity; thankfully we have the tools to reduce inflammation and the pain it exacerbates: Anti-Inflammatory Foods.

Anti-Inflammatory Foods Fresh foods, vegetables, fish, poultry, beans, nuts, fruits, seeds, healthy fats, and whole grains.

Colours of The World Try different fresh greens, colourful fruits, and veg.

Spice Up Your Life! Turmeric, Black Pepper, Red Pepper, Garlic, Ginger, Cinnamon, Clove - all decrease inflammation.

Turmeric + Black Pepper + Natural Fat + Heat is a power combo of inflammation fighting foods so if you love curry, you are in luck! Yellow Spanish Rice, which has most of these ingredients, is another example of this tasty combination.

The Mediterranean Diet incorporates fresh fruits and

vegetables, healthy fats like olive oil, whole grains, legumes and fish and the option of moderate amounts of red wine.

Omega 3 Fatty Acids that are found in some fish and nuts lower blood pressure and are good for your heart.

Out of Sight Out of Mind - If possible keep foods that cause inflammation, grogginess, or pain out of your house. Failing that, do not buy foods high in sugar, processed food, carbohydrates, fried food, or fast food.

Food is Love. Love your Body. Tell your body you are alright and treat it to nutritious fresh foods. Avoid punishing your body with heavy greasy foods that leave you feeling knackered.

Ditch the typical American diet. Processed food, fried food, sugar, and carbohydrates all cause inflammation.

Shop around the outside of the Supermarket. Real non-processed foods tend to be there, so avoid the inner aisles that are filled with packaged foods. Opt for the produce section. Farmers Markets are fantastic for finding nutritious foods.

Convenience is Key. Create easy ways to make healthy eating work for you. Try CSA local farm deliveries, meal planning and portioning, crock pot meals, and shopping around the outside of the grocery store.

It's never all or nothing. If you need to "cheat", there are usually healthier (not to mention tasty) curry options at your Indian Take Out than at fast food restaurants. Treat yourself with kindness.

It's important to pay attention and enjoy what you are eating. There's a difference in savouring one of your favorite indulgences vs mindlessly binging on a box of junk food.

Everyone is different. There is no one meal plan, smoothie, or miracle food that works for everyone with Fibromyalgia as far as current science goes. Discover what works for you by listening to your body and trying an Elimination Diet if you think it's right for you.

Change and Results Take Time. It may take a few weeks to notice any changes but don't be discouraged. Any steps forward are progress. Learning what does and doesn't work for you is a major leg up on Fibro.

Build Your Strength

Try a new food or recipe with Anti-Inflammatory Foods or Spices.

Breakfast Recipe:

Heat 1 bowl Oatmeal with 1 tsp of Turmeric + Black Pepper + EVOO or Butter

Be sure to check out our Next Article on The Purpose of Anxiety.

www.ChristineHarrisTherapy.com

twitter.com/YCWBTherapy Let's connect!

Foodbank use increases by thirteen per cent

The Trussell Trust has provided 658,048 emergency foodbank supplies to people in crisis between April and September 2018, a 13% increase on the same period in 2017.

The charity says if the five-week minimum wait for a first Universal Credit payment is not reduced, the only way to prevent even more people being forced to foodbanks this winter is to pause all new claims to Universal Credit.

The inability of benefit levels to cover essential living costs and issues with payments remain the most common reasons for referral to a foodbank.

Disability Rights UK has previously voiced its concerns over the increased use of food banks forced on disabled people as a result of changes to the benefits system. Philip Connolly policy manager of Disability Rights UK said

“More than half of food bank users are disabled people or those with a long-term health condition. The initiatives by Trussell Trust shows that society is reaching out to them but they must wonder why there is a government denying them adequate social protection.”

Universal Credit is not the only benefit people at foodbanks are experiencing problems with the new system is increasingly driving referrals due to benefit delays, which include waiting for a first payment or having problems with a new claim.

While the Trussell Trust welcomes changes to Universal Credit announced in the recent Budget it highlights that much of the support will not come into force until July 2020.

In addition, the Trust says that while the Government has now introduced 100% advance payments to manage the five-week wait, these must be repaid.

To protect people who will move onto Universal Credit before that point, the charity is calling for the Department for Work & Pensions to be resourced to reduce the five-week minimum wait for a first payment.

BRAIN

Just a line to say I'm living,
That I'm not amongst the dead
Though I'm getting more forgetful
And mixed up in the head,
I've got used to my Fibro,
To my dentures I'm resigned,
I can cope with my bifocals
But - Ye Gods - I miss my mind.

Sometimes I can't remember
When I'm standing on the stairs
If I'm going up for something,
Or have just come down from there.
And before the fridge so often
My mind is full of doubt
Now did I put some food in there,
Or come to take some out?

If it's not my turn to write dear
I hope you won't get sore,
I may think I have written
And don't want to be a bore.
So remember I do love you,
And wished that you lived near,
But now its time to mail this
And say, "Goodbye my dear"..

I'm standing beside the mail box
And my face it sure is red
Instead of posting this to you
I've opened it instead.

Yvonne Haycock



The 12 Days of a Fibro Christmas

*On the 1st Day of Christmas my Doctor gave to me:
1 examination*

*On the 2nd Day of Christmas my Doctor gave to me:
2 lots of pills*

*On the 3rd Day of Christmas my Doctor gave to me:
3 weeks to recover*

*On the 4th Day of Christmas my Doctor gave to me:
4 weeks sick leave*

*On the 5th Day of Christmas my Doctor gave to me:
FIBROMYALGIA*

*On the 6th Day of Christmas my Doctor gave to me:
6 leaflets to read*

*On the 7th Day of Christmas my Doctor gave to me:
7 weeks of hydro (therapy)*

*On the 8th Day of Christmas my Doctor gave to me:
8 of his excuses*

*On the 9th Day of Christmas my Doctor gave to me:
9 months waiting list*

*On the 10th Day of Christmas my Doctor gave to me:
10 physio sessions*

*On the 11th Day of Christmas my Doctor gave to me:
11 TENDER POINTS!*

*On the 12th Day of Christmas my Doctor gave to me:
HIS LONG AWAITED ACCEPTANCE!*

Reach out to your Fellow FM'ers



It is easy to feel isolated when you suffer from fibromyalgia. There are physical groups thriving around Britain:

http://ukfibromyalgia.com/pages/support/support_map.php

And if you are happy with social media we have our 24,000+ strong Facebook Group:

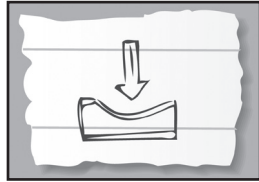
<https://www.facebook.com/groups/UKFibromyalgiaPrivate/>

But there are a lot of people out there who perhaps aren't mobile enough to attend meetings and don't get on with the internet -which is why we run this FM Telephone Friends page. But we need more of you to send in your names and your phone number so that when people are feeling isolated there are people who understand out there at the end of the telephone line. So, if you have the time to help and you want to do something for the Fibromyalgia cause this month then please register. You can ring UK Fibromyalgia on 01202 259155 or send an email to office@ukfibromyalgia.com **THANKYOU!**

Jennifer Carter	Hailsham, East Sussex- 01323 848590 - 7 days a week
Ms Gill Galyer	Newark, Notts - Ring between 11am and 4 pm Monday to Friday 01636 526160
Bede Francis Thomas	West London - 020 8840 7759 -Not mornings
Mrs Viv Norrie	Angus & Mearns Fibromyalgia Support Network (Montrose, Scotland) Monday & Friday 5pm to 7pm 0844 887 2389 or e-mail: am-fm@hotmail.co.uk
Margaret Evans	Cardiff - 02920 258526 - 12noon-6pm weekdays
Yvonne Singleton	Fibromyalgia support group - South Wales - 01639 681468
Janice Dipper	Winchester Fibromyalgia Support - 0844 887 2608 winfibrosupport@gmail.com
Mrs Ulla Deichelmann	Redruth, Cornwall - 01209 213123 - 10am-10pm ulla.deichelmann@btinternet.com
Bexhill & Hastings	Bexhill On-Sea, East Sussex - 0844 887 2425 Tues 10am-12pm
Janette Leeds	Fibromyalgia Support Group - 0844 887 2371 - 11am-5pm
Alan Smith	Rhondda Valleys - 01443 433027 - Please call 6pm to 10pm
Maddie Seacombe	Bristol - Tel 07790130403 - best time is 3pm - 8.30pm.
Claire Hilton	3 Alexandra Road, Thornton Cleveleys (nr Blackpool) Lancs FY5 5DB Tel 07912 792250 Any day 11am-6pm shelbyeatenton@hotmail.com
Linda Holder	Luton, Bedfordshire - 01582 570240. Phone chats or meetings phone in the afternoon.
Mrs Teresa White	Bracklesham/Witterings/Selsey Support Groups West Sussex telephone support/group meetings/social lunches 01243 670 783 any pm or evenings
Denise Shotter	Guildford and Bordon monthly meetings 08448872358 5-7pm email denise.guildfordfibro@yahoo.co.uk
Mrs Natalie Hicks	Chorley Fibromyalgia Support, Lancashire - Contact number: 01257 275145 Please leave a message if no answer. Email: nataliehix@gmail.com
E.L.F.S	Edinburgh & Lothian 0844 887 2380
Deb Cooke	Swindon and Salisbury Foggy's 0844 887 2377
Gary Yates	FM/ME/CFS Support & Carers Group based in Milford Haven Mob: 07867 482 929 Tel: 01646 694 521 E-mail: fibrowestwales@hotmail.com
Paul Peccioli	Happy to take calls from anywhere .I assist in PIP & Blue Badge Form Filling dealing with local District Councils and DWP problems. A listening ear and support and am able to aid those with a variety of other problematic areas. I take calls from 08:00hrs till 21:00hrs 7 days a week. 0844 887 2591
Daventry FM Group	



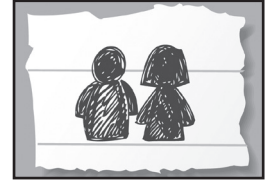
UK Fibromyalgia Website
www.UKfibromyalgia.com



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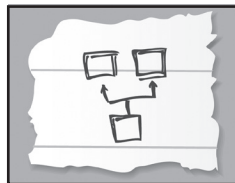
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www.bit.ly/hx5voC



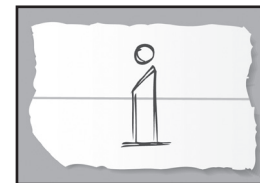
UK Fibromyalgia Support Groups
www.bit.ly/g5TDa8



The Fibromyalgia Shop Website
www.FibromyalgiaShop.co.uk



Fibromyalgia Forum
www.bit.ly/1f0jBNg



The Fibromyalgia Exercise & Diet Guide
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