

The

Fibromyalgia Magazine

Support for the FM FaMily

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Fibro Parenting: 10 Tips for a Cool Summer

by Brandi Clevinger



Also including:

How to set up and run a Fibromyalgia Support Group

By Julie Barker

Mind over Matter

by Emma Stark

Your Amazing Mind/Body Connection

By Linda Hall





How to set up and run a Fibromyalgia Support Group: Part One

By Julie Barker – Chairperson Fibro Active

(Anyone can start a group – why don't you? – ed)

Introduction

My name is Julie Barker and I am the Chairperson of Fibro Active Long Eaton and Ilkeston. I have been kindly asked to write a series of articles on best practice setting up a support group. In this first article, we will look at partners who came on board to help launch the group, the hurdles we came to along the way and the development of the groups aims.

Throughout this series, the secretary, treasurer and myself will cover key areas such as: programme content, setting up a committee and formalising the group, funding and KPI's, membership and growth, marketing and promotion, fundraising and self-sustainability and volunteers and training and hopefully by the end you should all have a do's and don'ts guide if you find there is a need in your area to set up your own support group.

The hardest part now is to write about me in as few words as possible and keep it interesting! I was finally diagnosed with FM in September 2013. I'd never been a well person right from an early age. My Dad had suffered most of his life with a series of Chronic illnesses and I was following in his footsteps. The first thing I did was read a book by a doctor and a book by a sufferer and I traced back to the beginning of my symptoms when I was 14 years old when I started the school year off with a month of Flu, mumps and sinusitis. From this point, onwards my life path changed. Identifying the symptoms put so many pieces of the puzzle together and allowed me to understand why things happened throughout my life when they did.

Sadly, I lost my dad 2 1/2 years ago in December 2014. I found myself isolated and alone in the worst flare of my life. Dad had been the only person I used to compare notes with and I didn't know anyone else who had FM or CFS.

About Feb/March 2015 I met up for coffee with one of my ex colleagues at Sporting Futures, Kev Hatton. He was now a development worker for Active Erewash. He was so shocked to see me bent over propping up a walking stick as the last time he saw me I was a boxing coach! He asked if I had any support. Kev suggested setting up a support group. At that time, I was too ill to manage anything like that. I needed a group to support me! I agreed to be an advisor as we set the group up.

We spent a good 9 months throwing ideas back and forth over emails. Kev liaised with the Wellbeing Team who came on board and contacted local health teams to banter ideas. The feedback was positive. We started to make plans and produced a 'to do' list before we could start.

Suitable meeting place.

We needed a regular meeting place, somewhere solid we can call a base. It's ok using free hire rooms but there is no stability. Moving around wasn't an option due to mobility and members getting mixed up where they need to be each week. We had to take environmental factors into consideration such as noise, smells and lighting. Also, members with higher levels of anxiety needed a routine, familiarity and to feel safe.

Kev used his contacts and approached Erewash CVS, our local volunteer centre who are based in an old Mencap building which has a hall, meeting rooms, a kitchen area for refreshments, lots of tables and chairs, disabled access, its quiet, there's parking and above all it has a friendly and professional team who have become an integral part of our success.

Kev was able to negotiate 6 weeks' free meetings while we waited for funding to come through. This enabled us to write a 6-week programme, book organisations and guest speakers and recruit new members. In the meantime, Kev started writing a funding bid to apply for room hire and setting up costs.

When would we meet?

The time and day you want the meetings to take place is important. It takes many of us a long time to get up in the mornings and we only have a short window of activity before we run out of spoons so the times were torn between 11am and 1pm and 1pm and 3pm. With many people having the school run we went for the 11am start. Also, how frequently would we meet. I felt a month was far too long to wait between meetings especially if you are alone. So, we opted for weekly.

Where would we get members? We need referrals.

Based in Kev's office is the Well-being team. They could email local surgeries and health practitioners and give them the information they could also welcome referrals.

Training and knowledge

I was concerned that if this group was to be run by the council staff then they would have to have some knowledge of how our illness affects us. If FM sufferers realised the course leaders didn't know much about Fibro, they wouldn't come back as they are using up valuable energy supplies to attend and that meant to keep them coming we needed to be on the ball!

I put together a training presentation highlighting symptoms and syndromes, flares and tender points etc. and a few interactive workshops to highlight how our illness affects us doing everyday tasks.

A select few attended who were interested in becoming involved with the group. At the beginning of the session I asked everyone in the room to make a note of any aches and pains, funny feelings, fatigue etc. during the course. I returned to this at the end and no one apart from Kev who has an existing back problem said they had felt anything. I had kept a note of my symptoms and held it up. The list was nearly a page long. I read it out and in that moment, there was a gasp of realisation and a sense of respect for FM sufferers. They couldn't believe that I had just delivered that session with all that suffering. They began to understand that we needed to keep the group positive.

Our aim

Our starting aim had to be **positive and inclusive** we were not going to be a negative forum! One of the most difficult hurdles in the beginning was getting members to sign up to the Facebook page because 'they didn't want to be on another negative forum!' Getting them to attend sessions that 'they thought were going to be sufferers moaning about how much pain they are in...' Can you imagine a room full of FM and CFS sufferers consuming each other's negativity? No I wouldn't want to be there either!

We also needed to look at the best practice in managing the illness. After seeing what my Dad went through, I didn't want to promote ineffective medications also, none of us are qualified too either and it would be irresponsible of us as there could be secondary illnesses and what works for one may not work for another. So, we opted for a healthy lifestyle and light exercise and learning your limitations route, that would help boost a positive and inclusive image.

We needed a name for the group. This I think was one of the hardest decisions and after brainstorming

options we agreed on Fibro Active to compliment this new positive and healthy image. We had the basic ideas together, enough to be able to launch.

Launch

I think it was new Year, Kev and his team started spread the word that we were going to hold a launch event on March 3rd 2016. We kept it simple by printing off some of the images from the training session and Kev created a signing in sheet. We planned a few refreshments and a meet and greet type session bouncing ideas around. A date was also set for the first meeting at the end of April.

After all the planning, I was called away at short notice and was not able to attend the launch. When I returned, I found we had 8 people turn up! I was a little disappointed because if it is estimated that 1 in 20 of us suffer with it, where was everyone?

In the next edition we will be looking at the programme, how it has developed and the changes made to accommodate room hire and funding requirements and more barriers to overcome.





ASK BRIAN

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

Dear Brian

In 2002 I joined the NHS as an Oncology Engineer. I had four bouts of viral illnesses in 2004. My Manager refused to accept that there was anything wrong with me. In April 2008 I was diagnosed with Polymyalgia Rheumatica and Fibromyalgia.

I am currently off work following three more viral illnesses. I tried really hard to keep working, even turning up to work after heavy snowfalls. I have, however, received little in the way of concessions from my employer to assist me to continue working.

Are my employers obliged to help me with this illness? What sort of help or support can I reasonably expect?

Graham

Dear Graham

Your two medical conditions could be regarded as disabilities under the Disability Discrimination Act, but each case would be looked at individually. To be afforded the protection of the DDA you must be regarded by the Employment Tribunals as someone who has a physical and mental impairment that has a substantial and long term adverse effect on your ability to carry out normal day to day activities. Some people with Fibromyalgia would be regarded as disabled individuals under the Act whilst others would not.

If you are regarded as a disabled individual under the Act your employers would have a duty not to discriminate against you on the grounds of your disability and to consider reasonable adjustments. This could include, for example, allowing you to work from home, work different hours or move you to a location closer to your home. There is no obligation on an employer to make such adjustments – they simply have to consider them.

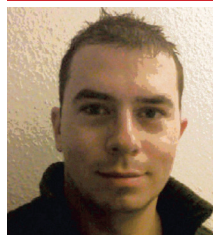
We recommend that individuals contact the Equality Commission for Human Rights as they are able to offer further assistance. Costs are rarely afforded to the successful party in Employment Tribunal Claims so if you would want to bring such a claim yourself you would either have to fund it or you might be covered by Legal Expenses Insurance, although that is doubtful.

If you have a great deal of sickness absence and it is not reasonable for your employers to be able to cope with that absence, your employers may well be able to go down the capability route with a view to dismissing you.

Brian

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THE FIBROMYALGIA EXERCISE COLUMN



Varying Your Training by David Jenkin

Any exercise is good exercise, and everything is better than nothing, but in order to really develop your exercise capacity, it is always advisable to vary your training from time to time. This stops the body from acclimatising to the same challenges and limiting the extent of your improvement. In practical terms this doesn't necessarily mean you should go from a yoga class to rock-climbing, but it does propose that ONLY doing yoga will mean that there are several components to health and fitness that will remain forever untapped, and for as long as the body is only exposed to the same challenges, other challenges will remain forever untouched

So what does exercise variation actually mean for you? Well first of all there are FOUR different exercise components – cardiovascular, muscular strength and endurance (gentle muscle strengthening of upper and lower body), core strengthening (strengthening abdominals, waist, lower back and postural/balance muscles) and flexibility. You should aim to achieve all of these through one exercise or another. For example, someone who goes to that sole yoga class, even two or three times a week, is comfortably meeting their goals of core development and flexibility, are lightly approaching some muscular strength and endurance training, but achieving nothing on the cardiovascular front. So my recommendation to such a person would be – keep doing what you are doing, but factor in some muscle strengthening exercises at home, and start undertaking some cardiovascular tasks like a 30min walk every day, or swimming, cycling or even something more strenuous like aerobics if you are able

So take a few moments to evaluate what exercise you presently do, and where your gaps lie, and set yourself the challenge of addressing these by incorporating new exercises in your regime to maximise your potential!

Martin Westby and I have 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://tinyurl.com/o9s6bw8>

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.

To contact me or enquire about 1:1 training prices www.davidjenkinfitness.co.uk



Why is sleep so important to Fibromyalgia Sufferers?

By N:rem Sleep System

Sleep helps the body and mind in many ways. When we're sleeping, our brains are actively working to process the information from the day in to our long-term and short-term memory. Good sleep not only helps our bodies and minds to rest and repair, it allows us to perform better too.

What happens when you sleep with Fibromyalgia?

Many Fibromyalgia sufferers say they feel lucky if they reach 5 hours' sleep a night. Do you ever find yourself stuck in a vicious cycle? Pain makes it difficult to sleep, but sleep deprivation means the body can not repair itself - making the pain worse. Lack of sleep also causes stress, lack of coordination and agility, weight gain and poor judgment. The last thing that a Fibromyalgia sufferer needs.



How to Drift in to a Restful Slumber

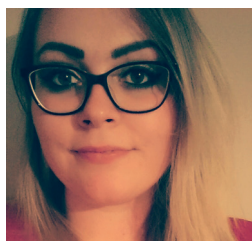
- 1. Resist the afternoon caffeine rush:** It will take your body up to 7 hours to process only half of the caffeine in your cup of coffee. We know it keeps us awake, so try to make your last caffeinated drink before 2pm to give your body chance to process it before you hit the hay.
- 2. Set a bedtime:** Train your body to feel tired and awake at the desired times by going to bed at the same time every night, even at the weekend. It will help you to fall asleep faster, sleep for longer, and wake feeling more refreshed.
- 3. Keep your cool:** When you sleep, your body temperature naturally drops. Keeping your bedroom cool (not cold) should help to ease you in to a deep sleep. The ideal temperature is between 18-21C.
- 4. Ditch the screens:** Your body will not produce enough melatonin (sleep hormone) to help you sleep if your brain is stimulated by the blue light emitted from your phones, laptops and TV screens. Stop using electronics at least an hour before bed. A good book and some soothing music is a far better option.

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Mind over Matter

by Emma Stark

Have you ever wondered how much your mind impacts your health? I know when you're having a bad day and everything is screaming at you the last thing you want to do is be cheerful, however, what if I told you this might be the best medicine? You can have the best diet and routine, but if you don't believe in it, chances are, it's not going to work.

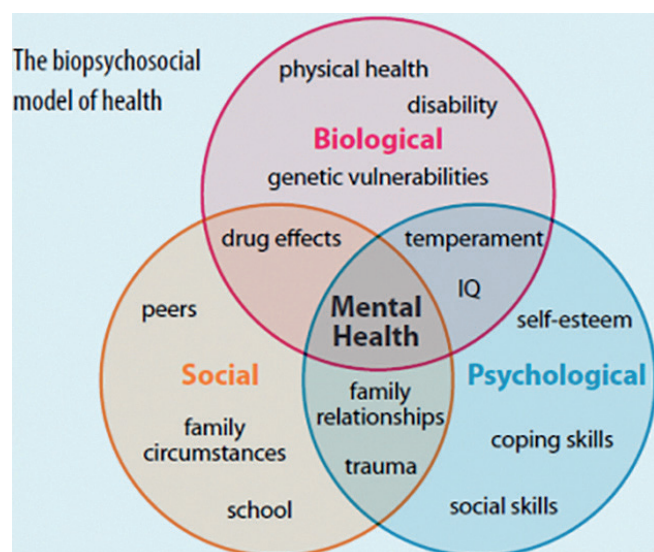
Last month we covered the importance of probiotics and how to spot food intolerances and sensitivities. However, not all stomach issues can be linked back to either of these issues. Unfortunately, Fibromyalgia wreaks havoc on our insides without there being further investigating required. I'd like to go into this a bit further and provide as many natural methods to give relief.

Let me explain.....

Many years ago, Drs. George Engel and John Romano carried out a study to demonstrate the effects of stress on the stomach. Their test subject, baby Monica, suffered from esophageal atresia which meant that she was born with an esophagus that didn't join up to her stomach. It's not uncommon, however; often requires several surgeries. Before baby Monica was considered for surgery she was the perfect test subject to demonstrate what stress can do to the stomach as the Dr's were able to monitor her gastric excretions with having immediate access to her stomach for feeding purposes.

The study involved getting Monica used to the two Dr's with one major difference. One would be playing friendly Dr and the other would be playing scary stranger. Ok, so this sounds particularly crueler than it is meant to. The main difference as that happy Dr (Romano) would spend lots of time with Monica so she was at the stage where she was excited to see him. It got to the stage that whenever he entered the room she was cooing away, smiling and happy to see him. Whereas for scary Dr (Engel) he wouldn't try to entertain Monica, just come in and out leaving her feeling uncertain and a little afraid.

What this proved is that how we feel and what we think, impacts our bodies. When happy Dr was in the room, her digestive juices would be flowing! However, when scary Engel entered the room her gastric secretions would stop. This is where the biopsychosocial model was developed, showing how biological, psychological and social factors impact health.



The biopsychosocial model I believe is one of the contributing factors to why fibromyalgia is different to each person. No one case is ever the same and it's often because we all have very different things impacting our health. Not just biologically, but socially and psychologically too. For some of us our diets being overhauled can make a huge difference when others eat well and continue to suffer symptoms due to being in stressful situations past and present. What I'm saying is that we are all different and sometimes it can be discouraging to try something new and gain nothing back but to really manage fibromyalgia we need to get to the causes of these symptoms and help ourselves improve them. It takes a lot of time get used to managing a chronic condition as you need to learn to manage so many different factors at once. To help ease the transition I thought it would be good to share some herbal and natural medicines so that we can at least ease off some of the symptoms.

It can be difficult to know what to take for your stomach issues with some of us already being sensitive to certain medications and interactions from others. I like to refer to the power of nature first and look for a natural route free of chemical nasties. However, you should always consult your doctor before taking any medicine, especially if you are already on prescribed medication or if you have other medical illnesses as they may interact with them.

Herbal remedies are often referred to as alternative medicine. This is a common misconception as most pharmaceuticals come from botanicals so herbal remedies should be seen and treated as a powerful medicine when used in the correct doses.

I went on holiday to Gran Canaria and while I was there I noticed there was Aloe Vera products everywhere! It's grown local you see so you get the freshest product and lots of local knowledge. I ended up buying an Aloe Vera gel with devils claw which I swear works better than deep heat and smells lovely and makes your skin soft! It really got me thinking more about the power of natural medicine. When it comes to Aloe Vera, it's a bit of a wonder plant really! If used externally as a topical cream it can soothe burns and treat wounds. If used internally it treats the inflammation which is caused by mouth ulcers, inflammation in the lining of the mouth and any irritation in the gastrointestinal tract. It's also a potent laxative if used in the powdered form.



Ginger is the most studied herb for nausea and vomiting as it helps with pretty much any kind of nausea with multiple studies showing great success and most importantly, no adverse side effects! I like to make up a hot drink with lemon and ginger when I feel nauseous and it does help settle my stomach as well as adding to my antioxidants of the day.



When it comes to heartburn and acid reflux, prevention is better than cure. I suffer from G.O.R.D and it used to drive me mad. I was forever taking anti acid tablets and that was on top of taking omeprazole to prevent it. There isn't really one size fits all with what triggers it. For instance, most people get heartburn from onions and spicy food where I could literally eat a bowl of spiced onions and be fine but if I have something fatty it's terrible. So, the most common triggers are – cooked tomato sauce,

excess caffeine, chocolate, carbonated beverages, fried foods, smoking, alcohol, animal fats, food high in fat and dairy. If you try and get on top of what triggers your heartburn you can begin to control it. For me, changing my diet to plant based foods only and getting rid of anything artificial has helped me leaps and bounds from reducing my inflammation to healing my stomach. As a bonus, you do tend to increase your nutrients by eating more plant based foods as you are more conscious of making up your nutrients from lack of animal products. While you figure out what the triggers for you, one of nature's remedies is liquorice, the type to take is labelled DGL which is the form of liquorice that doesn't increase your blood pressure. You should also speak to your doctor about getting tested for the Helicobacter Pylori bacteria that may need treated separately.

Peppermint slows down the gastrointestinal tract by slowing down the movement of food from the oral cavity to the colon and inhibits smooth muscle cell contraction which means you'll have relief from your spasms and cramping. If you are going to buy peppermint tablets, make sure they are enteric coated otherwise they will cause heartburn. I tend to just drink a few cups of peppermint tea each day to gently calm things down a bit. Everyone's different a little trial and error normally helps!

The above natural remedies are purely for gastrointestinal issues. There are lots more remedies out there for all sorts, however; I know it can sometimes be tricky to know what the right thing is to take. For anyone interested in some further reading on natural healing and how your mind impacts your health there are lots of great books out there. I have recently listened to the audio books by the great courses on the Science of Natural Healing and Mind and Body Medicine. I'd recommend giving them a listen, I always believe knowledge is power and there is a lot of points that relate to fibromyalgia.

If anyone has any questions please don't hesitate to get in contact with me. Also, if there is anything you would like to see me cover in future articles please don't be shy! Get in contact, I love to hear from you.

Emma qualified as a nutritional therapist after struggling to deal with the symptoms of fibromyalgia and M.E. She has previous experience of strength and conditioning from being a rugby coach for years before becoming a mortgage advisor and having to leave her job for health reasons. Now she is committed to helping others with what she has learned and continuing recovery.



Fibro Parenting: 10 Tips for a Cool Summer, Part 1

by Brandi Clevinger

Summer is here: the sun is hot and the kids are squealing. Everyone else seems so excited for summer... so why are you dreading it?



If you are living with fibromyalgia, dealing with the heat is enough of a battle, so adding in the challenges that go along with the kids' break from school can be tough for fibro parents. In an ideal world, we would be able to just stay inside from the oppressive bright light and heat while all our kids lived harmoniously together. The summer would be one long air-conditioned Saturday filled with watching movies, snuggling with our kiddos, and enjoying the family time. Sounds heavenly, doesn't it?

But if you're like my husband and me, at the beginning of each summer, we break our necks to create a detailed list of activities for the family. Afterwards, we are ready to take on the coming months, full of energy. However, by the end of July, we realize that we haven't done anything on the list; we have just taken each day as it came. Regardless, the kids always have a great time, and that's what matters to my husband and me. Looking back on past summers, I wish we would have taken a more relaxed approach and just had some guidelines in place rather than a detailed to-do list that only stressed us out. Keeping this relaxed approach in mind, and with so many days of heat ahead of us, here are ten tips for a cool and refreshing summer that will keep your kids having fun and staying happy. And hopefully, they will help you look forward to summer again!

1. Safety First

Dehydration is always a primary concern during the summer months. Dehydration can lead to muscle fatigue and headaches – which happen to be the most common symptoms of fibromyalgia. If fibromyalgia symptoms plague your body, you have enough to worry about, so make it easy on yourself and drink up! While there is no clear-cut rule as to how much water is best, a good rule of thumb is to cut your weight in half and drink that many ounces of water each day (so if you weigh 150 pounds, drink at least 75 ounces of water each day). Two of my favorite ways to stay hydrated are eating fresh produce such as watermelon, and infusing your water with fresh fruit to add sweet flavor. These combined strategies should keep you hydrated, whether you are

inside soaking up the air conditioning, or outside basking in rays of sunshine.

Speaking of rays of sunshine...while they may be warm and enjoyable now, the ultraviolet, or UV rays can cause severe long term health effects if you don't protect yourself. They can easily penetrate the top layers of skin, reaching down to the deeper layers. Prolonged exposure to these UV rays can cause skin cancer, the most prevalent cancer in the United States. To stay protected this summer, slather the sunscreen on you and your family. The best sunscreen is one with a sun protection factor (SPF) of 30 or greater (for the UVB rays) and zinc oxide (for the UVA rays). Apply 20 minutes before sun exposure and every two hours after that for as long as you are in the sun.



Going to the pool can be a real treat for my kiddos and me, but I always stay alert at the pool no matter how experienced my kids get each summer. My kids are still learning to swim, so they are always supervised by either my husband or me, and we stress to them the importance of following pool rules, such as no running around the pool deck. We reinforce this each time we head to the pool. I get a lot of eye rolling and "I know, mom" from them, but I'd rather that than risk someone getting hurt. Drowning can happen fast, and it's more common than you might expect. According to the Centers for Disease Control and Prevention, drowning is the fifth leading cause of accidental deaths in the United States. Stay safe at the pool and avoid becoming a statistic. These few basic precautions will help keep you and your family safe during the long, lazy days. No matter what your plans are for the summer months, remember that a safe summer is a fun summer.

2. Quiet Indoor Activities

No matter how much my kids love to play outdoors with their friends and siblings, the hottest times of the day between noon and four can be unbearable. During these times, I encourage the kids to play indoors with their friends. You can imagine that having five children of my own plus a handful of friends under one roof can be a bit much for my sensory sensitivity and anxiety. Luckily, I have found a compromise: quiet indoor activities.

My kids don't enjoy playing their mobile devices for extended periods of time, so having quiet indoor activities at the ready is a must for my sanity.

Some ideas for activities include:

- Paper plate toss: Cut out the middle of paper plates and try to toss them onto an empty paper towel tube.
- Ball toss: Throw a ball into various sized buckets lined with a cloth to minimize the sound.
- Balloon tennis: Hit balloons with fly swatters for a quiet game of tennis.

Find more ideas at: <https://tinyurl.com/l8dfhun>

3. Refreshing Outdoor Activities

Even when my kids are outside playing in the less oppressive morning or evening hours, the scorching sun can still be a lot to bear. They can become cranky and miserable, too, as the hours outside add up. Keeping the kids cool with water games makes it fun and refreshing for everyone! Some ways to keep cool include filling a pool with water for wading and splashing, turning on a water sprinkler, or having a water balloon or water gun fight. Frozen treats such as fruit popsicles always helps, too. Choose whichever works best for you; just keep the kids cool and hydrated while having fun outside!

4. Routine, Not Schedule

In my article, [Why Routines are Important with a Chronic Illness](#), I stress the importance of having a routine rather than a schedule. A schedule is a set of activities done at specific times, while a routine is a set of activities done regularly, but at no specific times. It's essential to know the difference because a schedule can dominate your day making it stressful to cope with day-to-day activities. A routine is your habit of doing certain tasks during certain times of the day. For example, brushing your teeth and getting into bed around nine or so each night is a routine, not a schedule.

Having a routine during the summer will make it easier during those lazy days and keep away any stress of activities. Waking up, eating meals, and going to bed around the same time each day are the essentials. It's a framework of what each day will look like. No matter what you fill in between those necessities, the kids can still rely on waking up, eating, and going to bed about the same time each day. The routine will keep the kids from getting too restless and acting out from the unknown. It's also a bonus for us with fibromyalgia, as it minimizes flares of body aches, fatigue, and tense muscles.

5. Keep a Summer Bag

Keeping a Summer Bag in the car always is something I started a few years ago after my youngest daughter was born. At the time, we lived at the top of Apple Mountain that had a river running along the base of it. When my sister would visit, we would spontaneously take the kids

to the river to wade after a day of errands in town. Being that we lived all the way at the top of the mountain, we wouldn't go home just to get clothes, towels, or sunscreen. I would inevitably end up driving home with five sunburned, soaking wet kids.

After the second of these impromptu, unprepared river trips, I created the Summer Bag. This bag, which I keep in the car, has all the summer essentials for the kids and me. It includes:

- Towel, change of clothes, bathing suit, and flip flops for each person
- Sunscreen
- Bug spray
- Picnic blanket
- Hand sanitizer
- Beach toys
- Brush and hair ties for the girls

At first, this random bag in the car drove my husband nuts. It always would get in his way when loading groceries or other items into the trunk. He doubted the bag's utility, and he implied that I never even used it. I couldn't blame him, though. He works all day, so he hadn't been burned (pun intended) as many times as I had without it. But one day, during a spontaneous trip to the beach, he thought the trip was ruined because we had no extra clothes or towels. Enter the Summer Bag, and voila! There was everything we needed. He has never doubted the bag again.

Remember that the summer is about having fun and enjoying the break from school. These first five tips will help everyone relax during these next couple of months. The kids will have a fun time and get tired enough for bed. A great day is one that ends with a kid falling asleep as soon as their head hits the pillow at night!

Be sure to check back next month for the second part of 10 Tips for a Cool Summer! For all the activities listed above and more, please follow my Summer Fun Pinterest board at

www.pinterest.com/beingfibromom/summer-fun/

I am the writer and creator of Being Fibro Mom (www.BeingFibroMom.com) as well as a member of the Board of Directors and Fibro Parenting program director for the non-profit organization Support Fibromyalgia.

I am a follower of Christ, wife to a supportive husband, mother to four sweet children, and a fibromyalgia thriver. Being Fibro Mom was created in 2013 with the hope of helping fibromyalgia sufferers become fibromyalgia thrivers.

My mission is to advocate for parents while enduring the hardships of fibromyalgia.



Your Amazing Mind/Body Connection

By Linda Hall

www.audiomeditation.co.uk

Linda Hall is a meditation teacher, personal development coach and audio author with over twenty years experience in the integrative healthcare field. She runs meditation and mind-body awareness courses for patients at The Optimum Health Clinic, a leading UK clinic specialising in the treatment of M.E./C.F.S and Fibromyalgia. Her guided meditation audios for relaxation and self-growth are distributed globally.

The way you think has a profound effect on your health and well-being through its direct influence on your autonomic nervous system and your digestive, respiratory and immune systems. Your thoughts have the power to alter your body's internal chemical balance, and determine whether you are happy, sad, angry, frustrated, anxious, stressed or calm by triggering the release of powerful stress hormones and feel-good opiates - which you experience as your emotions and feelings. The intricate network of connecting pathways linking your mind and your body means that where you go in your head, your body goes too! The information highway works both ways: a long bath, soothing massage, pleasant stroll in the country or invigorating jog round the block, all demonstrate how relaxing the body calms the mind.

An organic bio-feedback system

This dynamic connection allows your body to act as an organic bio-feedback system, making information available to you about your needs and well-being so you can look after yourself appropriately. It also serves as a natural learning enabler. Vast amounts of information are stored in your neural pathways and 'body memory', making it unnecessary for you to consciously remember everything. Rather than being two separate units that communicate with one another, your mind and body form one interconnecting whole that constitutes the mind.

How habits are formed

Every experience you have is laid down in bundles of neural pathways and cellular memory, much like a software programme on the computer. Each time you repeat a behaviour, the neural pathways created to 'do' that particular behaviour are re-enforced - this is how habits are formed. It also gives rise to Classical Conditioning, otherwise known as the 'Pavlovian response', whereby your mind/body naturally becomes conditioned to expect outcomes associated with repeated past experiences. In this way, the 'fight, freeze or flight' stress response can all too easily become a default mode, creating a vicious circle of stress especially if you happen to be living with unresolved trauma, chronic illness, anxiety or pain. Over time, your mind/body tends to normalise states it has

become familiar with, and that's why you probably fail to notice just how stressed, exhausted or depressed you are until things have escalated to the point where the damage has already been done



Shaping your experience

How you think about any physical discomfort or emotional distress whilst it's actually happening to you, significantly effects your experience of it and your ability to manage it. Viewing your situation in a negative light or over-focusing and obsessing about things is likely to make matters worse because of the anxiety and tension this creates. Your nervous systems' stress response was designed to put your body on 'red alert', and limits your capacity to be rational and emotionally balanced. You need to be able to think calmly and feel steady in yourself when managing a challenging and stressful situation or condition.

Neural plasticity

You may not realise that you have any choice in the matter and, like most people, find yourself repeating old patterns of thinking and behaviour even when they don't necessarily serve you that well. Yet due to the extraordinary neural plasticity of your brain, you are able to grow an almost infinite number of neural pathways during your life time. This means you have a much greater capacity for change than you probably think! Old unhelpful habits can be exchanged for new, more useful ones. All that's required is for you to trust in the capacity of your mind and body to return to a relative state of equilibrium, (given the opportunity), and that you make a commitment to regularly practicing some basic mind/body awareness and mindfulness. As the mind/body connection works both ways, this can be done through a combination of a 'bottom-up' approach (engaging the body so as to address the mind) and a 'top-down' approach (engaging the mind so as to address the body).

Mind/Body Awareness Day-to-Day Practices

Bottom-up approach

Notice any tension caused by your physical posture and allow it to become more relaxed by doing the following several times a day:

1. Uncross your arms and legs and relax your hands
2. Breathe out fully. As you do so, allow your body to soften, loosen and lengthen
3. Allow your shoulders to lower to release tension in your neck, arms and spine.
4. Relax your belly
5. Slow your breathing down and breathe more from your diaphragm/belly
6. Become aware of the support beneath your body and the ground below you
7. Notice the feel of the air on your skin and the sensation in your nostrils as you breathe it in and out.
8. Become aware of your surroundings
9. Breathe out down the full length of your body, allowing any tension and tiredness to flow out

Notice what it feels like to put your shoulders back and lift your chin. When you walk, notice what it feels like to swing your arms, relax your knees and put a spring in your step. If possible, take up some form of regular gentle exercise or body-focused meditative practice such as yoga, tai chi or qui gong. Play your favourite music and move or dance to the rhythm. Treat yourself to a nourishing massage treatment or a trip to the local Spa.



Top-down approach

Notice any habitual stress and anxiety thinking patterns. Practice each of the following as often as you can every day:

1. Pause every now and then and come away from your thoughts, back to the present moment. Notice that your thoughts are not all of who you are and are just something that's happening in the moment. Let them go if they are unhelpful.
2. Be pragmatic. If the way you are viewing something is causing you stress, ask yourself "How can I look at this in a more useful way?"
3. Focus on the good things in your life, rather than the negative. Become a 'Cup Half Full' person!

4. Practice gratitude - bring to mind something you are thankful for, no matter how small.
5. Be kinder to yourself. Let go of negative self-talk and self-criticism. Use positive affirmations and appreciate yourself regularly.
6. Use guided visualisation audios to boost your endorphin levels (feel-good hormones which act as natural pain killers)

I hope you've enjoyed this article and found it useful. I wish you a good month. Go well!

Linda at audiomeditation.co.uk

More about the mind/body connection:

Watch my mind/body awareness meditation videos on YouTube: (new videos are posted weekly)

www.youtube.com/user/AudioMeditation

Learn to meditate: see my audio course 'Step Into Meditation – The Foundation Course', available on CD and MP3

<http://bit.ly/2cRNQpD>

Read my article 'How to Deal With Stress – The Power of The Imagination':

<http://bit.ly/2nKIT8t>



To help you keep on track

This month's Post-It Reminder: Are my thoughts helpful right now?

(Stick your Post-It reminders where you'll easily catch sight of them: the fridge door; your computer; the mirror;

the back of the loo door; the front door; your bedside table).

Practical Guidance

Conscious Process: An MP3 audio programme to help manage the symptoms of M.E./Chronic Fatigue and Fibromyalgia and support recovery. Download the first 4 Sessions Free

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How to Avoid Stress when you need it most

by Karen Crosby

As a Stress Management Consultant I give coping strategies to my candidates all the time on how to deal with stressful situations, and one of the things I teach in the workshops are stress related illnesses – so no surprise to you all that Fibromyalgia can be brought on by stress alongside lots of other similar conditions like CFS, depression, anxiety and so many more.

Everyday we are bombarded with the demands of our busy lives, and these demands can pressurise us constantly. However, when that pressure turns to stress depends on only one thing – us! When we are born we have no mortgage to pay, or rent to find, or bills to pay, or work pressures, or relationship problems, and how we are shaped the minute we leave the womb, depends on our life events from that moment. How we are nurtured, or not, what events happen throughout our lives until today, and all these differing factors, good or bad make us who we are in adulthood and for the rest of our lives. This goes a long way to explain why some people are stressed all the time, and some people thrive on the pressure put upon us on a daily basis. We are not strong or weak, rather we are the product of our background, family lives, siblings, nurturing, our own natures, and all these shape how we cope, or not, with stress.

There are lots of stress tables that list the most stressful events we can face, among the top ones are: -

Bereavement, break up of a relationship, getting married, and moving house.

Since I am currently in the midst of one of these life events (moving house thank goodness), and I am a Stress Management Consultant, I thought I could share with you all how I am coping in a very busy and very potentially stressful time!

Firstly, I am aware that as a Fibro person, I need to be good to myself, so that I can cope calmly with the 1001 things I need to do!

The ways I keep on top of all the things to do are: -

1. Make a list of all the things to do each day, do this the night before, and list things in order of priority, like ringing the solicitor, doing paperwork etc.

2. I take frequent breaks to have a cup of tea, sit down, and calmly meditate or read something that has nothing to do with what I am doing, so I can focus my mind on something else for a while, or I take a walk with my dog to the river and get exercise and fresh air into the bargain.

3. I pace myself to not make my list for the day too overwhelming and I don't worry if I have not done everything on the list because this can add to the stress.

4. I keep a file with date, time, phone call or email and what was the outcome, like how I let my utilities know the moving date and their procedures by asking them, taking a name, writing it in the file and saving/printing it out into my folder.

5. When something important is done, I write DONE in red letters in the file so I know I don't have to re-address this later, and it is satisfying enough to give myself a high five!

6. If I am in front of the PC for long periods as I am for my work, I take my arms back and down periodically so I don't get tension build up in the neck, and can avoid headaches this way.

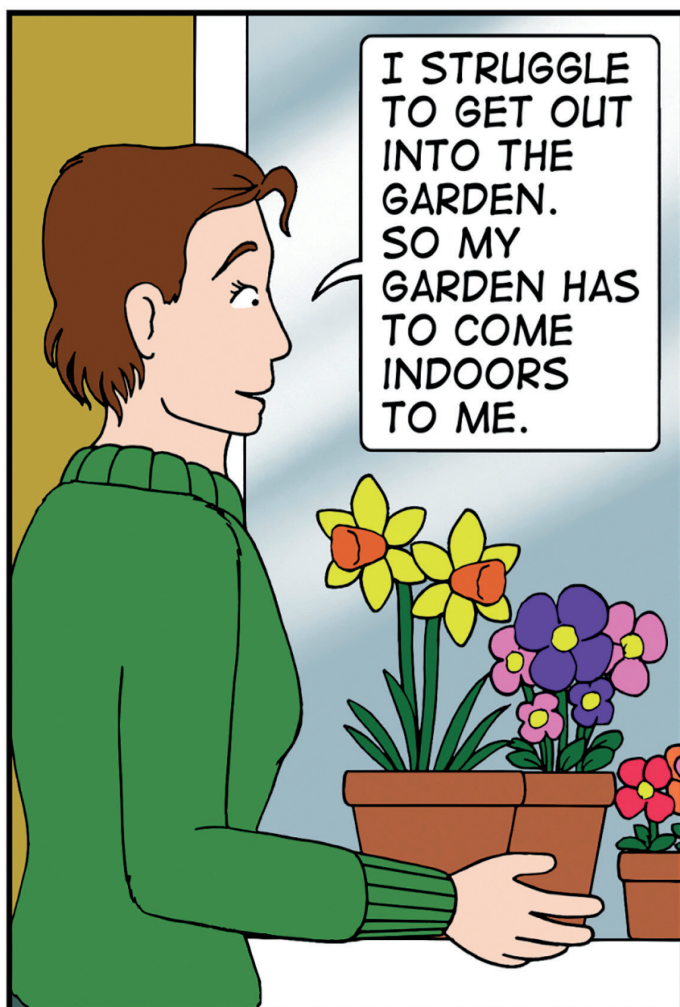
7. When I am really tired, usually after lunch, I take a short power nap (see May Issue last month) because it makes me more alert and refreshed ready to pack another box!

8. I sit and do deep breathing slowly to keep the feel-good chemicals flowing and therefore promoting calm throughout the day.

9. I award myself little treats every day like a little of my favourite chocolate or to practice some of my yoga and meditation to keep strong and keep aches and pains at bay (as a yoga teacher my mantra is "yoga is the answer, what is the question")?

10. Ask for help! This is obvious, but surprisingly enough there are too many people trying to do everything themselves and this is unnecessary, unrealistic and brings about much more stress!

I know that these tips cannot possibly cover some of the deeply sad emotions with some much more stressful situations, but lots of things need arranging and sorting out whatever the stressful event, so by structuring everything, keeping calm and focussed, the above will help.



BRENDAN KEELEY

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* Taylor, A., Anderson, J., Riedel, S., Lewis, J.E., Kinser, P.A., Bourguignon, C. Cranial electrical stimulation improves symptoms and functional status in individuals with fibromyalgia, Pain Management Nursing, 2013, 14(4): 327-335. Taylor, Ann Gill, Anderson, Joel G., Riedel, Shannon L., Lewis, Janet E. and Bourguignon, Cheryl. A randomized, controlled, double-blind pilot study of the effects of cranial electrical stimulation on activity in brain pain processing regions in individuals with fibromyalgia, Explore, 9(1):32-40, 2013.

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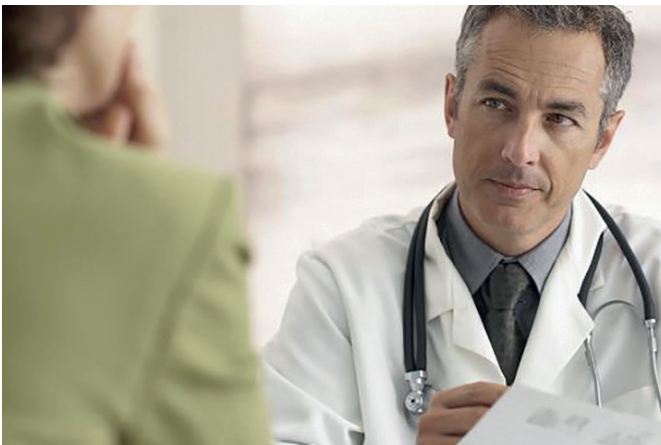




Riding the bumpy road to acceptance

By Sarah Phillips

I'd been waiting what felt like a lifetime to find out what was wrong. I'd been poked, and prodded by numerous professionals, had to explain my symptoms what felt like a thousand times, and each time the doctor thought they had cracked it. Then results came back negative and they were just as stumped as before, what was wrong with me? After going through this cycle a number of times, I finally reached a diagnosis of Fibromyalgia, then what?



I went to my diagnosis appointment, like all of my appointments, alone. I went hopeful of an answer, so that I could begin to get better, to take action to battle against the pain and fatigue, yet when I got that answer, I didn't reach the climax of relief I thought I would. Instead, I was scared, lonely, and confused. It was like somebody had pulled the plug on my future, my career, and my whole being, I felt like I had been sentenced for a crime I didn't commit. Being on my own made my head go into a complete spin, and I'm not even sure how I got home. What I do know is that when I did the hopelessness flooded out of me like a tidal wave and I was in more pain and more fatigued than ever. The diagnosis rollercoaster was about to begin.

I spent the first part of the ride figuring out what to do. The process I followed could be likened to grief; I even doubted that the doctors had got the diagnosis right at all, which is a classic denial symptom. I longed for the person I used to be, I felt like I had lost all my identity, and that I would never regain it. Anger and denial came hand in hand for me.

I had already discussed with my rheumatology consultant my wish to treat the fibromyalgia as naturally as possible; I'm not somebody who likes to take paracetamol, let alone any serious medications. I had agreed that I wouldn't rule out taking medication, but for now I wanted to start gently and work my way up, working holistically with my body, and seeing how I got on. Was this too much to ask? When I said this it became

quite clear that this was a path that I was going to have to pursue on my own, after all, holistic naturopathic care is not something the NHS currently, nor in the near future will provide. I asked if there was anything at all that could be done and made suggestions on how they could help me, knowing full well the answer would be no as the services simply aren't available. I bargained hard but bargained with the wrong people. A few days later I even emailed my rheumatologist with some suggestions for further test to rule out other possible conditions that had a more robust treatment plan, desperation and bargaining at its worst.

I felt that I had to be proactive. I had to use the pain and the desperate need to not be defined by the Fibromyalgia to my benefit. The first thing I did was to do A LOT of research into exactly what fibromyalgia is believed to be, and the evidence that can be used to base my treatment on. Was the research reliable, and had other people, those with Fibromyalgia symptoms similar to mine found benefit? The information available was overwhelming, I spent far too much time doing this and it made me focus negatively on my diagnosis, which was not the best, both physically and emotionally, I was drained. I enter a depressive state, I felt like I would never get better, that nobody could help me and feared that I would lose my job.

Then I began speaking to others who live with fibromyalgia about their symptoms on social media sites and forums and soon realised that while no one fibromyalgia warrior is the same, we do all one goal - an urge to get better and to live our lives to the fullest extent possible. This will look different for each one of us, but on the whole we all have the same aim in mind. To do this we all need different treatment regimes, some with minimal medical support and some with very heavy medical support. There is no treatment plan that fits everybody and so to find out what works for you, you need to try a number of techniques, one at a time and find out which ones work and which don't.

This was the point where I accepted my diagnosis and I began to feel more positive and hopeful. I need to stress that this cycle of grief, denial, anger, bargaining and depression, took place over an incredibly intense period of time that only lasted about 2 weeks, but was tiring. However, it takes time for the heart to accept what the mind already knows.

As I accepted my diagnosis, I started to become honest with people that I knew about my diagnosis, not to gain sympathy, but so that they could begin to understand why I wasn't quite my old self.

When you share, news very quickly spreads, like a wildfire actually, but while some may perceive this to be gossip, I found it very useful. Why? Many people, as a result of hearing my news, shared their own stories with me, or knew somebody with fibromyalgia that I could speak to, living with the beast that could relate to me. There were also a number of people, who upon hearing my news would offer up their skills and expertise, or those of a relative or friend, to help me on my journey. This is the point when I no longer felt alone and the positivity flowed throughout me, I finally felt that maybe, one day, I would be a new sort of 'well'. Optimism was now a word in my vocabulary again, which was difficult to find in the wake of a fresh diagnosis, when things were scary, uncertain and I lacked control. Without the support of my peers I would never have reached this point.

So here I am today, flitting somewhere between buoyancy on some days and frustration on others, and that's ok. People will tell you to be positive, upbeat, and that everything happens for a reason, but that doesn't mean that you have to be excessively happy. For me part of having a chronic illness is learning to deal with the rollercoaster of emotions that comes with it, riding the waves if you will. Along with simply going through the motions, part of accepting a chronic illness is being able to articulate just how terrible some days are to family

and friends, without the fear of judgement. Being falsely happy all of the time, for me, is actually somewhere close to denial of the beast that lives inside you, and while you remain in denial there is no way of moving on. My loved ones now know that while on the whole, most days, I can be positive and bright, there are the occasional days when I just need the fibromyalgia to be acknowledged and take a step back to get myself back on track. What is important is that I don't allow myself to wallow in a cycle of negativity, by being mindful and acknowledging my symptoms but then being hopeful that this shall pass and a good day will come again.

Sarah Phillips lives with fibromyalgia. She works full time as a senior midwife in a busy London Hospital, is married to Matthew and together they have 6 year old twins, Edith and Emily. Sarah writes regularly about fibromyalgia on her blog:

runningmama2013.wordpress.com,

Facebook page -
www.facebook.com/livingwiththefword

Twitter - @newmidwife0904

Instagram @the_f_word_blog

General Election on 8 June: Three questions to ask your parliamentary candidates

We as disabled people make up 1 in 5 of the UK population - that is all of us living with an impairment or long-term health condition. Let's make our votes count!

Below we have suggested three questions you can ask the candidates in your constituency, as well as suggestions in bullet point on issues you may wish them to particularly respond on.

Make it clear that their answers will make a difference to the way you vote. Feel free to add any other questions that are important to you.

1. Are you committed to the rights of disabled people to participate fully in society?

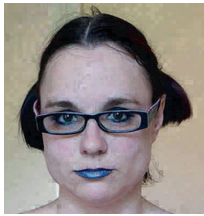
- In practice, if elected, would you work with disabled people and our organisations on an action plan, with short and longer-term goals, to ensure the UK meets its obligations under the UN Convention on the Rights of Persons with Disabilities?
- Do you support our rights to independent living, accessible transport, education, employment and public life?
- Will you work to ensure our rights are protected and developed post Brexit?

2. Will you change the way the benefits system works for disabled people?

- Are you committed to replacing the Work Capability Assessment and sanctions regime for disabled people claiming benefits?
- Are you committed to no further benefit cuts affecting disabled people in the next Parliament?

3. Are you committed to a health and social care system that enables disabled people to lead full, independent lives?

- Will you work to stop the rise in compulsory detention and forced treatment of people with mental health issues or learning disabilities?
- Will you work to phase out restraint and seclusion?
- Will you work for a social care funding solution that offers all disabled people more choice and control in our lives?
- What are you going to do about the amount we have to pay in social care charges?



The Benefits Agony Aunt

by Nim McCoan-Thornhill

ESA & PIP Problems

Welcome to the monthly benefits problem column for people with Fibromyalgia. The essential focus is PIP and ESA, but if you've other problems, do please also bring them to my table and I will do my best for you. In order to submit your problems please email office@fibromyalgia.com.

With grateful thanks to Lucrecia Herrera who responded to this weeks question.

Dear Nim,

I have recently failed my Work Capability Assessment (WCA). The DWP telephoned me to let me know. They also explained that I could call my Jobcentre and apply for JSA if I chose to do so. I am very distressed because my condition makes it very difficult for me to carry out any type of work. The process of applying is hard enough for me to get a job, let alone do it. What are my options?

Harriet

Dear Harriet,

It is heart-sinking to be at the end of the telephone line of a DWP officer who is delivering bad news. This starts a long process in connection with two separate benefits, one that claims that you are unwell to work and another based on the idea that you are fit and ready to join the workplace.

As you have experienced, the DWP usually calls rejected ESA claimants on the day the next ESA is due to be stopped after their decision. During the call is made, they inform them of the following (If other members are expecting such a call, make sure you the DWP provides the following info):

- The reasons why claimants have failed their WCA
- The option to apply for JSA/Universal Credit and their telephone number
- The assurance that the Jobcentre will take into account their medical background and will provide them with a plan to suit their ability to work, this is known as 'flexible conditionality' (more below).
- Their entitlement to ask for a Mandatory reconsideration of your assessment. They may ask you if you intend to apply for it.

Probably you have been told all the above. So what lays ahead in terms of JSA?(For MR look at my other articles)

First of all, do contact the JSA department number immediately (preferably on the same day). Otherwise you may lose benefits and/or you will have to submit evidence of all your savings, income, etc. Then visit the jobcentre on the date the JSA department has agreed for you to visit them during your telephone call.

Approaching the job centre

The first day you turn up at the job centre you will be expected by a work coach who will draw a Claimant commitment with you - it is basically a work plan. This is an agreement whereby you agree to look for work whilst you get job seeking benefits. It is what nowadays is called 'Working for your benefits'. As part of it jobseekers will be expected to spend the equivalent of a normal working week (37.5 hours) applying for jobs, attending workshops, preparing CVs, volunteering (no more than 50% of the time), etc. However, do not despair, as the rules are slightly different for people with limitations due to medical conditions, such as ex-ESAs who have failed their WCAs.

When you arrive:

- Explain you have been disallowed for ESA (or you have a chronic incapacitating condition) and will be applying for JSA whilst you launch a Mandatory Reconsideration (MR).
- Ask to see the Disability Employment Advisor (DEA). Unfortunately the number of DEA have been decreasing in recent years, so there may not be one available. But if there is, try to make an appointment with him/her, even if it is on a different date. Explain that you would like to work through your Work plan with a DEA.

If there is no DEA available in that office or during the coming days, do accept a regular work coach.

- Either way try to attend the appointment with a relative, a friend or an advocate and bring some evidence of your illness (more below) because the outline of the Work Programme will be crucial for the coming months as you go through the MR, Appeal stage (if it comes to that) or the coming year.

Flexible Conditionality: drawing a Work plan with your best interests at heart

Flexible conditionality is a scheme whereby jobseekers who have:

- failed his/her WCA; or
- has a disability, or a chronic or incapacitating condition

can agree to search for work, but can place some limitations to suit their health needs.

This means that you can place restriction on job searches by:

- A. Limiting your working hours (say, you can ask to work 4 hours a week instead of 37.5)
- B. Limiting the types of jobs (say, you can ask for jobs that involve no typing, no standing, no outdoors, etc)
- C. Limiting travelling time (say 30 min. In London jobseekers have to be ready to travel 90 min)

And can establish other issues (ie Signing on every couple of weeks if fatigue, mobility or pain are an issue).

Hopefully, you will not have to fight with your Work coach for all the above. Your coach should have been trained on Flexible conditionality, but if s/he is not very forthcoming you may have to point out kindly but firmly that your situation requires this flexible approach. This is why it is important that you bring a witness.

When you attend the appointment DO bring copies of:

- your diagnosis and details of your condition (bring correspondence by specialists, GP, mental health therapists)
- medication you are on and, most important, the ill effects it causes (dizziness, palpitations, swelling, tiredness, wind, diarrhoea).
- Any other details (carers, wheelchairs, hearing aids, etc)

After your first visit, you may be asked to come in for one or two more visits (for example, to see the National Career Service officer (to prepare your cv). If you feel you cannot come too many times to the office, let them know to spread the visits, or to put all the appointments on the same morning.

Also ask to make an appointment with the regional DEA if there is no local one. It shows you are a genuine 'patient'. Besides s/he can provide plenty of useful information on special equipment or assistance.

Signing on regularly and avoiding sanctions (this is incomplete \$\$\$\$\$)

- *Bring your Work Plan at every sign-up session. Every time you see a new work coach, let them know about the fact that you have some limitations due to illness. Work coaches are not an easy lot to deal with, so be patient. Above all do not assume they know your history.*
- *Arrive earlier than your time. If you cannot attend or you are late, do ring the telephone number on the Work Plan to avoid any sanctions. You may have to justify it with evidence.*
- *Do not tell your work coaches too frequently that you feel too ill to work. They will reply that jobseekers must be available for work, and they will insist that you produce a sick note if you cannot. The problem with this is that the maximum sick leave you can*

take in 1 year is two 14-days leave and one 13-week leave. Too little for someone with a chronic condition. Try to walk the thin line between doing some job searches and applying only for jobs that you feel you could do. Therefore, the more realistic your Work Plan is, the less chances there is that you will default and you will avoid sanctions. If you can only work 8 hours a week, say so. Do not agree 16 hours on your Plan.

- *If your work coach is on another floor and there is no lift, you can ask for your work coach to come to the ground floor (I experienced this last week). This shows evidence of lack of mobility, fatigue*

A tricky one

What about if you turn up on your first appointment at the JC with a sick note? This is a bit complicated because the Jobcentre can decide to refuse you for JSA because you are not fit for work. This, in turn, can affect other benefits (ie Housing). Bear in mind that when the DWP call you to let you know you have failed your WCA, they also notify the Council if you were on Housing Benefit (HB). If the Council takes you off their Housing benefit list, they can only reinstate you when your JSA or any other benefit kicks in. In circumstances like this perhaps it might be better to say that you can work 1 hour a day than nothing at all. Remember that when a person signs up for JSA is because s/he is actively looking for work. Do seek legal advice with this matter.

If you have questions on JSA, MR, Appeals or other benefits do seek advice from all the support groups in your area regularly. It is extremely difficult having to go from office to office when fatigued and unwell, but it will help you to put together all the pieces of the jigsaw.

Hope these tips help

Nim

www.turn2us.org.uk/



Coming off your meds (with help)

By Naomi Harvey

A year ago I made the very difficult choice to come off my medications in order to give myself the best possible chance of conceiving a baby. After 10 years of trying all other routes I needed to do this to start the IVF process, but that's another story. The past year has been a string of ups and downs and while not something I would recommend to anyone without serious assistance from their medical professionals it hasn't been the hardest thing I have done. I have become pretty adept at managing the increased issues I have from not being able to medicate away the pain, from natural remedies to pure stubbornness at times.

Over the year each one of my meds has been assessed as to what to remove and when in order to limit, as much as possible, the side effects and my bodies reactions to it. I have not suddenly become an advocate for pure holistic therapies, or do I suggest you all try to remove your meds as well, believe me there are many times I desperately want nothing more than to resort to the heavy pain meds.

Surprisingly the first medication I was weaned off were the heavy duty pain meds, the theory being that even though I was reducing the pain meds I still had others in place to help manage my bodies reaction. I thought at the time that this would be the hardest part, the beginning of the come down. I had thought pain would be the worst thing to deal with each step as I knew that I would have a lot more than I was without the meds to dull the edges of it. That wasn't the issue though.



Tramadol – coming down off this was pretty much similar to quitting any other addiction. My body cried out for the meds, and even though it was just the start of my long year I was at many points ready to call it quits. The pain levels raised quickly without the tramadol and I was faced with a constant headache. My body did pretty much shut down at some point and most of the 3 weeks of weaning it out of my system was spent with me flipping between knowing it was the right thing and wanting nothing more than to go right back to the full dose and avoid all the pain and withdrawal symptoms.

Gabapentin – In all my doctors wisdom I came off both the gaba and the tramadol at the same time. I still haven't decided if this was one of the best or worst decisions I made. The symptoms of withdrawal came hand in hand with the tramadol ones so that its hard to see which was the worst. I did notice a huge change in my hunger levels though and nearly put on more weight than I had lost in the past year.

Arcoxia – This is the one I miss still, not in a need the drug way, but in that I still have to find a suitable, workable solution without the anti inflammatory and muscle relaxant. Without it my muscles went in to full rebellion, I get more cramps and spikes in my Myofascial pain, and can't get much relief from the worst of the muscles cramps. I rely on my tens machine and heat packs but as always they never really do more than add 5 mins of relief.

Buscopan/Omeprazole – My anti spasmodic was a god send for years, especially when combined with an antacid. Between the two my stomach/IBS issues were relatively manageable, even with the increased stomach issues I get from the fertility meds. It goes without saying that removing these two has had a detrimental effect on how my body handles its reaction to IBS flares and I have had to become even stricter on my diet to limit how many flare ups I get. It also made me appreciate how well the antacid worked when all I can use right now is over the counter things that barely make a dent in the intense burning pain.

All in all these were the easiest ones to remove from my system. Yes the pain levels ratcheted up and the stomach/IBS issues become a nightmare at times, but I coped. With the addition of extra heat pads, muscles rubs, and a almost permanent reliance on my tens machine. It took close to 6 months with each med staged in reduction and removal. My doctors watched each step and made sure there were alternatives to move too if needed to get through. I still have a standing prescription on order when I want to get some pain relief as I go if I decide I can't cope. So far though my own stubbornness and the end goal has been enough to keep me going. I tried not to think of the scariest med reduction.

Three weeks ago I made the hardest choice, and up to this point I had thought it had been easy to slowly and systematically remove the meds, each side effect was managed and found a solution that would be baby safe and not do more damage to my already messed up health. I really have begun to question my own sanity at the latest choice, which seems appropriate. Coming off my heavy duty, 20 year reliance on anti-depressants was a tough decision that I still question my own reasoning on, but no anti-depressant is truly baby safe, with my only real option

to not come off would be to swap to a very low dose of prozac, which never really worked for me anyway. I was diagnosed with clinical depression at 15 and for the following 20 years kept it at bay with a variety of different anti-depressants, which got stronger each time. I honestly didn't know how I would feel without them. I was always highly strung and felt things deeply but without the anti-depressants to remove the edges of the intensity of these emotions it has been a very difficult time. In the past three weeks I have gone down from a daily dose to nothing, reducing slowly as I went. The past week has been with no doses at all and even though its still in my system, I really am struggling. At times I wanted nothing more than to call the doctor and take the prozac, if not go right back on my old meds, I have been so emotionally raw that even the simplest thing can make me cry, or rile at the world. God knows how my poor husband has dealt with me, even when adding in the increased hormone meds adding mood swings. Without the anti-depressants though I will have to let you know how I get on, I'm still adjusting to it.

I've not become an advocate for the med free alternative, I still rely on paracetamol for the minimal pain reduction I get and even that will have to stop when I get pregnant. I live covered in heat patches, support bandages and my tens machine lives next to me at all times. I haven't added any other alternative meds or herbs into my routine, that's just never been me, but I am learning so many different ways

to adjust. I'm not even sure where I am going with this article except to point out that it is possible, with the right incentive, but that it must be followed with the help and guidance of a medical professional. I couldn't have coped with each med removal without my entire team of doctors. From the endocrinologist, neurologist, rheumatologist and my awesome GP team.

The reasons we have for coming off the meds can be very varied but if you decide you want to please make sure you speak to your doctors first, all meds should be come off of with all due care as you never know how you will react.

<http://crackedbroken.blogspot.co.uk/>

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UK Fibromyalgia's Top Ten... "Support"

by Karen Lovegrove

Here at UK Fibromyalgia we have several different ways of accessing excellent support resources. This month we are looking at how you might plug into some of them.

1. Facebook Group Support

We have four groups available for Fibromyalgia sufferers which also includes access for any of your main carers. The first and main support page can be found at this address:

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

or by searching for UK Fibromyalgia Private Group. We now have nearly 19,500 members not just from the UK (Although most are), the group has volunteer staff (also sufferers) working on shift patterns monitoring the group, which makes the group a safe environment for sufferers. It is a fast-moving group, lots of posts and extremely active/interactive. When joining remember to read the Code of Conduct before posting, as there are certain rules that need to be upheld at all times. This group is a closed group, so only members can see what is posted on the group board. Check out the file section of the group, lots of helpful information gleaned over the last 4 years from members.

2. Facebook Images Group

This group was set up for all members of the UK Fibromyalgia Private Group so that everyone could post all their lovely photos and motivational messages etc. Again, there is a strict Code of Conduct so please ensure you read this before posting for the first time. Like the main UK Fibromyalgia Facebook Group, this is also monitored by moderators at all times. The address for this group is:

<https://www.facebook.com/groups/FibromyalgiaImages/> or search for Fibromyalgia Images. This group is a closed group, so only members can see what is posted on the group board.



3. Facebook Men's Group

A CLOSED group for all men with fibromyalgia who need support and advice. Feel free to say what you please so long as you're not deliberately offending anyone, usual rules apply about respect and blatant product

endorsement. Similar to our main UK Fibromyalgia Private Group as listed above, this group is for men only, you are welcome to join all of our groups, so many come to this group if they want to address a male audience. The address for this group is:

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

or search for Men and Fibromyalgia. This group is a closed group, so only members can see what is posted on the group board.

4. Facebook Group for Young People - A CLOSED group for young people with fibromyalgia.

For people aged up to 30 and for parents worried about their young children's health. Young people are also welcome to join the other groups, but might feel more confident chatting to others their own age. The address for this group is:

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

Or search for Young People With Fibromyalgia on Facebook. This group is a closed group, so only members can see what is posted on the group board.

5. UK Fibromyalgia Forum

<http://ukfibromyalgia.com/forums/>

A very interactive forum away from social media, so you can log on anonymously and ask questions or gain support on specific boards. This has its own moderators, so everything is monitored. There are many topics available so you can browse and read what has been suggested in the past, this includes topics on benefits, fundraising and research and young people with Fibromyalgia to name just a few.

6. UKFM face to face support groups

A full list of the available groups can be accessed via the website:

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

You then need to click on the nearest area to you, there you will see listed contact telephone numbers and email addresses for the group leaders. All are very friendly and don't mind queries regarding meeting up at their next group meeting. This can be an excellent resource if you are not keen on chatting to people via the internet. Your GP/health professional may also refer people to these groups. Most meet up monthly.

7. UK Fibromyalgia Website

www.ukfibromyalgia.com

has excellent information areas. Worth checking out all the links. There is a quick help guide which can be found here: <http://ukfibromyalgia.com/pages/quick-help.php>

which is worth reading if you suspect you might have Fibromyalgia, but are not sure.

8. UK Fibromyalgia Magazine

Which can be ordered on the following link:

<http://ukfibromyalgia.com/magazine.php> You are able to buy a digital or paper delivered copy, if you would like to try before you buy there is a link on the website that enables you to read a back issue.

<http://ukfibromyalgia.com/cmsadmin/uploads/file/february-2016mag-28pp.pdf>

9. Free monthly Newsletter

Order a copy on the following link:

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

Over 24,000 people worldwide read our free email Fibromyalgia newsletter that arrives in your inbox on the first Friday of every month. Each issue contains many links to the best of world and UK Fibromyalgia news from research documents, blogs, forums and websites that are not included in this month's printed Fibromyalgia magazine.

10. UK Fibromyalgia Shop

<http://www.fibromyalgiashop.co.uk/>

Put together by members of our Facebook support group, a one stop shop where you can buy all things Fibro, including self help books, supplements and aides. We also have a shop Facebook page which can be found here:

<https://www.facebook.com/ukfibromyalgiashop/>

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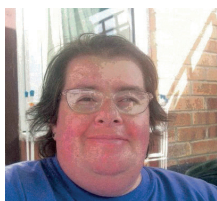


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WALKING!

By Helen Watts

One of the things I'm often asked when people phone up to find a support group is if I use a walking aid or wheelchair. For myself I use two crutches around the house, manual wheelchair outside if I have a strong person with me to push or electric wheelchair if going any distance. I wondered what others used so asked the Facebook group.



'KP' commented "When I can walk I use a stick, most days its very hard with pain at the top of my legs and my feet drag".

'SG' replied "I generally can walk unaided but for Christmas 2015 my parents bought me a 'Gandalf stick' to help me walk on my tougher days. I didn't want to use a normal walking stick so this 'walking pole' suits me completely".

'SP' added "I have been using a stick out of doors for about 2 years as my knees give way unexpectedly, leading to falls. I am also very limited to how much I can walk and avoid lots of activities/ social events because of the walking involved. I can manage for about 10 mins max (at a very slow pace) and then after a proper rest another 5 or so. If I push it beyond that the pain is horrendous and I am likely to go into a flare".

'GB' said "Indoors I can manage to get around, most days, unaided (although I 'furniture walk' according to my OT). If I need to walk less than a few yards then I use my crutches but any more than that I use an electric wheelchair. I have a car with a ramp that will take my wheelchair".

'MML' replied "I walk unaided but struggle on certain days as I mostly trip up over anything if the grounds uneven. I do have a walking stick though and I'm sure

it will come out of the closet one day".

'AJ' replied "I use 2 sticks but really thinking about asking for a walking trolley with a seat as sticks make my arms and elbows so sore and painful. Also after a while I need to sit down which can be a bother as never a seat around when you need it".

'PJ' commented "I don't use any walking aids but own a stick just in case. Have used crutches and wheelchair in the past. Now I just waddle across the room!!".

'SV' said "I walk unaided as much as possible, but often need to use my Smart Crutches. I tried a walking stick but was too uncomfortable on my hands/wrists and painful after just a short time. The crutches are comfortable to use (inc arm rests), easy to adjust to personal requirements and pink!".

'SM' replied "My walking has now become so bad that I don't really go anywhere if I can help it. I fall in the house sometimes, have started using my stick indoors more and more, I'm very slow, in pain before I even get to the end of my small garden, and usually end up shaky, sick and exhausted after a few minutes".

'ED' said "My walking is not great at times I've had to invest in a walking stick now. When I'm out I have to take regular sit down breaks".

'YP' stated "I use crutches from house to car. Three wheeled walker around house unless my hip/groin area has gone then I use my power chair around kitchen. I find because of numbness and pain in feet I cannot walk far and I'm pushed about in wheelchair when outside house. Walking is too exhausting even though I keep up with exercises to help with pains".

Lots of great comments, why not come over to the Facebook group and chat. There were more comments than space allows so look out for part 2 later in the year.

Helen Watts

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



Worldwide Research

Local cold applications performed on the trapezius muscles of patients with fibromyalgia significantly decreased their pain.

Sisters' campaign to have debilitating illness recognised

Marvellous Magnesium

FM treatment by Robert Bennett

A new cannabinoid-based treatment for fibromyalgia and peripheral neuropathic pain called ZYN001 has begun initial clinical testing in America

The effects of acupuncture versus sham acupuncture in the treatment of fibromyalgia: a randomized controlled clinical trial

Association between fibromyalgia syndrome and peptic ulcer disease development

**Risk for Irritable Bowel Syndrome in Fibromyalgia Patients:
A National Database Study**

Mum's dramatic recovery with very unusual cure

'It robs you of your very being': Life with the invisible illness

Christine's Recipe

Stock cubes and gravy mixes are easy to use, but for a healthy alternative try making your own vegetable stock - it's also far tastier than the pre-packaged varieties available in the shops. Home-made vegetable stock adds flavour to stews and soups, or may simply be poured over your steamed vegetables. It can be frozen or stored in a refrigerator for 3-4 days. I have included an example of how the stock may be used.

Home-made Vegetable Stock

Makes 600 ml (1 pint)

1 tsp sunflower oil
4 parsley stalks
1 potato, chopped
1 sprig thyme
1 carrot, chopped
1 bay leaf
1 celery stick, chopped pinch freshly ground black p
1 onion, chopped 600 ml (1 pint) filtered water
2 garlic cloves

Heat the sunflower oil in a large saucepan, then add the vegetables. Cover and boil gently for about 10 minutes. Add the herbs, mix and pour the water into the pan. Bring back to the boil, then simmer gently, partially covered, for 40 minutes to concentrate. Strain, season with the pepper and use as required.



Bean and Vegetable Soup

Serves 4

225 g (8 oz) carrots, diced
225 g (8 oz) parsnips, diced
1 onion, sliced
2 potatoes, peeled and diced
1 green pepper, deseeded and diced
50 g (2 oz) lentils
1 x 213 g (7.5 oz) can red kidney beans, drained
1 x 213 g (7.5 oz) can butter beans, drained
25 g (1 oz) organic unsalted butter
450 ml (3/4 pint) vegetable stock, or home-made vegetable stock (see recipe above)
450 ml (3/4 pint) soya milk
1 bouquet garni
4-6 sprigs of fresh parsley

Melt the butter in a large frying pan and add the vegetables. Sauté for 10 minutes, or until softened. Add the lentils, stock, milk and bouquet garni, bring to the boil, cover and simmer for 15-20 minutes. Remove and discard the bouquet garni. Add the beans and heat through. Serve garnished with sprigs of parsley.



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.

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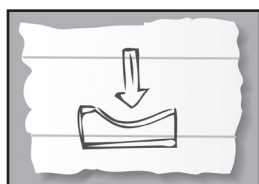
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Ms Gill Galyer	Newark, Notts - Ring between 11am and 4 pm Monday to Friday 01636 526160
Bede Francis Thomas	West London - 020 8840 7759 -Not mornings
Mrs Viv Norrie	Angus & Mearns Fibromyalgia Support Network (Montrose, Scotland) Monday & Friday 5pm to 7pm 0844 887 2389 or e-mail: am-fm@hotmail.co.uk
Margaret Evans	Cardiff - 02920 258526 - 12noon-6pm weekdays
Ann Adams	Ring Anytime 01304 382335
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
Mandy Wordsworth	TEL: 0113 2795936 - Leeds. Contact anytime.
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Alan Smith	Rhondda Valleys - 01443 433027 - Please call 6pm to 10pm
John Allen	Swindon & area Wiltshire Fibromyalgia information & support 01793 751920 (answer-phone phone buddy etc support) highfly29@hotmail.com (emails preferred) 21 Heberden House, Cricklade, Wilts SN6 6AS
Maddie Seacombe	Bristol - Tel 07790130403 - best time is 3pm - 8.30pm.
Claire Hilton 4	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
Diane Jaques	Burnley, Lancashire - 01282 701390 after 7.30pm Mon-Fri if you would like to chat
Diane Leak	Darlington Friendship Group - 1st Wednesday of the month 12pm-2pm. Upstairs Café of the Darlington Dolphin Centre.
Mrs Jane Wallace	Bursledon Hampshire Contact number: 08448872409 Email: bursledonfibrofriends@gmail.com
Mrs Natalie Hicks	Chorley Fibromyalgia Support, Lancashire - Contact number: 01257 275145 Please leave a message if no answer. Email: nataliehix@gmail.com
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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
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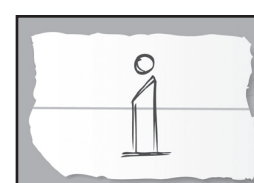
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