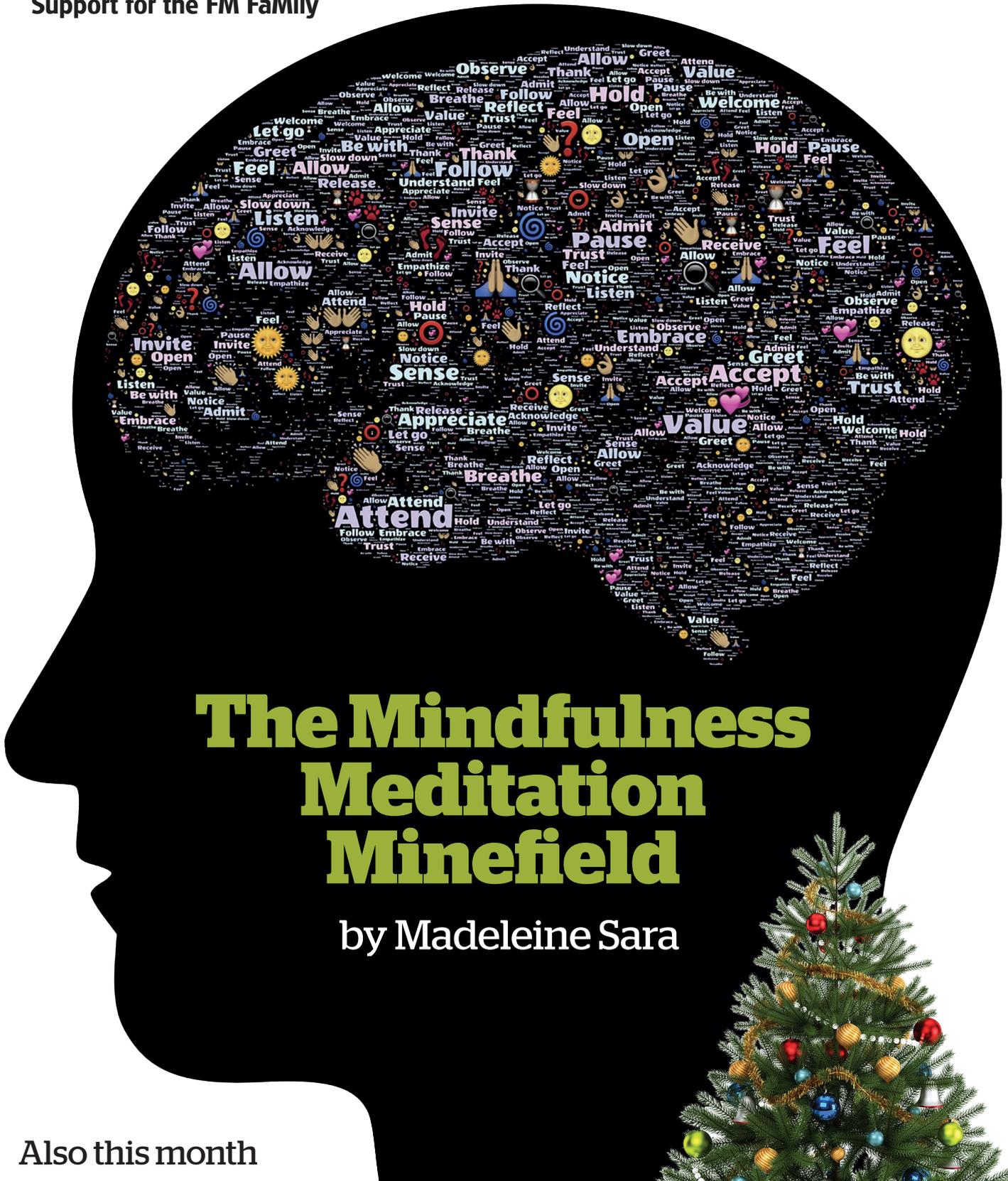


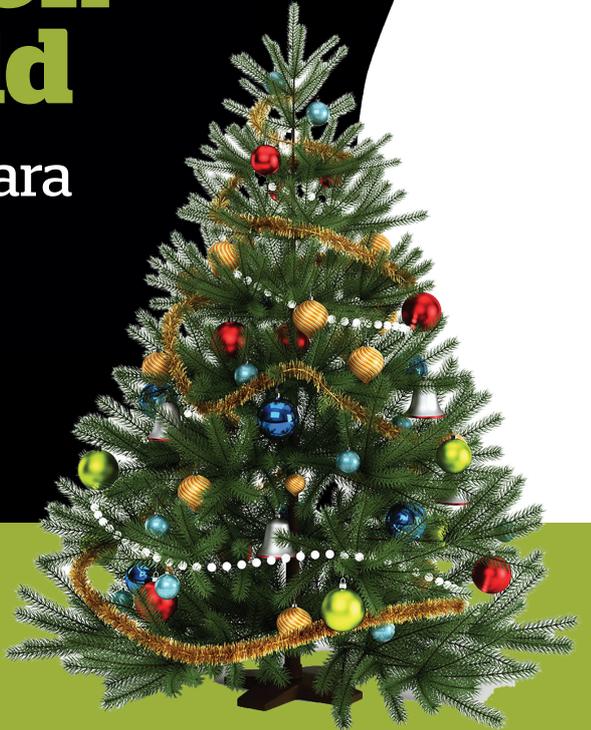
The Fibromyalgia Magazine

Support for the FM FaMily



The Mindfulness Meditation Minefield

by Madeleine Sara



Also this month

Surviving the Christmas Holidays By Karen Lee Richards



The Mindfulness Meditation Minefield

by Madeleine Sara

Have you ever tried Mindfulness Meditation? Those of us with Fibromyalgia know only too well how chronic stress develops. We are told to do Yoga, Tai Chi or Meditation, as a way of rebalancing our mental wellbeing. Maybe you've checked out a book from the Library, downloaded an App or even bought an audio book? Then the reality sets in. Those negative voices in your head, shout louder than the meditative voice to which you are supposed to be listening:

- It's not going to work!
- I'm a doer. I just can't sit still and do nothing!
- My mind is too busy to train!
- I thought this was supposed to be easy!
- I don't have time to spend listening to this voice droning on.
- It's not going to take away what's *actually* making me stressed and unhappy!
- I still feel stressed out, so it *can't* be working!
- How dare this charlatan presume to direct my thinking!

Does all this sound familiar?

Many people grow frustrated with mindfulness, because not only are they so used to focusing on EXPECTATIONS, but they are afraid that it won't work, so their subconscious steps in to sabotage the whole process. Their minds are so unused to just being still, that the impatience and frustration jangles and rages against the quieter voices of their Meditation Guru.

Mindfulness is about switching off your brain to something neutral for just ten minutes or so, in order that those unhelpful thought-processes that are stuck on a loop; like a scratched record jumping over the same, relentless soundtrack, can be stilled.

Mindfulness is not about evaluating past memories or resolving present and future concerns. If you do find that any painful, past memories begin to resurface as a result, then I would strongly advise you to see a counsellor to help you come to terms with them. For some, the ANGER that Mindfulness is not the cure-all they had anticipated, burns a hole in their attempts to make it work, thus proving, in their minds, that they were right; it is just a load of hokum! Again, if this is you, perhaps a course of Cognitive Behaviour Therapy and counselling might be helpful.

Stresses and worries are like an insect bite. If you keep on scratching the bite, it will continue to irritate, get worse and make you miserable. Meditation is the soothing ointment. When you keep washing it off with

negative expectations, impatience and frustration, before it's had a chance to work, then it cannot begin to make a difference to your stress levels and mental wellbeing.

Finding the right meditation guru/ exercises for you, is also important. My first encounter with meditation was at the end of an unsatisfactory yoga session. I realise that the yoga positions were incompatible with my personal, physical difficulties. As the tutor went through the wind-down exercise, it was clear that she was distracted by the noises outside the window and not focused on us, which was distracting and unrestful. I decided Yoga was not for me.

Later, I downloaded some free Mindfulness tracks from the Internet, but the voice was a jarring, twang that did not induce restfulness and peace. The Headspace App[1] made a lot of sense, but it still wasn't quite right for my needs. However, the Williams and Penman book with audio CD [2] was a revelation. Williams' voice has a mellow, soothing quality, (like the Bagpuss narrator, Oliver Postgate) and there are 7 different Mindfulness Meditations from which to choose. Happy by Fearn Cotton [3] is also a worthwhile read.

However, having decided to persevere with Mindfulness, then the next set of barriers present themselves:

· I don't think I'm doing it right!

Don't worry. The more you do it the more familiar and comfortable you should become with it.

· When I'm asked to focus on my breathing and breathe naturally, I find I can't!

If you find focusing on breathing a problem, remember to just breathe-in for four counts and breathe-out for six counts or longer. (Vagus Toning Technique)

· The voices in my head still keep intruding!

It will get better the more familiar and comfortable you become with the technique.



It is worth noting that Mindfulness can work for children with ADHD [4], so it stands to reason it should be able to work for anyone, willing to give it a chance. However, if all of this fails to inspire, there are some great alternatives to try:

1. Go for a walk and take in all the sounds or smells you come across without trying to identify, label, judge or interpret them. Just enjoy hearing them.

2. Do an absorbing chore / craft in which you solely focus on the job, the materials you are using and not thinking about your stresses and worries.

3. Go to a 90 minute singing class a week, or put on your favourite music and sing along for an hour a week. Singing helps cardiovascular/ brain health and happiness.

4. If you can find a view where you can just sit quietly and watch a field of sheep taking a step, lowering their heads, nibbling grass, lifting their heads, taking another step, bending their heads, nibbling grass...; it's one of the most tranquil, mindful pastimes my husband and I have enjoyed.

5. Learn a poem and recite it to yourself all the way through, three times. I always say The Lord's Prayer before I sleep. If I'm particularly frazzled I may say it over again. I don't worry that my sleepy brain might get it wrong. I know The Lord won't mind. Alternatively, saying your poem should work just as well.

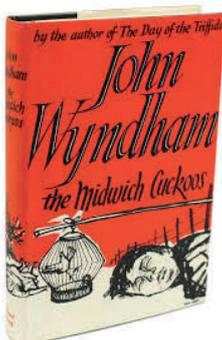
6. Imagine you are drawing out a glowing energy from the sun/moon, through the top of your head. Imagine drawing it down through your head and face, down into your neck and shoulders and slowly down through each part of your body, picturing it all the while, until it reaches your feet. Then imagine releasing it in an effervescent burst into the ground. Do this twice more and see if that doesn't relax you.

7. Laughter is regarded as contagious. It boosts people's health, communication, positive thinking and creativity. Laughter Therapy sessions may seem ridiculous, but they could give you the lift you need and help you understand how you, personally, process life, so that you can better relax and cope with challenges.

The 1960's adaptation of John Wyndham's Novel, 'The Midwich Cuckoos' [5], comes to mind, where George Sanders' character must think only of a brick wall in

order that the mind-reading, alien children, cannot discover what he has planned. As in meditation, you are switching off your mind, for just a short space of time, so that the heckling intruders cannot badger you.

So, why not GIVE YOUR BRAIN A MENTAL VACATION ?



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:

[1] <https://www.headspace.com/headspace-meditation-app>

[2] Mindfulness a Practical Guide to Finding Peace in a Frantic World by Mark Williams and Danny Penman. (2011 Piatkus)

[3] Happy: Finding Joy in Every Day and Letting Go by Fearne Cotton; Orion Publishing Group; 2017

[4] The Doctor Who Gave Up Drugs. Dr Chris van Tulleken's patience is tested when he joins a group of hyperactive children on ADHD medication as they try meditation as an alternative treatment. However, six weeks on, the results speak for themselves.

[BBC 17 May 2018 <https://www.bbc.co.uk/programmes/p067g6l1>]

[5] The Village of the Damned, the 1960 film adaptation of John Wyndham's novel, The Midwich Cuckoos.

The Fibromyalgia Exercise Guide

by David Jenkin

The guide is designed to teach people how to be active managers of their health in relation to living with Fibromyalgia.

£16.95 including post and packing to a UK postcode.

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Are you 'wallowing' in pain?

by Nikki Albert

"One of the most powerful strategies we have seen in treating pain is when we don't allow patients to discuss their pain with anyone – expect with medical providers. People can become so wrapped up in their pain that they lose themselves in it. They become their pain. I had no idea how much time patients spent discussing their pain until I asked them not to. For some, it felt like I had just dumped a bucket of ice water over their head. They'll say, "I feel shallow and phony by not sharing what is really going on with me." That is a sure sign that he or she has become their pain. We have witnessed several things occur when people successfully stop discussing their pain. The pain may not immediately abate, but they feel lighter".

Now I do not wallow in pain. I ruminate. And maybe that is just semantics. But communication about our pain is necessary. So I do not understand this don't talk about it at all thing.

When pain is high...

I know when I am in high levels of pain... those peak levels where you are utterly non-function... I cannot get enough distance from the experience. It is about getting through. And distraction is impossible. So you are immersed in the experience and it impossible not to think about how horrible it is.



And when I was immersed in my depression I would think myself into a sinkhole of despair when it came to thinking about pain. It compounded the pain experience so severely that I suffered more mentally and emotionally. Thinking, then, became dangerous. Again, I had no real distance from the pain experience to get perspective on

it because the pain was unmanaged and the depression wasn't treated.

When pain is moderate...

When our pain is moderate, or baseline average for ourselves, we engage in a lot more coping strategies. Such as distraction. Put your mind on something else so you do not focus so intently on the pain.

And I think of this experience: There were times when I would be in a support group for people who also had fibromyalgia or chronic migraine where it was detrimental for me. People, like me and so many others, have difficult times with pain management and treatment. We can be discouraged. We can be hopeless. And when I spent a lot of time with people who were as frustrated, as hopeless, as me it was difficult to distance myself from my own suffering. So I do limit that now.

However, do we 'wallow' in pain on a more everyday level?

When pain is more managed for portions of the day we have our ways of coping. And this includes proper self-care and rest to manage the intensity of the pain. Distraction so we do not get too immersed in the pain. Because thinking about it always seems to make it darker and deeper.

But, man, well, pain is demanding. It is constantly insisting you pay attention to it. and we are constantly finding ways to cope with it insisting we focus on it. Not to mention the problems it creates with focus and concentration. And the mental and emotional suffering it causes. I can ruminate on this. I can catastrophize this. I have a difficult time thinking about even the future with chronic pain. The present is hard enough to cope with without thinking about endless pain.

Maybe we give to much time for it. Maybe if we talk about it a lot we focus on the reality of it more.

However, I do complain when it is severe. I can't help it. I feel like I need it to be acknowledged. I need others to understand that day is a real struggle. And there is nothing wrong about that. Saying 'Hey, this is a bad day. I cannot function.'

And in this, we have the idea of how much of our attention and focus is allocated to discussing or thinking or complaining about the pain experience.

But I have found it is healthy to only give a certain amount of time to think about illness and chronic pain. To not give it too much space in your head. To not consume too much of our thoughts.

There is a distinction between coping and wallowing

When I ruminate about pain I can really sink into the horrific reality of it. About how hard it is to function. About how hard it is to do anything. How it is just endless. And my worries over the future. And sometimes pain swallows us whole and we are incapable of thinking about anything else. It can consume. And even when it is our baseline pain it is extremely hard to think through and function. Thinking about it happens. Like just thinking about how hard it is going to be getting through that day of work. Or the next day of work when you are in too much pain to sleep.

When I cope with chronic pain I acknowledge the pain. It is there. And I have to deal with that reality. I have to adjust accordingly. Severe high pain is complete rest mode. And every other day is based on intensity. I consciously pace my activities. I am careful with my time and energy. I rest when I need to I respond to every migraine with a strategy (Ice, migraine balm, meditation, maybe medication that day, or maybe it is a non-triptan day).

And my level of functionality adjusts to the level of pain. I do try to engage in things that I use for distractions; writing, blogging or reading. All sorts of things.

Fact is, we are aware of pain all the time We are aware of it. And that is how we adjust to it.

I do not honestly know if verbalizing our experience frequently causes that distance we try to keep from the experience to be narrower. If it makes us dwell on it. Or ruminate more. Maybe it does. And maybe that does mean we need some sort of journal to just complain in once a day. To get those frustrations out that we always have. I don't know. But I don't think complaining about it when it is severe is a problem. I am stuck in a four-day migraine right now. Today the intensity has gone down. But day one was severe. Day two was epic pain levels. I was laid flat out by it. I made the entire house as dark and quiet as humanly possible. I did everything I could to manage the pain. Nothing touched it. I just lay on the couch all day, enduring it. Telling my spouse about it makes him understand I am not functioning. It enables him to understand what I am doing to get through it as necessary. No light. Quiet. When pain is that high up there my management of it alters to 'just get through it' mode. And making others aware of that mode means they are less inclined to turn on a light or make a lot of noise. And they know activities just are not going to happen. Plans not achieved. No accomplishments or productivity possible.

So maybe informing is a good idea. Maybe not complaining, or wallowing as the article suggests, but informing. My psychologist had told me my stoic nature didn't help my spouse understand where my limits were that day. And that I had to communicate more. I am very into suffering silently apparently. There is still a part of us that wants people to comprehend the depth of the experience. I like the idea of a complaint journal, for like mid-day, and then my gratitude journal in the evening. So yeah, I don't want to wallow in it. But the reality is that sometimes it does consume us due to its very nature.

Check out my blog

<https://brainlessblogger.net>

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

Surviving the Christmas Holidays

By Karen Lee Richards

Does the thought of another holiday season fill you with joyful anticipation or overwhelm you with fear and dread? The average person considers the holidays at least somewhat stressful. For people with fibromyalgia, who are already struggling to cope with daily life in general, the added demands and stresses of the holidays can trigger a flare of fibromyalgia symptoms. While you may not be able to totally avoid all stress, you can reduce your stress level significantly by giving yourself a G.I.F.T.

G - Guilt Must Go

Guilt is born when you fail to live up to your own expectations for yourself. Year after year you are bombarded with a "magical mythical model" of the idyllic holiday scene - complete with family, friends, food and festivities, encompassed in a spirit of peace and goodwill for all. If this is the holiday image you are trying to achieve, it is time for a reality check. The fact is, you have a chronic pain illness, which limits what and how much you can do. It's time to stop blaming yourself because you can't provide the elaborate holiday festivities you once did or because you can't do everything you think your family expects you to do. It's time to remember what the holidays are really about - expressing your love and thankfulness for family and friends. There are many ways to express those feelings without damaging your body in the process.

Decide right now that you will refuse to accept any feelings of guilt because of what you cannot do. Instead, focus your attention on what you can do. Then gather that old guilt up into a big ball, kick it out, and lock the door behind it!

I - Importance Rules

Do not let the holiday season descend upon you like a heavy weight. Decide which aspects of the holidays are most important to you and your immediate family. Focus on accomplishing the most important things and let everything else go. (If spending quality time together visiting is more important than a huge home-cooked meal, have your holiday dinner at a restaurant so you can relax and enjoy each other's company.)

Once you have decided what is most important to you for the holidays, share this with your immediate family. Then ask each family member what is most important to them (an elaborately decorated house, lots of baked goodies on hand, a big home-cooked dinner, visiting with other relatives, etc.). Family traditions are important but, just as families grow and change, some traditions may have to change as well. Hold on to the traditions and rituals that are most important to your family, but understand that it may be time for some traditions to

change. Work together to come up with a compromise that everyone can live with. Ask each person in the family to take responsibility for some part of the holiday plans. Knowing ahead of time what the priorities and plans are will avoid disappointment and hurt feelings later.

F - Family Matters

During the holiday season, extended families come together, often travelling great distances. While it may be wonderful to visit with relatives not often seen, you need to plan ahead to avoid being physically drained by what should be an enjoyable experience. Whether they come to your home or you go to theirs, talk to them ahead of time and explain that you have a chronic illness, which limits your activity and requires you to rest at regular intervals. Then, when you decline an invitation to go sightseeing or politely excuse yourself to go take a nap, you do not have to explain or feel guilty.

Keep in mind that your first responsibility is to yourself and your immediate family. If you are not feeling up to a large family gathering this year, simply explain that, as much as you would love to see everyone, your health will not allow you to participate this year.

Good communication with your family is a key to a happy holiday season. However, sometimes when we are not feeling well our attempts at communication may sound more like whining or complaining. Try to speak in a calm, logical, factual manner as you make plans or explain your limitations to family and friends. Be aware that some people may not understand at first but, if you calmly stand your ground, most will eventually come around.



T - Think ahead

A large portion of holiday stress comes from the last-minute rush to get everything done. Begin to plan your holiday season at least two months in advance. Put your plans on paper so that they are not lost in an unexpected attack of "fibro-fog." Make a gift list, write out menus and formulate a "to do" agenda. The next step is to simplify and delegate. Look at each item on your list and ask yourself, "Is this really important to me and/or my family?" If not, take it off the list. If it meets the importance criteria, ask, "Can someone else do this for me?" If so, delegate it. If not, your final question should be, "What is the easiest way to accomplish this?" Sometimes we make things harder on ourselves than they have to be simply because we don't take time to figure out whether there is an easier way.

Once you have fine-tuned your list, look at the remaining items and try to accomplish at least a portion of your plan each week. Accept the fact that you will have some bad days. Allow yourself extra time in your schedule so that one or two bad days will not ruin your entire holiday season. By not waiting until the last minute to do everything, you might just have enough energy left over to actually enjoy the holidays.

Give yourself a G.I.F.T. this year and have a happier, healthier holiday season!



Six Tips to reduce holiday stress

- 1) Avoid the stress and exhaustion of holiday shopping by ordering your gifts from catalogues and online. An added benefit is that out-of-town gifts can be sent directly to the recipients, saving you the hassle of finding a box, packaging the gifts and waiting in line at the post office.
- 2) Use gift bags instead of traditional wrapping. (Dollar-type stores, catalogues and TV shopping channels often offer low-cost assortments of gift bags.)

3) Each year, between busy schedules and increased postage costs, fewer and fewer people send holiday cards. If you still feel you must send some cards, be selective. Only send them to close friends and family whom you seldom see.

4) When everyone is coming to your house for dinner, ask each one to bring one or two dishes, leaving yourself only one or two simple items to prepare.

5) If you are going out of town to visit relatives for the holidays, consider staying at a hotel for at least part of the time. Having a separate haven will reduce your stress by giving you a sense of control over your own space and activities for at least a portion of each day.

6) If the demands of your extended family are more than you can handle each year, consider making an annual holiday vacation a new family tradition. (Try a chalet in the mountains, or a warm beach.) This can be a special bonding time for you and your immediate family. You will not feel compelled to cook, and you will probably reduce the size of your gift list because everything will have to fit in a car or on a plane.

At the time of writing **Karen Lee Richards** was **Vice President of the National Fibromyalgia Association and Executive Editor of its magazine, Fibromyalgia AWARE.**



BRENDAN KEELEY

Immune System May Play Role in Fibromyalgia, Study Suggests

<https://fibromyalgianewstoday.com/>

Through a new genetic analysis, researchers have found evidence suggesting the involvement of the immune system in fibromyalgia (FM), a study reports.

Inherited mutations in genes that provide instructions for the production of three immune molecules — called CCL11, CCL4 and MEFV — impact the immune system and may be associated with the risk of fibromyalgia, according to the researchers.

The study, “SNPs in inflammatory genes CCL11, CCL4 and MEFV in a fibromyalgia family study,” was published in the journal Plos One.

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0198625>

Previous family studies have suggested a genetic component linked to fibromyalgia, with several pieces of evidence pointing to a role for genes involved in inflammatory pathways.

In another study, researchers found that the levels of several inflammatory chemokines - proteins secreted by cells - were elevated in fibromyalgia.

Among these were the chemokines CCL11 and CCL4, located in a chemokine gene cluster in chromosome 17, which is associated with immune-related disorders, including atopic dermatitis and inflammatory bowel disease (IBD).

Researchers in this study performed a sequencing analysis of the chemokine gene cluster identified in chromosome 17 in 100 fibromyalgia patients. Their DNA was extracted from blood immune cells, called lymphocytes, or saliva. The same analysis was performed in the DNA from unrelated, gender and age- matched individuals used as controls.

Researchers focused their analysis on single nucleotide polymorphisms, or SNPs, which are variations of single nucleotides - the building blocks of the DNA sequence.

The analysis first revealed a total of 4,332 SNPs, but to shorten this list, the researchers proceeded to analyse those occurring in at least 10% of the 100 fibromyalgia patients. A total of 413 SNPs met this criteria.

“Based on the hypothesis that FM has an immune component, we further selected only those SNPs found in the chromosome 17 cluster of 18 chemokine genes,” the researchers wrote.

They identified only four SNPs in four chemokine genes - CCL11, CCL8, CCL23 and CCL4 - which were further studied.

They analysed the transmission of the four SNPs from parents to fibromyalgia patients, and only one of them in the CCL11 gene, called rs1129844, was significant, meaning it was associated with a risk of the disease. Among a group of 220 fibromyalgia patients, researchers identified 36.8% who had at least one copy of this SNP.

Researchers performed further analysis to understand the effects of this variant, and found it affected the normal production of the CCL11 protein. They noted, however, that the levels of CCL11 protein are statistically higher in most of fibromyalgia patients.

“While the elevated expression of CCL11 is a common event, the inability to generate a robust CCL11 response predisposes up to 36% of patients with a higher likelihood of FM,” they wrote.

They currently have no explanation for this phenomenon but argue that although further studies are necessary to validate these findings, this SNP may be used as a marker of fibromyalgia risk.

“This study provides evidence that rs1129844 in CCL11 may be a useful marker for FM and that the high frequency of this SNP in FM patients (36.8%) argues for an underlying immune connection,” they said.

The levels of another chemokine, CCL4, were also decreased in the SNP variant of CCL1 compared with controls, suggesting a possible relationship between the two chemokines and their variants, and that both chemokines are involved in fibromyalgia.

Moreover, researchers found several variants in the MEFV gene, which provides instructions for a protein called pyrin, with a significant transmission bias. This protein’s function is still not fully understood, but research suggests it is likely to help keep inflammation under control, which provides another link supporting the role of the immune system in fibromyalgia.

“Considering that activation of the immune system is often associated with neurological systems such as pain, the involvement of the immune system in FM does not rule out the prevailing hypothesis that FM is predominantly a pain syndrome,” the researchers wrote.

“With this in mind, further studies on larger number of patients may help to validate the link between pain and the immune system in FM,” the study concluded.

<https://fibromyalgianewstoday.com/>



Embracing Solitude: How Chronic Illness Has Taught Me To Enjoy Alone Time

By Katie Zulak

I went out for lunch with a friend who recently began working from home. She described dreading the long hours on her own, and the resulting cabin fever of spending so much time in one place. As I listened, I realized what a significant transformation my own feelings about solitude have undergone during my illness experience.

As an extrovert, I've never looked forward to spending an entire day by myself – never mind a succession of days. I prefer to be around people. I'm happier spending an afternoon in a café than my living room. When chronic pain forced me out of grad school, I was at a loss of what to do with myself at home all day.

But I think it's about more than being an introvert versus an extrovert. Looking back, I don't think I ever distinguished between loneliness and solitude. I wasn't comfortable with my own company. As I reflected on what I have learned about embracing solitude, I came to a few conclusions about the lessons my experience has taught me and what I'm still working on.

Being Present For Simple Pleasures

The first step on my path towards becoming a reformed extrovert was learning to value being present. A year or two after being diagnosed with fibromyalgia and endometriosis, I was referred to a Mindfulness-based Stress Reduction course at my hospital – an eight week program on using mindfulness meditation to manage pain. I often credit mindfulness meditation for maintaining my sanity, but one of the most important lessons that I've learned is that there are many enjoyable moments in ordinary life that can enrich our lives if only we pay attention in the present moment. The sun on your face, bird song out the window, a great cup of coffee, or a snuggle with your pet are all examples of simple, everyday pleasures that are available for us to enjoy. Being on autopilot most of the time meant that I was oblivious to these experiences. It's often easier to savour these times on your own rather than in company, and that's one of the reasons I have come to value my alone time.

Exploring New Horizons (From Home)

A second change in my perspective has come from exploring my interests and finding new hobbies. In other words, I learned to unleash my inner geek. From reading, and watching and listening, I've discovered that I love historical murder mystery books, political news, blogging, archaeology documentaries and calligraphy. I feel fortunate to live in an era of podcasts, online libraries, free e-courses, audiobooks and streaming.

If your illness keeps you at home much of the time, being able to explore new horizons from your couch is fantastic. Whether or not you are crafty, artistic, musical or nerdy, there's something out there for you to geek out on. I honestly haven't found anything else I prefer to do on my own as much as to feed my curiosity. Learning more about the world helps you understand your own place in it better. Discovering new interests, and new talents is deeply rewarding. Spending time that way really transforms loneliness to solitude.

Making Time For Meaningful Self-Care

Finally, seeing the dividends of investing in self-care has made me more open to making time for myself. This isn't an easy thing to do. You often see advice about self-care that makes out like it's as simple as lighting some candles and taking a bath now and then. I think it's really about changing your relationship with yourself. Who wants to spend time with someone they don't like very much? No one. If you have an inner critic with a megaphone, of course you don't want to spend alone time together. The prospect of too much time alone meant that I was always looking for a distraction. In the age of scrolling through social media and binge watching TV, I think enjoying me-time is almost a lost art form (not that I don't like binge watching as much as the next person!)

It takes a change in mindset to identify negative self-talk, challenge it and replace it with a kinder and gentler perception of yourself. Self-care is really about self-compassion, and accepting that you're only human, just like everyone else – it's okay to be imperfect and make mistakes. For many people there is a lot of worry, guilt, frustration and self-blame tied up in developing a chronic illness. Cultivating self-compassion in the face of difficult circumstances is a long process, and I've found that many lessons need to be re-learned over time. Journaling, meditating, Cognitive Behavioural Therapy, and therapy are all ways to improve your relationship with yourself. Learning to be more comfortable in my own skin has made me enjoy my own company much more than before. And now I'm much more likely to enjoy a quiet cup of tea, listen to music, meditate, or actually do any of the self-care activities by myself that are listed in the lifestyle magazines!

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Marie-Louise Olsson
Chairperson at

 Fibromyalgia Association Sweden



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An appointment for Dinner

By Cynthia Webber

A friend of mine wrote these words to me many months ago, and to me they sum up our experiences with an activity that most people just take for granted.

"I remember I used to 'cook dinner', and it was no big deal. Now I have to 'think' about what I'm going to fix, then I have to 'think' if I really want to thaw something out or just have soup because I hurt so bad. Then maybe I decide I'll fry that chicken, so then I have to go to the freezer, and it's not an upright, so I have to lift the lid, and find something to prop it open. Then, of course, the chicken is on the bottom, so I have to pick everything out of there which is cold and frozen, until I find the chicken. Now that I've found it, I have to put everything else back. Then I take the chicken to the microwave and put it on defrost. Then I suppose that I have to cook potatoes to go with the chicken. Now I have to walk back to the laundry room, get the potatoes, bring them back to the kitchen table, where I sit down for a minute because the pain in my shoulders just won't quit. I've forgotten the knife, so I have to get up, which really hurts. I never want to get back up after I've sat down, but I get the knife, and sit back down and peel the potatoes, which takes a little time because my fingers and hands hurt so bad. Once that part is done, I have to go get a pan, take it to the sink, fill it with water for the potatoes, wash the potatoes, cut them into pieces, and put them in the pan. The pan is very heavy at this point, so I may ask for help carrying it or just go for it, depending on how bad my hands are. I haven't even gotten to the chicken yet or set the table. Most people just do this stuff automatically every night, while the people with fibromyalgia just have to take it one step at a time, and it can be gruelling. The same thing happens when I go out for dinner. I never sit in a booth because it hurts so bad trying to get up, so now we always ask for a table. There are just so many adjustments that we have to make just to 'get through' a day."



Before I developed fibromyalgia, these problems weren't as exhausting for me, but now it is too much work to have to continually explain why I can't or shouldn't do something. I'm praised for fixing a nice dinner, yet the

dishes are left on the sink for me to do before I go to bed at night. The dusting just isn't done, and even though two of my family members have allergies, they don't make the effort to do it.

As my friend wrote, just thinking about preparing a meal can be exhausting, but actually doing it can be painful and it becomes a major chore rather than something pleasurable to do.

It is emotionally exhausting to have to continually remind people that we just can't do certain things. Sometimes it is easier to either just not do them, or force ourselves to do the minimum of chores so that our homes don't become overwhelming with dirt or clutter.

We may be mourning for the lives that we once had, yet since our pain and fatigue is usually invisible to those around us, we don't always receive the understanding which we desperately need. I've been told by many well-meaning friends to get my family to help more, but they aren't living my life for me. It is difficult enough to just get through some days without people placing greater expectations upon me.

Not only must we change the way in which we live our lives, we must also deal with the losses that we've sustained to our self-esteem. For most of us, we hate to feel like non-productive members of our families or our communities, but the reality is that we have to stop and think before doing almost anything now. Sometimes the chore seems so overwhelming that it's easier to just do nothing, yet that can lead to depression.

There is no one simple answer for each of us, and we have to learn to listen to ourselves rather than let others tell us how to live our lives now.

At the time of writing Cynthia Webber was contributing editor to Suite101.com's Coping with Fibromyalgia site, which features articles, links and discussions on living with fibromyalgia. Visit her web site at <http://www.suite101.com/welcome.cfm/fibromyalgia>.

Christine's Recipe

There are lots of good reasons for eating wild salmon - apart from its great taste. For a start, it contains omega 3, the essential fatty acids known as the 'super-unsaturates', which boosts energy, lowers cholesterol and increases overall health. Eating salmon on a regular basis can also help to prevent heart disease, cancer, arthritis, depression – and because Omega 3 acids are the basic building blocks for nerve tissue and brain cells – it is excellent for reducing 'fibro fog'. However, farmed salmon is full of toxins, so should be avoided. Start your meal with a healthy minestrone soup, which is very easily prepared. Enjoy!

Minestrone soup (serves 4)

1 onion, roughly chopped
690 bottle passata or two 400 g cans of chopped tomatoes
2 large carrots, peeled and roughly chopped
2 large celery stalks, roughly chopped
½ small swede, diced
1 courgette, roughly chopped
2 tbsp tomato puree
1 litre water
2 bayleaves
1 tsp mixed herbs
black pepper
50 g soup pasta or small pasta shapes



Place all the ingredients except the pasta in a large saucepan and bring to the boil. Simmer for 15 minutes. Add the soup pasta and cook until tender. Serve.

Peppered salmon (serves 4)

200 g potatoes
4 salmon fillets
juice of half a lemon
freshly milled pepper
100 g peas
10 ml/2 tsp olive oil
1 tbsp parsley, chopped



Pre-heat the oven to 190C and put the grill on a medium heat. Cook the potatoes in boiling water for 10-15 minutes. Lay the fillets on a foil-lined baking tray. Squeeze lemon juice over the salmon and sprinkle with pepper. Bake/grill the salmon for about 6 minutes, until the flesh is opaque and flakes easily with a fork. When the potatoes are nearly cooked, add the peas and cook for a couple more minutes. Drain through a sieve and return to the pan. Season the potato and pea mixture with pepper, then add the oil and parsley. Crush roughly with a wooden spoon or masher. Serve the salmon on heated plates, on top of the crushed potato mixture. A sprinkling of fennel seeds makes an interesting alternative to milled pepper on the salmon fillets. Steamed or lightly boiled cabbage is delicious with the potatoes, instead of peas.

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.

Reach out to your Fellow FM'ers for Awareness Month



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
Pamela Buckle	Warwickshire - 01789 765587 - Tues/Wed/Thurs 17.00-22.00
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	



The Implication of pain medication on exercise

by David Jenkins

Many of you reading this will be on one or more painkillers. This months column will explore some of the most common painkilling medications, their main side-effects (identified by the British Medical Association, 10th Edition), and how that is likely to affect exercising:



Amitriptyline

Common side-effects include: drowsiness, blurred vision, dizziness, fainting, sweating, dry mouth and constipation. If overdosed, amitriptyline can cause cardiac arrhythmia, seizures and even coma. This is because Amitriptyline is a mild sedative, especially aiming to improve sleep. The medication is usually taken as a single dose at night, so side-effects are not likely to affect exercise too much in the day time if taken with the correct recommendations. However, if you take Amitriptyline, you may want to postpone any exercise until late morning at the earliest, to ensure the medication is out of your system

Gabapentin

Common side-effects include: drowsiness, dizziness, early fatigue and muscle tremors. Usually prescribed for neuropathic pain, Gabapentin is an antiepileptic medication primarily. Exercising should be conducted in safe environments if you are affected by any of these side-effects, or if this is a new medication for you, or if you are in the middle of dosage changes

Morphine/Diamorphine

Quite a heavy duty pain medication, prescribed for more severe pain. Common side-effects include drowsiness, nausea, vomiting, constipation and dizziness. Exercising while on morphine will require careful monitoring, and those who take morphine may well have already been given advice about activity, but if not – it is wise to seek advice from your GP as to the best exercise suitability for you

Pregabalin

Headaches, drowsiness, dizziness, nausea, blurred vision, and weight gain are common side-effects of Pregabalin. Much like Amitriptyline, this is an antiepileptic medication and used for neuropathic pain. Again, you may want to delay exercising until later in the day

Tramadol

Again, Tramadol can cause dizziness, tiredness, nausea and also a dry mouth. Prescribed for moderate to severe pain, acute or chronic. Effects usually wear off after 4 hours for short-acting relief. It may be wise to ensure you are feeling no effects from the medication before you attempt to do very much in the way of exercise

These are just a few of the more commonly prescribed pain relief medications, you may be on some of these and/or take different ones, it is always best to research your medication to assess what side-effects are likely to occur. A good tip I can offer is to use the nhs website or a reference book like the British Medical Association (BMA) or British National Formulary (BNF) which will tell you not just all the side-effects but which are common, and which are rare, along with guidance over things like risk of dependence, overdose risk levels and so on. Always remember your GP or specialist is there too to offer advice and support. While pain medication is hopefully serving you very well, it is worth ensuring that it remains safe and you are able to exercise in confidence.

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



FOOD GLORIOUS FOOD OR NOT!

By Helen Watts

For many people with fibromyalgia food can be a problem and can trigger unpleasant symptoms and bring along associated conditions like IBS. Recently I asked the Facebook group members if they took steps to avoid certain foods or drinks.

'SB' "The only thing that makes it worse for me is alcohol, if I've excessed as my body can't process alcohol normally and then makes me really ill, my own fault but maybe once a year I have a huge blowout which I pay for for about a week afterwards. Other than that, food is good".

'DLR' "I've found that drinking fizzy drinks feels like I've been stabbed all over my body, it's SO painful so I avoid at all costs".

'MR' "I find junk food and sugar the worst offenders".

'SB' "I cannot eat too much processed food as it makes me unwell. It is hard sometimes as cooking fresh is hard when you are having a bad time".

'CH' "I had to cut out sugar. I was a major chocoholic and loved anything sweet, loved cakes, cookies, toffees, fudge, anything really. I have found that only by avoiding as much sugar as possible, that I can hope to keep the pain levels bearable".



'CB' "I am gluten and dairy free but if I eat anything that includes preservatives that also gives me a pain flare plus cystitis. Going gluten and dairy free hasn't cured my fibromyalgia but has lowered the pain levels a lot which is a huge blessing because I can't take painkillers as I get sick. Also like others sugar increases pain but I do have that occasionally without too much trouble".

'KL' "I'm vegan and gluten free. It really makes a huge difference. The gluten free especially has almost hidden my symptoms. I am now going raw which I have already noticed has helped so much. I've not taken any meds and I am needing to sleep less. What we put into our bodies massively affects us, we are what we eat for sure and I think diet can really help so many people. It's not a cure-all by any means, but it can really help more than people realise".

'HW' "I have certainly become more intolerant over the years. I also struggle with my weight and have tried many diets but nothing works, I lose weight but it's only a short term thing and I end up putting the weight back on and more as well. I try to take vitamins and supplements which I find helpful.

'PJ' "I find that, despite trying many things, diet doesn't affect my fibro. However, coffee triggers my ibs and if I eat a lot of junk - especially chocolate - it can make me worse. If I maintain a healthy diet, I'm fine. Red wine and beer make my muscles really heavy, though".

'BF' "Not directly. If I eat certain things that trigger my migraines, the migraines have a knock on effect and start off a flare. So I keep a food diary which I jot down what I eat and drink and also my emotions, where I've got pain and my pain scale, so I can look back to see any triggers or emotions and 'try' to avoid them".

'DC' "I have become lactose intolerant since being diagnosed".



So is this all sounding familiar to you? The official advice for everyone, whether they have Fibro or not, is that you should eat a well balanced diet, with lots of fruit, vegetables, whole grains, low fat dairy and protein such as fish or chicken and eat as fresh as possible but this is often a problem for Fibro sufferers particularly if you have pain or weakness in your hands or arms. How do you cope? Drop into the Facebook groups and join the conversation.

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 are your best ways of keeping warm in the cold weather?

As a lot (not all) of people with fibromyalgia find that the cold and winter months are the worst for them we decided to ask our Facebook group "What are your best ways of keeping warm in the cold weather?", this month we decided to let members add their own options to be voted on too. These are the results of our survey:

Heating on all the time	144 votes
Lots of Blankets	141 votes
Wear many layers	109 votes
I run hot all the time so am always warm	82 votes
Hot water bottles	74 votes
Stay in bed (member added option)	67 votes
Dressing gown (member added option)	56 votes
Electric Blanket	42 votes
I snuggle with my pets for warmth	42 votes
I snuggle with the husband and steal his body warmth (member added option)	36 votes
Heat Pad (member added option)	28 votes
Have the heating on so if it drops below a certain temp it come back on (member added option)	27 votes
Very rarely cold, but use a blanket if I am. (member added option)	26 votes
Warm? I am never warm	18 votes
Thick socks (member added option)	11 votes
Fleece throw in sofa (member added option)	11 votes
Super Warmth Thermal Duvet (member added option)	9 votes
I just keep one room warm	7 votes
Hot water bottle (member added option)	5 votes
Hot bath as it warms the body from inside out (member added option)	2 votes
Keep a regular Flask of hot drink or soup nearby (member added option)	2 votes
Wear thick clothing and support bandages (member added option)	2 votes
Wearing natural materials such as wool to help regulate temperature. (member added option)	2 votes
Gentle exercise	1 vote

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

MAH said "I overheat easily but can also feel frozen to the bone a few minutes later. Which is why I tend to avoid turning the heating on and rely on my electric blanket, the cats, or their human dad."

YJ said "Cats make good hot water bottles."

SS said "I find it hard to keep, warm, thermal socks, and I lots of layers in bed, plus hot water bottle, my family think I'm totally bonkers "

CD said "I wear layers mostly because I can't control my body temp go hot then cold etc etc "

SG said "Quite often have fingerless gloves on indoors & a scarf in the autumn & winter. Socks & gloves at night but often little else in bed but several blankets as I get night sweats - can't win. Can't use duvets as feel too heavy on me. "

JG said "take a lap blanket with me everywhere I go. I cant stand a draft "

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



Osteopathy for Fibromyalgia

by Karen Crosby

Years ago, I went to an osteopath with a slipped disc in my lower spine that was causing me a lot of

pain. Of course I only stepped into a room to cause the slipped disc, but I didn't know I had fibro back then!

He did some pretty strong manipulation on each appointment, for which I had about six.

After that, I came slowly off the painkillers, and was more careful for a while, but it was the only thing that helped at the time.

I have been thinking about osteopathy for fibromyalgia, and have come to realise that as the osteopath is much more than a structural manipulator, as a lot of people think, but looks at the person's physical, emotional, mental, and spiritual health, and can therefore tailor the treatment for the individual!

Osteopathy works on four basic rules: -

1. The human being is a dynamic unit of function.
2. The human body has self-regulatory mechanisms in place that are inherently self-healing.
3. Structure and function are interrelated strongly on all levels.
4. Rational treatment for the individual works on these basic principles.

Because the symptoms of fibromyalgia are both complicated and involving widespread pain and other symptoms, osteopathy can help with so many things like: -

1. Gastrointestinal problems like IBS, with the accompanying abdominal pain and discomfort.
2. Nervous system dysfunctions causing the pain messages to be inherently more sensitive, thus causing more pain.
3. Sleep patterns and therefore a lot of fatigue.
4. Depression and fluctuating emotions, some of which are frustration and disbelief at the unfair suffering in the first place, for having fibro.

The Osteopath looks at not only the symptoms above, but also the whole environment in the patient's life like: -

Drugs (prescribed or otherwise).

These can bring side effects, add to fatigue, cause other symptoms like headache and mood swings.

Diet, and nutrition.

Some people have a healthy diet, some don't, and this is nothing to do with or everything to do with fibro. Having a healthy diet is directly affected by mood, fatigue, pain levels and a whole lot more. Obviously sometimes we will be good, other times not! I love my cake and chocolate, but also eat fruit, vegetables and salad, and sometimes

I feel so bad that I eat more naughty food than I should (especially after a 4 mile walk when I am hungry).

Emotions.

Here we have depression, anxiety, fear, frustration, mood swings and you can probably name even more. The osteopath will look at the person's beliefs, behaviour, and levels of the aforementioned emotions and help with the whole picture.

As another principle of Osteopathy looks at the body as a self healing and regulating energy being, that the structure of the body is always hand in hand with the functioning, this area of medicine can look at how the body can be manipulated (Osteopathic Manipulative Treatment – OMT).

The patient can be physically manipulated, alongside medication, exercise, diet, and lifestyle to realign to body into a self-healing stronger position, both physically and functionally.

The Osteopath will look at the musculoskeletal structure of the body and other systems, and identify the entry points needed for treatment for OMT and other therapies.

Then the rational treatment is reached using the other principles by considering the unity of all parts of the human body, mind and spirit, alongside and affecting the self-healing and regulatory capabilities, which are all inter-related, and thus developing a management plan.

When looking at the structure and functioning of the human body consider joint motion – this is important, since the joints need to work properly to be able to regulate lymph drainage and vascular drainage back to the general circulation.

When we look at a particular symptom of fibro, which is sluggish lymph, this is important, since osteopathy improves the structural movement of the body to keep such circulation flowing.

Cranial Osteopathy.

This is another part of the Osteopaths arsenal of therapy, since its use is great for headache, pain, fatigue, stress etc. Ringing bells now?

The cranial osteopathy helps maintain brain functions, and since there are a lot of brain abnormalities like little or no serotonin and tryptophan, balancing of the brain, spinal cord and the cerebral fluid is vital for the relief of fibro!

There have been some good results for fibro patients, even after a few sessions of the above, and can reduce the other symptoms of fibro too!

If you are considering going to see an Osteopath, remember to check their certification, experience and have an initial consultation first to explain all that you have to face with your symptoms. Write everything down and be completely honest.

The sessions are usually an hour or more, and will cost roughly £45 - £60 per session, depending on length and overhead cost levels to the practitioner in question.

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.

Here at Firzone, we stock a range of portable FIR saunas and blankets to suit all requirements and budgets.

FIRZONE 

www.firzone.co.uk
Tel: 0845 680 7671 E: sales@firzone.co.uk

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 - Keeping costs low during major changes to the group

By Julie Barker - Chairperson

In this article we will be exploring the processes including keeping costs low when going through major changes to the group.

When there are big changes in a group or organisation there are financial consequences too. Things to consider are: rebrand, existing commitments, timing the announcements and ensuring you have notified as many people as possible.

Don't just rely on social media

The digital and online information can easily be changed with little cost, however, there are still people who do not have email, Facebook or an Internet connection and a few don't have a mobile phone. This has especially become evident during our outreach programme when people approach the stall and have never heard of us, even though we have heavily advertised in social media and in the local community magazines.

Over the past 2.5 years we have regularly posted on Facebook in all the local community and selling sites, but found that people will react most when they have seen our photo and article in the local magazine. So, although advertising is low cost and effective online we also need to be mindful that we need to reach the community with more tangible methods.

The first major change

The first major change to the group was the split back in January. We were fortunate to be able to keep the group name and branding. However, our leaflets contained 50% information that was now obsolete. I hated the thought of having to throw the old leaflets into the recycling, it seemed such a waste but, in this instance, we had to absorb our losses and design and print a new leaflet. The pop-ups and banners had both groups' names on, but we continued to use the pop-ups at our group's meetings and the banners we didn't need for the time being.

Breaking News

To announce a major change, it's usual practice to do a press release. This can be emailed to all your contacts and published online and in the local magazines in the community section, to reach all audiences and it doesn't cost anything. Immediately after the Special General Meeting we sent our press release to all our connections and to the local magazines. It was also posted on our Facebook group page. This didn't cost anything and was the most affective method of 'breaking news'.

Launch your new look

We took our time re-designing the leaflets as we were being advised by our funders about the government's '5 ways to Wellbeing' and how groups were being encouraged to incorporate them into their programme. We unknowingly had already done this and it was just a case of presenting it, so we used the time to design the website and leaflets, giving the group a fresh look but keeping the original logo. As other parts of our programme were falling into place we were able to launch everything at 'Spring into Action' in April and the 'Awareness Day' events in May.



Reducing room hire costs

A few weeks after the launches we were notified that the room hire was due to rise in September. Initially, we were determined to stay put because of the support we receive from Erewash CVS, which we had received right from the group's incision. However, realistically, we hadn't covered the rent with subs alone since we started and raising the costs would mean even more pressure on fundraising as funding pots are getting harder to find. We had a look at a couple of venues; they were either not suitable in the winter or too expensive. We tried our luck at Petersham Community Hall, the rent was nearly half the price we would be paying. Jane and I had trained there for the past two years at our Tai Chi classes. It was a lot quieter as we would be the sole users of the hall. We knew it would be really hard to get in there, but we were able to get two, two hourly slots each week and with a little jiggle of the meeting times we were accepted! This has saved us £30 a week.

Moving needs planning

We were able to move the Tai Chi classes at the beginning of the next course, which started at the end

of July. This was straight forward as all we needed to do was change the details on the leaflets prior to sending them for print. The move would still be straight forward for the group, but we would need to fulfil our current commitments to the July and August programme. After giving our notice to Erewash CVS, we used the time to send out press releases and write articles for the local magazines. We put notices up on our outreach stalls and kept referring to the change on our Facebook group page to ensure members didn't forget.

Keeping costs low

It was also time to look at the pop-ups and the banners as we would soon need them, and I was able to get our printers to cover the group names with our website address. This cost £35, as they were economic with the space on the material, as opposed to £300 to completely replace them.

We don't seem to have much luck with our leaflets, first we split, and now we are moving! We still had 700 leaflets, so I approached the printers and they said it would be just under £70 for printed stickers to cover the old venue details. They suggested that we discard the leaflets and just have them printed again which would be £125! Jane and I discussed it and we thought it would be unethical to throw away all those leaflets, at the cost to the group, so we looked into buying our own stickers and printing them. The stickers cost £18.99 and we will print them, as we need them to absorb the costs over time. Another £100 saved.



Keeping group information generic

One thing we have learned from this year is to try to keep the information on the main advertising mediums as generic as possible to reduce the amount of changes that may need to be made. Having said that, sometimes you just have to put it out there, to stand out from the crowd and invite people in.

At this point we also looked at the information about the Tai Chi Sessions and decided to separate the Tai Chi information from group information and to make the leaflets more generic. The Tai Chi information will be mostly electronic, sign posting people to our website, so reducing costs for printing.

New programme

Changing venue also meant changing the programme and this is where we could incorporate more costs, as

the new venue is available on a weekly basis, so we are able to extend our programme content.

The first thing I was able to do is move the monthly walks to a weekend, enabling us to include our Facebook members. The walks are essential to the 'active' part of the programme. However, they were not as popular as we would have liked them to be, also, it broke up our member's routine if they were not planning to attend.

The Tai Chi could now be alternate weeks all the way through the programme. This brings greater consistency to the members who are learning the programme.

We are now able fit in the popular arts and crafts that our members have requested and devote a whole meeting to it. This will enable us to look at making things to sell on our fundraising stall and help sustain the group.

Open Minds have been interested in working with us for about a year now, but we were unsuccessful in gaining funding for them. They are coming along once a month to add some spice to the cuppa and chat sessions and with their own funding! We have also gained space for some holistic therapies including: hypnotherapy, Reiki and natural wellbeing products.

Moving has given us greater capacity in the programme as a whole and we have our own notice board so that other hall users can see what is happening.

We have made it through a roller coaster year and we have come out of it savvier, less complacent and much stronger. We have a fabulous new look, new website, new programme and we have kept the costs low!

I would not have got through it without the support of our Treasurer: Jane Gordon. Her commitment to ensuring the group runs smoothly and her passion for Tai Chi has helped me drive the group forward.



In the next article I am going to feedback how our fundraising and outreach season as gone including how the Fibro 5 Challenge went, debrief and discuss starting plans for the next outdoor season.



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 would like to know whether the Fibromyalgia that I have developed is because I was in a road accident. My doctor says it could just be coincidence. How do I know whether it has been brought on by the road accident or not?

Kate

Dear Kate,

The doctors whom we instruct for our clients will generally ask themselves the same sort of questions when trying to work out whether the accident has been the trigger for the Fibromyalgia.

They will want to be sure that there were no pain complaints before the accident similar to those experienced after it and they will obviously be looking for a history of a trauma such as a sudden, acute trauma as happens when your car is hit by another one.

The doctor will see whether your pain ever disappeared completely at any stage. He will want to know whether it continues to be a problem even though it may have improved, stayed the same or worsened.

You will appreciate that lots of people who develop pain after an accident will not develop Fibromyalgia. It takes time for the Fibromyalgia to become apparent and doctors will generally wait at least six months from the onset of the accident to make a definite diagnosis. The jerking of the neck in an accident will often cause soft tissue injuries which could go away within weeks or may take several months. By six months, the major healing of soft tissues, sprains or other injuries would have occurred, leaving the doctor able to make a reliable diagnosis of Fibromyalgia and link it back to the accident if that was the probable trigger.

Brian Barr

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by
Kayleigh Roberts
& Christine Harris



Food for Feelings

Politics and religion aside, few issues seem to spark debate and trigger emotions at the dinner table more than people's eating habits. What has everyone so passionate and disgruntled over veganism, gluten free diets, whole foods plant-based diets, grain-free diets, vegetarianism, and other food lifestyles? The conversations often seem less about health or personal decisions and more about emotions. Of course, there are always new eating trends; social and economic reasons for these choices, but all that aside, let's explore why food is so emotional.

The olfactory sense of smell intimately connects with memories. Naturally, the sense of smell and taste are closely linked; that's why we say "that smells so good I can taste it". It's no wonder some food tastes like childhood or what Mum used to make, and sends us off into an emotional nostalgia... and also possibly a mindless binge.

Food and emotions are heavily linked, and likewise food and health are integrally connected. What you put in your body fuels your life. How your body feels largely controls your emotions.

We've all done it. We have tried to eat our feelings only to be left with an empty ice cream container, emptiness and guilt. So how do we get what we truly want out of food without compromising nutrition, taste, time, and money?

Slow Eating allows you to savour and enjoy your food. It's estimated it takes your brain around 20 minutes to register that you are full.

Whole Foods and Plants are packed with nutrients your body needs. Try incorporating new fruit, veg, and legumes into your meals.

CSA or Community Supported Agriculture subscriptions provide a share of what is being grown at local farms that is generally delivered to your house or a nearby pickup location. Because it's such a direct exchange, CSA subscriptions help local farms and helps customers save money and time at the grocery with a subscription of boxes of fresh fruits and vegetables.

<https://communitysupportedagriculture.org.uk/>

Meal Prepping saves time throughout the week. After the initial time investment to cook large portions, divvy them up into serving sizes, and freeze or store them. You are then left with ready meals when you are in a rush or don't feel like cooking. Ditch constantly going out and fast food. Crockpot meals surprisingly can save more time, not to mention money, for on hand meals throughout the week.

Conscious Choices are yours to make. Food impacts us far beyond feeling or sensing immediate satisfaction. It can be difficult to gain control of these cycles with food, mind, body, and emotions, and it's often hard to know what actually is healthy beneficial food.

What better reason to start new memories and new habits? Start the kind of food memories that make you feel energised and empowered. Be in charge of your health and your body by making conscious decisions about what you put in your body.

Gradually change your food regime. Start cutting out or reducing inflammation causing foods: sugar, soft drinks, fast food, packaged food, and gluten. Add plant based whole foods together with lots and lots of fruits and vegetables.

It's not all or nothing. Starting anywhere is progress. Small but markable goals like challenging yourself to eat vegetarian once a week, not adding sugar to tea, or enjoying the sweet taste of fresh local fruit makes a difference if you are consistent.

Black bean soup is a great starter. Black beans, peas, and lentils are excellent ways to reduce inflammation.

Eat Less, More Often. Eating smaller portions more frequently when you feel hungry makes it easier for your body to digest and use nutrients.

Create a routine. Make nutritious food fit with your lifestyle. It may mean trading a snack cake for pitted dates or a fresh smoothie.

Pay attention to what you're eating. Take the time to chew and experience each bite. Slow down. Savour your experience. How does it make you feel afterward? Does it give you energy?

What type of lifestyle and food memories do you want to pass on? Moving away from mindless eating, and instant gratification, we can choose eating habits that empower and enable us a greater mobility and emotional stability.

Build Your Strength

Turn off the distractions and pay attention when you are eating. How do different foods make you feel? More resilient? Sturdier? Or, stronger?

Be sure to check out our Next Article on Starting Easy with Natural Anti-Inflammatory Foods.

www.ChristineHarrisTherapy.com
twitter.com/YCWBTherapy Let's connect!

The Therapeutic Effects of Pets on Fibromyalgia

If you've ever owned a cat or a dog, you know first-hand how pets can be a source of comfort. Their loyalty and unconditional love work wonders, especially for those of us suffering from fibromyalgia.

Pets can be especially comforting when our fibromyalgia causes us to lose our job, important relationships, or the ability to do the things we used to enjoy. Caring for a pet helps us to focus on someone other than ourselves. We need to walk them, bathe them, feed them, and clean up after them. But we also get to enjoy snuggles with them.



Pets have a built-in sensitivity to our pain and sadness. They can crawl up onto our lap or lie beside us in bed and help us to feel comforted.

Studies have shown that spending even a short amount of time with a pet can help to reduce stress, anxiety, and pain.

In one such study published in the journal Pain medicine researchers added a trained 40-pound Wheaten Terrier therapy dog to a chronic pain waiting area. When fibromyalgia patients were waiting for their doctor or therapy appointments, they were given a choice to either spend time in a traditional waiting room with a television and magazines or go to a different room with the therapy dog.

People were asked to rate their symptoms before going to either waiting area, and again after spending just 15 minutes there. The results are likely not a surprise to those of us with pets.

For this project, 84 people with fibromyalgia spent time with the dog and 49 waited in the traditional waiting room. The conclusions researchers came to were that:

- Spending time in the regular waiting room didn't make symptoms substantially better or worse.
- Spending time with the therapy dog significantly reduced levels of pain, anxiety, and distress.

Pain was rated using a pain scale rating from zero for no pain to 10 for excruciating pain. The study looked for a drop in pain severity of at least two points on this scale to represent what's referred to as "clinically meaningful pain relief."

Clinically meaningful pain relief occurred for one in three people meeting with the therapy dog (34 percent of people) and only 4 percent of people waiting with the television and magazines. Those are amazing statistics! Spending time with the therapy dog was also shown to improve people's moods, with absolutely no change in the patients in the regular waiting room.

Who would have thought that just spending a little time with a dog is all we need to do to make our fibromyalgia symptoms lessen?



What can those of us with fibromyalgia learn from this study? If you have a dog or even a cat at home and have thought, "I feel so much better and much less stressed when I spend some time with my pet," you've just validated this study. People with a pet dog, cat, or any pet, really, often find time with their pets to be soothing. It's more than just a distraction — it can truly help you feel better.

If you don't have a pet, perhaps you might consider volunteering at a local animal shelter. Shelters are often looking for volunteers to walk dogs or cats. Just think, you could get a healthy dose of pet time without the added daily responsibilities of pet ownership. Just a thought.

<https://fibromyalgianewstoday.com/>

Make your workday a less painful experience

Give your body a break, especially if you're working in a sustained position or performing repetitive actions. Turn away from your computer to relax your neck and rest your eyes, or get up and walk around the room.

Arrange your work area so you have easy access to everything.

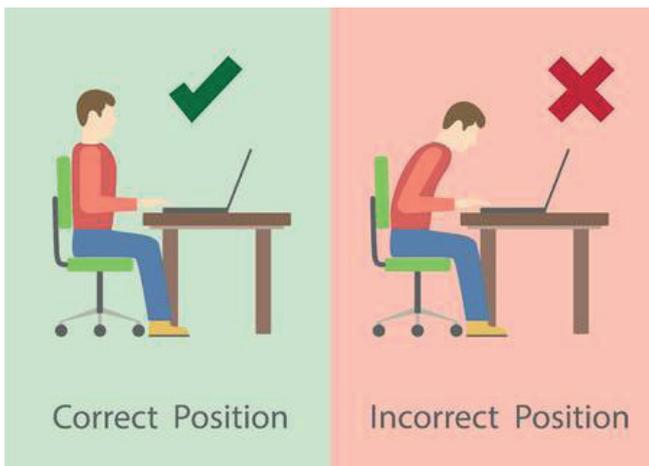
Pace yourself. Don't attempt all your heavy assignments at once. Plan ahead—but realize those plans may change based on how [you] feel."

Make sure your computer screen is at the proper height, so that you don't crane your neck to read the screen.



Wear a headset when you talk on the phone. Do not cradle the receiver between your shoulder and your ear.

Establish good ergonomic habits. "Have the body in the most neutral position you can," says Hagen. "Legs should be at a 90 degree angle to the floor. Arms should be at a 90 degree angle to the keyboard." She recommends using a chair without armrests, and not only because the rests are usually set at a height that contorts the body. "Any time you lean on something, or you have a part of your body resting on something, you're putting pressure on it," she says.



Allow your chair back to support your back. Help the postural muscles with pillows and firm backrests. Rest your feet flat on the ground, making sure there is a space cleared beneath your desk so you have plenty of legroom.

Stand on a padded mat to decrease fatigue.

Wear padded gloves to reduce vibrations from machinery.

Exercise. Home exercise programs can include aerobic exercise, strength training, postural, balance, and neural mobility exercises. Use a document holder, rather than laying a document on the desk and craning your neck to read it.

Install an anti-glare screen on your computer monitor.

Adopt pain modulation techniques. These may include breathing techniques or movement therapies such as Feldenkrais.

Experiment to find what's comfortable for you. "here's no one answer for everything."



Whether you need to rearrange your schedule, buy an ergonomic keyboard, or move your office furniture, take control of your workday and make your workspace work for you—not against you!

Endocannabinoid Levels Elevated in Fibromyalgia, but They're Not Ideal as Biomarkers, Study Finds

Endocannabinoid (EC) levels in the blood are elevated in women with fibromyalgia. However, the findings do not support using these factors as disease biomarkers, researchers said.

Their study, "The relationship of endocannabinoidome lipid mediators with pain and psychological stress in women with fibromyalgia – a case control study," appeared in *The Journal of Pain*.

Researchers currently regard the endocannabinoidome, which generally describes the endocannabinoid system, as a potential therapeutic target for chronic pain. This system is composed of lipid (fat)-based neurotransmitters known as ECs, which bind to specific receptors throughout the central nervous system.

The endocannabinoid system is part of the immune system and affects pain and inflammation. Different ECs have shown analgesic properties via activation of cannabinoid (CB) receptors 1 and 2. The endocannabinoid system also includes N-acyl ethanolamines (NAEs), which are lipid mediators that do not target CB receptors.

Besides their role in pain and inflammation, research suggested that components of the endocannabinoid system could be crucial regulators of emotions and cognition.

The research team from Sweden had previously described different levels of NAEs in women with chronic widespread pain, a typical manifestation in fibromyalgia, than in controls. However, the evidence on these mediators is still limited.

The scientists now analyzed plasma levels of different ECs — arachidonylethanolamide (AEA), palmitoylethanolamide (PEA), oleoylethanolamide (OEA), stearoylethanolamide (SEA) and 2-arachidonoylglycerol (2-AG) — in 104 women with fibromyalgia and in 116 healthy controls.

They assessed correlations between these compounds and pain characteristics, psychological aspects, and health status, while also exploring their potential as biomarkers for fibromyalgia. All women were required to rate their pain, anxiety, depression, and current health status.

Results revealed that levels of OEA, PEA, SEA, and 2-AG were significantly higher in fibromyalgia than in healthy controls, but only OEA and SEA remained significantly different after accounting for age and body mass index (BMI).

The data also showed that the higher the concentration of 2-AG — one of the better characterized ECs — the longer the duration of fibromyalgia and the higher the BMI. However, 2-AG correlated negatively with pain, anxiety, depression, and health status.

These results of 2-AG may suggest this compound is the strongest candidate to serve as a biomarker for fibromyalgia, but the large variability in its levels indicate other factors may be better suited.

In the group with fibromyalgia, levels of AEA were higher in women with higher depression ratings. However, no differences were found between AEA levels in women with fibromyalgia compared to controls.

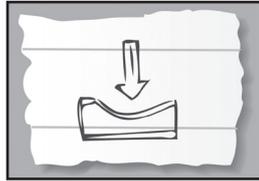
"The elevated circulating levels of endocannabinoidome lipids suggest that these lipids play a role in the complex pathophysiology of [fibromyalgia] and might be signs of ongoing low-grade inflammation," the scientists wrote.

But because their role in clinical manifestations is uncertain, the authors said that "plasma lipids alone are not good biomarkers for [fibromyalgia]."

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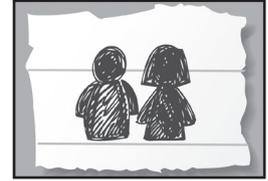
UK Fibromyalgia Website
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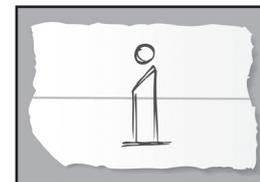
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