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The Fibromyalgia Magazine

Support for the FM FaMily

Painful Perceptions

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The Pet Prescription: Why Adopting an Animal is Good for Your Health and Wellbeing

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Medical Marijuana Petition update -13,500 and counting

Thank you very much to all the people who have taken the trouble to sign the following petition:

UK Fibromyalgia asks the government to relax the current legislation to allow general practitioners to be able to prescribe medical marijuana to sufferers of fibromyalgia and for all other patients with similar chronic pain conditions.

https://petition.parliament.uk/petitions/236693

We are still a long way short of the 100,000 signatures we need to have our cause discussed in parliament, If you have not yet signed please do so as it will only take 5 minutes and could change all our lives, If you have signed - can you now lobby your friends and family to sign it as well? If we can all get 5-6 people to support us, we shall hit our target.

Once a petition passes the 10,000 mark, we receive a written government response, and this is what they sent at that milestone:

The Government believes its approach is proportionate and evidence-based, and whilst the evidence-base remains limited, it is right that the decision to prescribe remains with specialist doctors.

This Government appreciates the frustration of patients living with chronic and difficult to manage conditions, it is however right that decisions to prescribe cannabis for medicinal use rests with doctors on the General Medical Council's specialist register. These doctors are experts in their field and as part of their continuing professional development are expected to keep up to date with all new medicines and treatments for their specialist area.

Cannabis based products for medicinal use are largely unlicensed. They have not been tested by the Medicines and Healthcare Products Regulatory Agency for quality, safety or efficacy and the evidence base is still developing. Restriction of prescribing to specialist doctors ensures that prescribing of these unlicensed products is by doctors with the best knowledge of the specific conditions for which cannabis-based products might be appropriate and minimises the risk of misuse, harm and diversion of controlled drugs. This approach has the support of the Advisory Council on the Misuse of Drugs (ACMD), NHS England and the Chief Medical Officer.

The law does not restrict the form of cannabis-based products for medicinal use, that can be prescribed, or the type of condition for which these products may be used. However, NHS England has made clear its expectation, that cannabis-based products should only be prescribed for conditions where there is clear published evidence of benefit or UK guidelines, in patients where there is a clinical need that cannot be met by a licensed medicine and where established treatment options have been considered and discounted.

In November 2018, interim clinical guidance was issued by the Royal College of Physicians, in liaison with the Faculty of Pain Medicine of the Royal College of Anaesthetics. The guidance states that there was no robust evidence available for the use of cannabis-based products for medicinal use in treating chronic pain, and that it is not currently recommended. The paucity of evidence of effectiveness of these products in pain management is also reflected in guidance issued to health care professionals by Health Canada and by the Therapeutic Goods Administration in Australia.

The National Institute for Health and Care Excellence (NICE), as the body responsible for issuing authoritative, evidence-based guidance for the NHS, has been commissioned to develop guidelines for the NHS on the prescribing of cannabis-based products for medicinal use by October 2019. NICE's process for developing such guidelines is world renowned and will include a review of published evidence and that submitted by stakeholders. This provides an opportunity for recent evidence, such as the report quoted in the petition, to be properly assessed. This new guidance will replace the interim guidance issued by the RCP, the British Paediatric Neurology Association and the Association of British Neurologists

In parallel with the change to the law and in recognition that the evidence base needs to be further developed, the National Institute for Health Research has also issued a call for research to help develop thinking in this area. More information about this is available from www.nihr.ac.uk by searching for 'are cannabis-based medicines effective?'. As more evidence of the effectiveness, short and long-term safety of these products emerges, further guidance will be made available.

Whilst the evidence to date, does not support the generic use of cannabis-based products for medicinal use in the treatment of chronic pain, the decision of whether to prescribe is ultimately one for specialist doctors to make on a case by case basis.

As with all new legislation, the Government is committed to monitoring its effectiveness. The Government will consider the outcomes of monitoring, any further advice from the ACMD and NICE and refine our approach where necessary.

Department of Health and Social Care

Page two - Medical Marijuana Petition update - 13,500 and counting

It feels like the can is getting kicked down the road towards the October proclamation from N.I.C.E. UK Fibromyalgia feels that the more the government recognises the strength of feeling in the fibromyalgia community right now, the more likely we are to hear an outcome in October that will help FM patients on a day to day basis, sooner rather than later.

We asked Fibromyalgia Action UK to support our campaign and following a meeting of the trustees, regretfully they decided against promoting our petition saying:

***"We do not support petition as there is an ongoing clinical led process in place to develop guidance i.e. NICE consultation".* Des Quinn FMA UK (Chair).**

Faced with these theoretical arguments Shel Bowden canvassed real fibromyalgia sufferers within our private Facebook group and asked how they felt. The overwhelming result was for a desire for GPs to prescribe medical marijuana for fibromyalgia. The comments show that there is a great deal of confusion and misunderstanding about the topic and a full parliamentary debate can only help that cause.

We are asking you about your use of CBD and whether you would use medical marijuana?

As we have a petition to Change legislation so G.P.s can prescribe medical marijuana for fibromyalgia, we decided to ask our Facebook group members about their use of CBD and whether they would use medical marijuana if GPs could prescribe it, members were allowed to add their own options and we have included some of their comments after the results of the survey:

If GPs could prescribe medical marijuana I would ask mine if I could try it	447 Votes
I have tried CBD and it works well for me	124 Votes
I haven't tried CBD as although it is legal it still concerns me	90 Votes
I have tried CBD and it doesn't work for me	48 Votes
If GPs could prescribe medical marijuana, I wouldn't ask mine if I could try it	19 Votes
I'm interested in trying legal CBD but don't know how much/what strength to take. (member added option)	11 Votes
I can't use CBD or cannabis products due to the nature of my work	9 Votes
I asked my GP about the chance of get CBD Oil and he would prescribe it for me if he could (member added option)	8 Votes
Is the CBD we buy over the shop counter different to what GP prescribe ? (member added option)	5 Votes
I can't take CBD as it isn't advised with my medical condition/medications.	2 Votes

There was some debate amongst members about whether or not GPs can prescribe as some members know of people who have had it prescribed in tablet form. But on the NHS website it states, "You cannot get cannabis-based medicine from your GP – it can only be prescribed by a specialist hospital doctor."

SL said "My daughter just bought me CBD but I'm nervous to use it"

SG said "A GP can't prescribe it, only a specialist & it is only for a couple of complex conditions. Even those with epilepsy that originally complained don't fit the criteria!"

HW said "Really want to try it"

KP said "As I am a nursery nurse I doubt I'd be allowed to try it"

HS said "I use cannabis to ease my pain and it works 90% of the time"

KAK said "I'm a pharmacy dispenser and was told in no uncertain terms by my previous boss that if I tried CBD she would sack me!"

MW said "I asked my doctor could I try it, He said yes but only at night. Anyway, it didn't work for me unfortunately."

JPE said "The CBD oil we can buy is so weak it doesn't really work. The prescribed stuff is a lot stronger so may well help more people. Although apparently it needs THC to really work. Not enough to get stoned but a small amount that really helps with pain"

AW said "problem is THC is what helps the pain but you can't drive while taking that"

FW said "As someone who has a low tolerance of many medications I would be interested to see if it would work."

DH said "I'm in the US- had been on 13 meds- specialist at pain centre wanted to add two more. I went to primary and said I can't do this anymore.

Started CBD oil daily-2 1/2 yrs in- lower inflammation markers, lower sugar number, lower blood pressure

Went off all scripts and started medical cannabis.

First real pain relief!!!! Life changing! My flexibility has increased as has my strength. The med weight fell off. Never looking back.!"

AB said "If it's safe to use and on prescription then I wouldn't hesitate to use it!"

SB said "I tried CBD, but it lowered my blood pressure and as I already have very low blood pressure, so I had to stop"

It seems like a lot of our members would like to try it if their GP could prescribe it, so help us get our petition debated by parliament. It is on the parliament petition site and is called " Change legislation so G.P.s can prescribe medical marijuana for fibromyalgia"

https://petition.parliament.uk/petitions/236693

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

Meanwhile in February 2019 the following report came out from Davos

UK Medicinal Cannabis Use Hampered by Lack of Doctor Training

Despite UK doctors being legally able to prescribe medical cannabis since November 1st 2018, patients still struggle to access cannabis medicines, according to a new report launched at Davos by legal cannabis expert, Prohibition Partners. Yet against this challenging environment, the report forecasts the UK's medicinal cannabis market could soar in value in 2019 as patient access is widened.

The European Cannabis Report™ 4th Edition, the most comprehensive study undertaken on the region's market, found the absence of professional medical education around prescribing cannabis has created a barrier for the fledgling UK market. Although the law has changed, doctors and healthcare professionals are playing catch up as formal educational programmes have not yet been established.

Treatment is also cost-prohibitive. Carly Barton, who suffers chronic pain from fibromyalgia, became the first UK resident to receive a medicinal cannabis prescription - but her treatment is not covered by the NHS and costs £10,000 per year.

Stephen Murphy, Co-Founder of Prohibition Partners, explains: "***A lack of educational infrastructure and prohibitive costs are impeding UK patient access to potentially transformative cannabis medicines. NHS doctors have little guidance on how to prescribe cannabis and many won't do it because they lack the infrastructure to support them should something go wrong. They are unlikely to prescribe cannabis for conditions other than those listed, notably chemotherapy-induced nausea and vomiting, HIV and AIDS, epilepsy, chronic pain and multiple sclerosis. These factors have slowed medicinal cannabis use and pushed patients into the black market."***

Genevieve Edwards, director of external affairs of the MS Society, recently voiced concern that, as far as the Society was aware, no patient with multiple sclerosis has been able to access cannabis-based medicine since the law changed. In response, NHS England has established a system to monitor the prescribing of cannabis-based products, with the first data expected by the end of March 2019.

Murphy says: "The legalisation of prescription cannabis has given people with chronic illnesses a glimmer of hope. Increased data and better education services for healthcare professionals will improve access rates and drive down cost, but progress is slow."

Nevertheless, the report predicts the UK's medicinal cannabis market is poised to take off in the medium-term. According to the findings, the UK medicinal cannabis market has the potential to be worth some £10m this year but without obstacles to growth, the market could be worth in excess of £1bn by 2022.

The World Health Organisation is reassessing the legal status of cannabis and European Union Committees are looking at how to regulate the market internationally. Moreover, the National Institute for Health and Care Excellence guidance, due in October 2019, will examine the effectiveness and safety of cannabis-based medicinal products.

Murphy says: "This wave of change supports the report's valuation forecasts, and longer term, we will undoubtedly see restrictions lifted in the UK and across Europe, opening up the market and fuelling unprecedented growth."

Positive experiences of cannabis-related treatments are also filtering through. A recent survey by the United Patients Alliance found more than three quarters of patients with problems including depression, anxiety, pain and spasms saw significant improvements in their condition with cannabis use.

https://www.prnewswire.co.uk/news-releases/prohibition-partners-uk-medicinal-cannabis-use-hampered-by-lack-of-doctor-training-davos-report-863538547.html

The Sixth month

By Naomi Harvey

Well I am at a point I never thought I would reach. Baby is well on the way to being healthy, unfortunately me not so much. A long with gestational diabetes, high blood pressure and anaemia my fibro has decided to rear its head again. I was doing so well in managing the symptoms I have, although greatly reduced by the hormones, that I think I convinced myself the whole pregnancy would go smoothly.

The pain levels are rising daily, and its hard to tell which is from fibro and which is from pregnancy. The pain in my lower back and hips is gradually getting worse so that I am relying more on my wheelchair then previously. I have muscle aches, and spasms that can't be helped by the support bands, and even the wheelchair leaves me in pain. No position is comfortable for more then 10 minutes at a time and I find myself constantly moving around. Even if sometimes that movement gets me stuck and I look like a beached whale and need help to get up.

The insomnia is through the roof, I think I am sleeping one night in three at the moment, and then get such vivid dreams it's not for a long time. My fatigue is so high right now I am struggling cognitively. Making for such interesting things that at one point I spent too long trying to put my computer mouse into my diabetes testing pouch and use the tester for the computer.

The mood swings are certainly a nightmare for my husband. All I seem to do is cry or shout, and the depression is not a fun thing. The slightest thing seems to set me off, even an advert about cake! I miss cake. If baby moves wrong, or seems quiet I go into panic. I worry about how I will cope once baby is born. I worry about how soon I will need to go back to my medications and if I will be able to breastfeed. All of this is just adding more pressure to my anxiety and triggering my depression even more.

The nesting instinct is currently the worst though. All my life I have struggled with cleaning urges, add in pregnancy nesting and I am an absolute mess. It doesn't help that we still have no nursery floor. I have so many baby items bought but they are all over the house and its so hard to get my cleaning/nesting fix with the whole place a mess. My husband is trying to do the floors but apparently we have a wonky house. So it is taking days longer making even more mess, and all I want to do is clean! Of course I can't actually lift anything to help as not only am I in too much pain, too pregnant but my husband is a complete pest by treating me like glass.

I am back to relying on paracetamol as much as I can, as well as trying hard to pace a lot more often. I need to nap about four times a day. I have been offered codeine as an as needed medication, but so far I am resisting the urge to take it.

Hopefully month seven is less difficult but so far I am not holding out much hope. Just have to hold on to the thought that the baby is worth every ounce of pain and discomfort.

http://crackedbroken.blogspot.com/

Naomi.

Painful Perceptions

By Madeleine Sara

Pain that can be triggered by the merest touch or pressure and felt throughout the body is a clear symptom of Fibromyalgia. For many, pain-relieving drugs do not have much effect. It seems as though the agony and discomfort just cannot be healed; while dread at the apparent inevitability of our condition, colours our outlook.

Knowing that the Fibromyalgia brain is mistakenly 'over-noticing' the most superficial of sensations around the body and intensifying them to uncomfortable levels is a useful clue to its management. Chronic stress has put our bodies on highest alert and it is responding by upping the ante. Since we apparently ignored the usual signals, it is shouting its message at us more loudly than normal. This creates the characteristic Hyperalgesia (extreme sensitivity to pain) and Allodynia (feeling pain from something that shouldn't be painful at all).

Nevertheless, unlike conditions such as Arthritis, it is helpful to remember, that Fibromyalgia does not cause inflammation or damage to muscles, tissues or joints. Michael Hyland and Anthony Davies(1) liken these differences to those between the hardware and software problems on a computer. Therefore, learning to recognise this discrepancy between authentic pain versus mistaken signals from the Fibromyalgia brain, is part of the recommended re-training approach.

Although the impact of pain on daily living varies between Fibro-convalescents; fearing the pain and focusing our attention on it, can become a barrier to the healing benefits of exercise and fitness.

Dennis Ngo, Martial Arts Grand Master and accident survivor, explains: (2) *"We all live with pain. A lot of people who have pain look for the pain, instead of allowing the pain to arrive…"*

Shifting the brain's attention away from continually highlighting these false signals, involves:

- easing the body through gentle exercises
- obtaining restorative, restful sleep and relaxation
- eating a nutritious diet to support the body and brain
- adopting distraction techniques for pain and stress management

Like many living with fibromyalgia, I spent a lot of time resting, thinking this was the best way to heal. My body had been on high alert for many years and this was taking its toll on my health. I became increasingly weak, tired and very stiff, as a result. As I tried to convalesce, under-stimulation and boredom fuelled my lethargy, threatening my self esteem and motivation. Gradually I realised that things needed to change.

We are constantly told by clinicians and in the media, how much the risk of most diseases will diminish, when we improve our fitness levels. The more we exercise our bodies and the stronger we become, the more benefits to our health and welfare increase.

Active, healthy muscles are excellent for:

- processing fat and sugar energy
- increasing our balance, stamina and strength
- reducing the risk of falls, breaks and sprains
- easing stiffness and tension, as we exercise
- reducing pain
- supporting our immune systems to fight infections and illness
- strengthening the muscles used for breathing and digestion
- transforming some of the draining fibro-fatigue into a healthier 'normal' tiredness.
- contributing towards a better night's sleep; soothing mind and body.

Nevertheless, in the midst of a chronic diagnosis, while we learn to adapt our environment and lifestyles to manage our more specific Fibro-dictated needs, we can often forget the normal. So, if you have allowed your exercise levels to decline and you are unsure about the best approach for your needs, then asking your doctor, oesteopath or physiotherapist for advice will enable you to better resume without strain or injury. Since limited exercise produces low muscle mass that cannot support the body as effectively, this inevitably contributes to greater discomfort.

So What Can We Do To Help Ourselves?

- GENTLE EXERCISING including YOGA, TAI CHI, WARM WATER AEROBICS, WALKING, TABLE TENNIS and LINE DANCING are all great work-outs for mind and body.

- Hobbies such as music, photography, crafts, modelling, painting, pottery, sculpture, films, poetry and creative writing, language learning etc., create MINDFUL DISTRACTIONS and social opportunities.
- Invest in a BACK SUPPORT arm chair/ back rest for a computer chair.

- When the raw impact of hard-flooring on the body, takes its toll, SPECIALIST FITTED INSOLES and CUSHIONED-SOLED FOOTWEAR, can protect the spine from the impact of walking on hard surfaces.

- Take a support CUSHION with you when visiting public places, where hard seats gnaw at pain and comfort levels.

- Invest in a BACK SUPPORT arm chair/ back rest for a computer chair.
- Using a combination of memory-foam and quilted MATTRESS-toppers, can help. Turn your mattress(es) every week.
- Changing to a RUCKSACK-STYLE bag, instead of a conventional one, may make another noticeable improvement to your discomfort.
- LOOSE FITTING CLOTHING during the day as well as at night, helps to reduce the symptoms of Hyperalgesia and Allodynia.
- Daily exercise routine, indoors and in the fresh air, does wonders for mental and physical health.
- Working with an ALEXANDER TECHNIQUE(3) practitioner introduces a way of moving and holding the body in a less tense, more relaxed and comfortable way. Identifying the harmful habits we build up over a lifetime of poor posture and stress can also help us ease our bodies out of the constant pain – fatigue cycle. After all, tense muscles place a painful strain on the body, too.
- Consider investing in a FITNESS TRACKER, that gives hourly notifications to get-up and move a minimum of 250 steps per hour. Make it work for you, rather than you feeling it is ruling your life. Increasing your daily step count is rewarding. However, it is not necessary to do 10,000 steps a day, unless you are training to run a marathon! 3,000 to 5,000 steps a day, is a more realistic goal to work towards, for those who have not been very active for a while.
- A welcome, evening muscle-soak, EPSOM SALTS BATH, that contains magnesium to relax muscles, is a great reward.
- Finding a good OESTEOPATH/PHYSIOTHERAPIST to work with, can be reassuring. Discussing problems associated with hunched-up hobbies, (including phone/tablet posture) that create upper back and neck pain can be useful, too.
- Remembering that accepting help and compromise is not failure, it is good self-care and damage-limitation management; allowing you to be a more effective member of the family/ social group in a different way.
- As well as regular movement, GOOD NUTRITION strengthens our bodies. So, increasing our consumption of foods rich in Protein, Vitamins D3, B3 and B6, Selenium, Magnesium, Bio Fish Omega 3 Oils / Sea Buckthorn Oils and Probiotics supports our muscles and bones for exercise to help alleviate stiffness and pain.

  Since vitamin supplements can affect other medication and conditions, it is important to seek medical advice before taking them; to get the correct dosage for your needs.

- Aiming to achieve as close to our TARGET WEIGHT as possible, will inevitably improve our overall health and sense of well-being.

Of course, when you have work and family to factor into your daily life, this fitness/ rest pattern can all seem unrealistic. Nevertheless, it is possible to include some gentle exercise and relaxation into daily routines.(4) Comfort and refreshment /meal-breaks at home and at work can, also, be used as part of your MOVEMENT(5) and MINDFULNESS(6) programme.

Of course, we have to offset all this with the inevitable fibro-fatigue and learn to pace ourselves. Remember that if your symptoms are made worse by overdoing it, then you must always stop and rest. Schedule in 30-60 minute rest breaks, as soon as your body and brain tells you to slow down and take it easy. Use a TIMER to take breaks every 30 minutes during hobby, activity and phone /tablet time, to stretch and move about. When we stubbornly soldier-on, ignoring the body's need to power-down, switch off, rest and relax; this can set us back, prolonging our recovery time. Likewise, when we ignore our body's signals to move and exercise, it will also scream for attention!

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. Body Reprogramming for Central Sensitivity Syndromes: A Guide to Recovery using the Hyland Model https://www.plymouthhospitals.nhs.uk/body-reprogramming

2. Dennis Ngo https://www.bbc.co.uk/programmes/p047z3rp

The Doctor Who Gave Up Drugs– Good pain, Series 1, Episode 2 of 2.

3. The Alexander Technique https://alexandertechnique.co.uk/alexander-technique

4. Toothbrush exercises; Resistance and strengthening; Balance ad core strength www.bbc.co.uk/programmes/articles/1wBY4y9KMwy02YjVSMhTfBt/can-i-get-stronger-without-going-to-the-gym : http://www.bbc.co.uk/programmes/articles/3y2PnNk6pby6xlm2Bpdk5cd/how-can-i-maintain-muscle-strength-in-later-life

http://www.bbc.co.uk/programmes/articles/2BKKFygWQXwRHQRb3v0czGy/how-can-i-improve-my-balance-and-core-strength

5. The Fibromyalgia Exercise and Diet Guide by David Jenkin and Martin Westby. (2015) UKFibromyalgia.com

6. The Fibromyalgia Magazine UK Fibromyalgia Year 19 Issue 1 – November 2018, (p1-2) The Mindfulness Meditation Minefield by Madeleine Sara

7. Fibromyalgia Information https://www.nrshealthcare.co.uk/articles/condition/fibromyalgia

8. Foot Balance Insoles: https://www.footbalance.com/

Fibro Parenting: To Struggle is to Grow

by Brandi Clevinger

As I walked in the front door of our home after dropping off my older kids at school and hung my keys on the hook, I noticed a subtle shift in the way our kids' school lanyards were hanging. One hook had a lanyard where there should be none. The only reason for that would be if the kids were having an *AWARDS DAY!!*

In a flash, I remembered my youngest daughter coming home from school two days earlier filled with excitement as she told me about receiving the Terrific Kid award for her class. All awards are a big deal for kids, but this one is a BIG deal.

She asked if I would be there, and I confidently told her I would make it. I forgot to add it to my calendar, and in that instant, I remembered it started at 8 am. It was now 8:15. Crap!!

Looking down at my clothes, I realized pajamas would not be appropriate. While frantically running upstairs and undressing, I was on the verge of tears. Abby would understand if I was unable to make it due to a flare in symptoms even if she would be disappointed. However, I had merely forgotten; another unfortunate side effect to living with fibromyalgia.

Gripping the steering wheel, it took all my concentration to not speed as I raced against the clock to get to my kids' elementary school. I was saying over and over, "Please don't let me be late. Please don't let me be late."

My brow was sweating despite the cold, and I had to crack the window to calm my nerves. It would be a blessing if I arrived to the school on time and not have to see the disappointment on her face. With so many struggles at the time, this would be my parenting fail that would be the proverbial straw that broke the camel's back. I needed to be there for my daughter. I needed to be there for myself as reassurance I'm not *completely* failing.

Fibro Parenting can be a struggle - and it's okay.

Living with fibromyalgia is difficult. Being a parent is hard, too. Being a fibro parent combines the two creating an entirely new challenge. It leaves us second guessing ourselves and feeling knocked down repeatedly not knowing if we'll ever be able to stand up again. We've all been there, right? Right. So get up. Again. And listen to this truth -

On the day I wrote this article, a friend posted an image online that said, *"Just because you are struggling doesn't mean you're failing."* It's true. Every fibro parent is struggling in some way. We are all learning how to juggle both parenting and fibromyalgia without losing our sanity and not feeling like a complete failure at the end of each day.

We go through seasons of life where some days are harder than others, but it's just that - a season. It will change. We are learning ways to better manage our symptoms, take care of our kiddos, and not feel the weight of both pressing down upon us. It can be overwhelming.

And while we go through our seasons of life, our kids go through it, too. They are learning about themselves, about others, and about the world outside their home. It's overwhelming for them, too. Sometimes you are in sync with one another, but sometimes you're not. This has no bearing of success or failure on you as the parent or them as the child.

This is why you get up again and again. Because each time you're knocked down, you're learning something about yourself, your child, or your illness. You learn how to do it different or what not to do the next time. So really, struggling is growing.

Tips to Being a Rockstar Fibro Parent

Okay, so maybe you won't be a rock star, but there are a few things I've learned over the years about being a fibro parent. There are too many to list here, but here are some essential ones you should keep in mind. For a printable version of this list, visit my website listed at the end of this article.

Plan for the bad days. A bad day could strike at any time, and it's best to plan for these days while you're feeling well. There are various ways to prepare for this.

- Assemble freezer meals with batch cooking or using leftovers. Be sure freezer meals have instructions for heating written on the container/freezer bag.

- Talk to loved ones about how to support you on the rough days.
- Keep a list of encouraging quotes, thoughts, or phrases to read.
- Ensure your flare day items are stocked so you have what you need when those flares strike. This can include essential oils, Epsom salts, medications, etc.
- Post a list in a common area of your home that includes ways your family can help on the flare days. For example, options for dinner, keeping volume levels low, making tea, etc.

Keep a box of flare day items. Reserve a set of activities, movies with special snacks, and other little toys or games for your flare days. Keep it simple and only bring out these items on your flare days so the kids don't lose interest in them too quickly. Some examples of activities or games include:

- Cards/travel games: These are great because they are portable and easy to play while in bed or lying on the couch.
- Coloring books and crayons: Coloring is therapeutic, so this will be good as self-care as well as entertaining your kids.
- Movies with special snacks: There are certain snacks my kids are not allowed to have regularly, so I save these snacks for movies on my flare days.
- Box of toys: Keeping a small box of various toys from the dollar store is a great way to entertain your kiddos while resting.

Have your kids help. Kids love to help in any way they can. When a child is helping, they feel included and valued, and it boosts their self-esteem and self-confidence. Small, simple tasks can make add up to a big difference. Keep these tasks age appropriate. Some ways they can help include:

- Vacuuming/sweeping/mopping
- Picking up their toys or dirty clothes
- Dusting
- Taking out the trash

Keep it simple. When you complicate things, you become overwhelmed which can lead to self-doubt and has the potential to spiral into a negative way of thinking. Do what you can with what you have at that moment.

Drop the guilt. Easier said than done. I get it. However, it does you no good and only adds hardship to your situation. When you start to feel guilty, figure out the why of it. Getting down to the root cause and working through those feelings can help resolve guilty feelings.

If possible, work through these feelings with your partner, a loved one, or friend. Getting a fresh perspective from an outsider view may be what you need. We are hard on ourselves as fibro parents, but most of the time it's just that - us being hard on ourselves.

Take care of you. Always remember to take care of YOU. There's a tendency as a fibro parent to take care of our families before we take care of ourselves. Once we are done taking care of them, we have little energy or want to do for ourselves. This way of thinking needs to change.

When I don't take care of myself, then I will more likely have a flare because I'm neglecting what my body needs. When I'm having a flare, I'm unable to take care of my family the way I want. However, if I do my best to take care of myself, then the likelihood of a flare goes down. This isn't to say we can altogether avoid a flare, but the chances of it decrease, and we can better manage our symptoms.

Self-care can be whatever you choose to do for you. Some ways I practice self-care:

- Thirty minutes prior to the kids coming home, I enjoy a cup of tea and read. In fact, I have a daily alarm set for this time.
- Periodically, I have lunch outside of my home. This is usually alone, but occasionally I do invite a friend.
- Sundays are rest days. Rarely do we make plans for this day of the week.
- I self-indulge from time to time. It could be buying a magazine, inspirational decor, or a special treat toeat.
- Keeping a journal for positive thoughts and processing negative ones.

To finish the opening story: Did I make it to my daughter's award ceremony on time? Yes! I was sliding into my seat just as the Kindergarten classes were finishing and her grade was about to begin. At one point she turned, searching the audience for me. When she locked eyes with me, she lit up and smiled the biggest smile. It melted my heart and brought tears to my eyes. I thought, "Yes, sweet girl. Mommy made it

I'm Brandi, the writer of Being Fibro Mom (www.BeingFibroMom.com).

I am also the Secretary and Fibro & Families program director for the non-profit organization, International Support Fibromyalgia Network. Being Fibro Mom was created in 2013 with the hope of helping fibromyalgia sufferers become fibromyalgia thrivers and advocating for parents enduring the hardships of fibromyalgia. Be sure to join my closed Facebook parenting group, Fibro Parenting, for the support you need as a parent living with fibromyalgia.

BRENDAN KEELEY

SUPPORTING THE SUPPORT

New Fibromyalgia Group

Tameside Fibromyalgia Warriors

T/A Fibro Fighters Manchester

Phone number : 07500355151

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Meetings are every 2 weeks on

Tuesday between

17:30 - 19:30

Coenzyme Q10 supplementation for headache and migraine: role in fibromyalgia

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

Introduction

In addition to the main symptoms of muscle pain and fatigue, fibromyalgia patients are subject to increased frequency of a number of other medical problems.

These include digestive dysfunction, thyroid dysfunction, osteoporosis and sleep problems, as we have reviewed in previous editions of Fibromyalgia magazine.

In addition to the above, fibromyalgia patients have an increased risk of headache or migraine; in this article we review how nutritional supplementation may benefit these symptoms.

How can you tell a headache from a migraine?

Headaches and migraines can differ in severity, and both are typically sub-divided into a number of categories according to symptoms.

In general terms, the pain associated with migraine is more severe and longer lasting than with headache; headaches are typically caused by contraction of muscles between the neck and head, whereas migraines result in part from changes in the blood supply to specific areas of the brain.

How common are headaches and migraines in fibromyalgia?

A large proportion (up to 70%) of patients with fibromyalgia suffer from increased frequency and severity of headache or migraine (Bhadra & Petersel, 2010; Whealy et al, 2018), further reducing quality of life (Beyazal et al, 2018).

The high degree of co-morbidity of headache/migraine in fibromyalgia has suggested a common underlying mechanism, and abnormalities of serotonergic/adrenergic neurotransmission, mitochondrial dysfunction, or increased oxidative stress/inflammation have been implicated (Nicolodi & sicuteri, 1996; Valenca et al, 2009).

How can supplementing with Q10 help?

A number of clinical studies have reported significant benefit of supplemental coenzyme Q10 (CoQ10) in reducing the frequency or severity of headaches or migraines in both adults or children in the general population; the dosage used was typically in the range 100-300 mg/day (Rozen et al, 2002; Sandor et al, 2005; Slater et al, 2011; Shoeribi et al, 2017).

The efficacy of supplemental CoQ10 for symptomatic relief in migraine was confirmed in a recent meta-analysis by Zheng et al (2019).

Specifically with regard to fibromyalgia patients, a clinical study supplementing 3 x 100mg/day CoQ10 for 3 months significantly reduced biochemical markers of oxidative stress, and resulted in a 50% reduction in the frequency and severity of headache symptoms assessed via the Headache Impact Test (Cordero et al, 2012).

What should I look for in a Q10 supplement?

With regard to CoQ10 supplementation, product quality and bioavailability are extremely important.

Because nutritional supplements are not regulated in the UK in the same way as prescription medicines, there is no legal quality requirement relating to defined levels of active substances and product stability; supplements may therefore, for example, contain lower levels of CoQ10 per capsule than stated on the product packaging.

The best way to avoid this problem is therefore to use a CoQ10 supplement that has been manufactured to pharmaceutical standards.

With regard to bioavailability (the proportion of an ingested substance that reaches the blood circulation), when supplemental CoQ10 is first produced (via a yeast fermentation process), it is obtained in the form of crystals that cannot be absorbed from the digestive tract.

It is essential that these crystals are dispersed into single CoQ10 molecules (and remain dispersed during the product shelf-life) to enable optimum bioavailability; adding CoQ10 crystals to a carrier oil without such dispersal results in substantially reduced bioavailability.

Disparity in the findings of clinical trials supplementing CoQ10 undoubtedly results from the use of supplements with inadequate bioavailability and/or insufficient dosage.

References - Available upon request

THE FIBROMYALGIA EXERCISE COLUMN

5 Common Mistakes in Resistance Training by David Jenkins

This month we are looking closely at the 5 most common mistakes that people often make when performing resistance exercise to strengthen muscles. Very often people don't even know they are doing these, and when they do, its only usually on a subconscious level. So without further ado, let's begin!

1) Using momentum to drive the movement

Imagine performing a rowing movement, or a lat pulldown for example. The upper body should be quite rigid with only limited movement throughout the exercise. Only the arms/shoulders should be driving the movement in order to recruit working muscle, if you simply hold onto the handles and throw yourself back then momentum/gravity is driving most of the movement and you will not be recruiting the muscles to be used – rendering the whole thing a giant waste of time

2) Poor breathing technique

When undertaking resistance exercises, try and breathe out on the work phase, and breathe in on the return phase e.g. on a press-up breathe out when you are pressing your body up/out and breathe in when lowering back down to the floor/in to the wall. Too many people begin rep number one by holding their breath and try and complete the whole set in the same way, occasionally gasping for a quick breath. Not only can this be disastrous for your blood pressure (leading to nosebleeds or even worse, a medical emergency) but can also lead to early fatigue and you won't finish the set

3) Ignoring the eccentric contractions

When you are working a muscle, you shorten it (a concentric contraction), this takes place during a work phase e.g. the curling action of a bicep curl. This element of an exercise is usually given the respect it needs, but the eccentric contraction (the return phase where the muscle re-lengthens) is often overlooked. I have seen people perform a lat pulldown nice and slowly but return the weight much quicker. The eccentric contraction is just as vital to resistance training as the concentric.

4) Choosing the wrong weight

Lift too little (not testing yourself) and you will not achieve very much, but lift too much and you risk injury, poor form and early failure – all of which are likely to put you off resistance training for good.

5) Not resting for long enough

A lot of people think that resting between sets is simply procrastinating, putting off the inevitable. Actually you NEED to rest between sets, around 20-30secs usually. This will allow you to regain breathing composure, time for your blood pressure to ease, and for power cells within the muscle (mitochondria) to be replenished, giving you a much better chance of completing that next set

So next time you are completing some resistance work, try and ensure you do not fall foul of these mistakes, then you will always know that you are working safely and effectively.

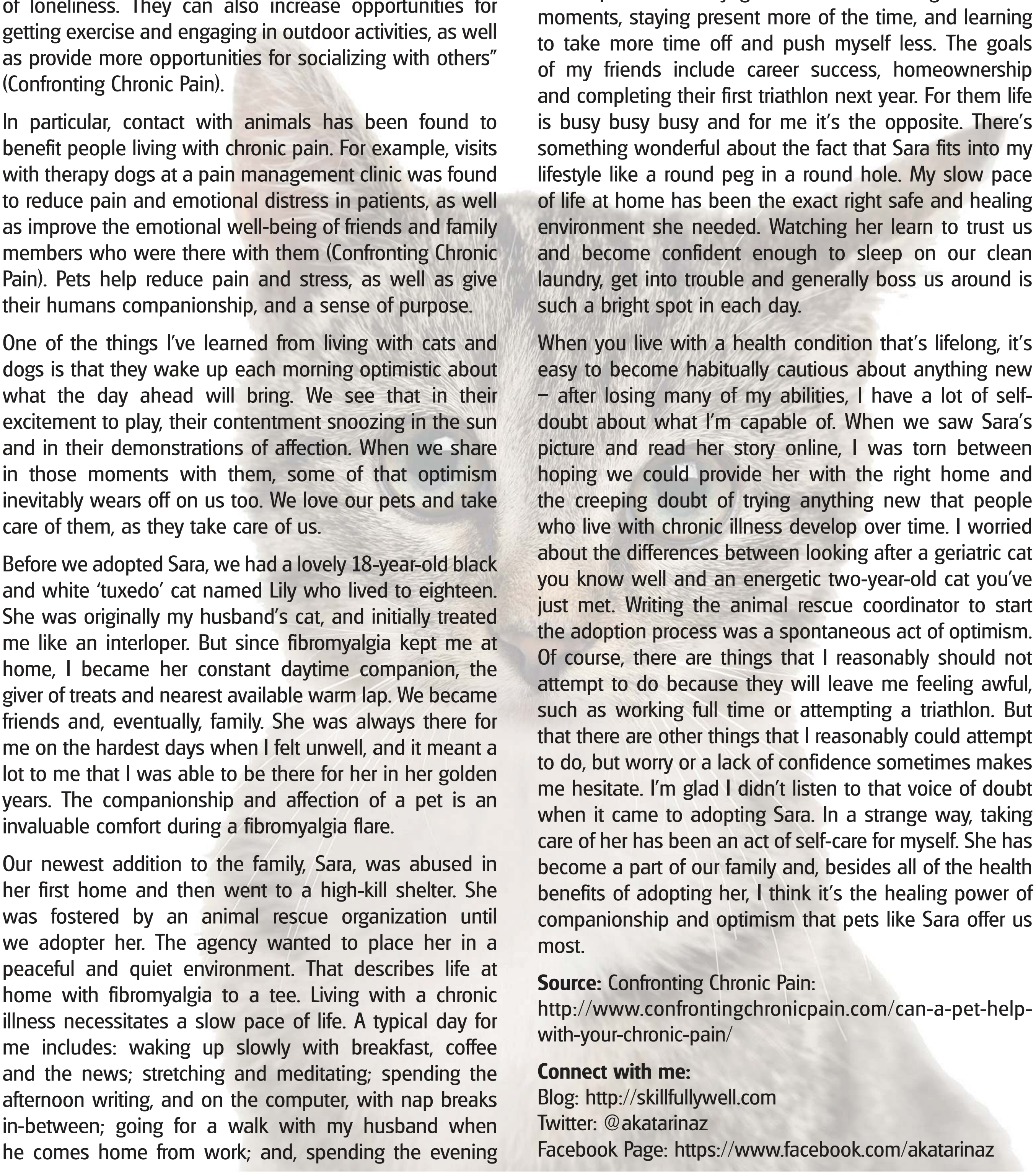
Martin Westby (your magazine editor) and I have recently co-authored a Self-Help Exercise Guide that includes a whole section on how to do establish this consistency effectively. To order a copy please follow the following web link:

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. 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

The Pet Prescription: Why Adopting an Animal is Good for Your Health and Wellbeing

By Katie Zulak



Just over a year ago, we adopted a cat named Sara who is an affectionate, but shy, three-year-old grey tabby. Adopting a pet is good for your wellbeing. Pets enrich our lives and the benefits can be measured in health improvements: “According to the Centers for Disease Control and Prevention, pets… can help lower blood pressure, cholesterol levels, triglyceride levels, and feelings of loneliness. They can also increase opportunities for getting exercise and engaging in outdoor activities, as well as provide more opportunities for socializing with others” (Confronting Chronic Pain).

In particular, contact with animals has been found to benefit people living with chronic pain. For example, visits with therapy dogs at a pain management clinic was found to reduce pain and emotional distress in patients, as well as improve the emotional well-being of friends and family members who were there with them (Confronting Chronic Pain). Pets help reduce pain and stress, as well as give their humans companionship, and a sense of purpose.

One of the things I’ve learned from living with cats and dogs is that they wake up each morning optimistic about what the day ahead will bring. We see that in their excitement to play, their contentment snoozing in the sun and in their demonstrations of affection. When we share in those moments with them, some of that optimism inevitably wears off on us too. We love our pets and take care of them, as they take care of us.

Before we adopted Sara, we had a lovely 18-year-old black and white ‘tuxedo’ cat named Lily who lived to eighteen. She was originally my husband’s cat, and initially treated me like an interloper. But since fibromyalgia kept me at home, I became her constant daytime companion, the giver of treats and nearest available warm lap. We became friends and, eventually, family. She was always there for me on the hardest days when I felt unwell, and it meant a lot to me that I was able to be there for her in her golden years. The companionship and affection of a pet is an invaluable comfort during a fibromyalgia flare.

Our newest addition to the family, Sara, was abused in her first home and then went to a high-kill shelter. She was fostered by an animal rescue organization until we adopter her. The agency wanted to place her in a peaceful and quiet environment. That describes life at home with fibromyalgia to a tee. Living with a chronic illness necessitates a slow pace of life. A typical day for me includes: waking up slowly with breakfast, coffee and the news; stretching and meditating; spending the afternoon writing, and on the computer, with nap breaks in-between; going for a walk with my husband when he comes home from work; and, spending the evening together catching up on our favourite shows. Sara has lots of company, plenty of time for cuddles, and no one interrupts her cat naps. I gain companionship, the endless amusement that cats can provide (like watching non-stop cat videos) and the enjoyment of taking care of something other than my health.

As a person with chronic illness, living in a society obsessed with productivity, I often feel like a round peg in a square hole. My goalsinclude savouring the small moments, staying present more of the time, and learning to take more time off and push myself less. The goals of my friends include career success, homeownership and completing their first triathlon next year. For them life is busy busy busy and for me it’s the opposite. There’s something wonderful about the fact that Sara fits into my lifestyle like a round peg in a round hole. My slow pace of life at home has been the exact right safe and healing environment she needed. Watching her learn to trust us and become confident enough to sleep on our clean laundry, get into trouble and generally boss us around is such a bright spot in each day.

When you live with a health condition that’s lifelong, it’s easy to become habitually cautious about anything new – after losing many of my abilities, I have a lot of self-doubt about what I’m capable of. When we saw Sara’s picture and read her story online, I was torn between hoping we could provide her with the right home and the creeping doubt of trying anything new that people who live with chronic illness develop over time. I worried about the differences between looking after a geriatric cat you know well and an energetic two-year-old cat you’ve just met. Writing the animal rescue coordinator to start the adoption process was a spontaneous act of optimism. Of course, there are things that I reasonably should not attempt to do because they will leave me feeling awful, such as working full time or attempting a triathlon. But that there are other things that I reasonably could attempt to do, but worry or a lack of confidence sometimes makes me hesitate. I’m glad I didn’t listen to that voice of doubt when it came to adopting Sara. In a strange way, taking care of her has been an act of self-care for myself. She has become a part of our family and, besides all of the health benefits of adopting her, I think it’s the healing power of companionship and optimism that pets like Sara offer us most.

Source: Confronting Chronic Pain: http://www.confrontingchronicpain.com/can-a-pet-help-with-your-chronic-pain/

Connect with me:
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Twitter: @akatarinaz
Facebook Page: https://www.facebook.com/akatarinaz

IT'S ALL IN THE TOUCH

By Helen Watts

Recently I was shopping and trying clothes on and was very aware of how harsh the labels felt and this led me to think about how many of my clothes I now don't wear as they hurt. This has a name Allodynia and relates to all touch, both human and material and I wondered how many other fibro sufferers had this so asked the Facebook groups.

DE "Yes today it was very sore/sensitive to put my arm on the couch"

GS "I struggle with sensitivity, if the weather is cold I cannot wear jeans, leggings, tights or anything that puts any kind of pressure on me as causes pain. I tend to wear really loose clothing that's not very heavy. I struggle with bedding sometimes"

SS "Yes get this quite a lot on arms, legs and sometimes other parts of body, feels like I've poured hot water on myself, feel it burning and slightest touch of own skin or clothes is agony"

WR "I find man made materials bad but not natural ones so much. It's more I don't like the feel of them on my skin than they hurt"

JC "I'm waking up all hours of the night as bedding hurts my legs so much, and they are painful when I touch them"

TA "If I wear a choker necklace it causes my neck to hurt"

VC "When having a bad flare up I find any clothing that is too close to my neck is irritating"

NP "I'm extremely touch sensitive - some days a hug is too much to take. I sleep with my feet outside my duvet as that is too heavy and hurts - and on really bad nights my legs can't bear to be against the mattress - pain killers don't help"

CS "This is the worst part of FM for me. Thank goodness it's not constant. I will suddenly get a feeling that acid burning through my flesh. Usually my forearms but can be elsewhere, eg, parts of my face. The pain is instant and unbearable, I could claw my skin off the bone. I take my strongest painkiller and apply large ice packs. The episode can last for hours. I'm also sensitive to the touch or tightness of clothes. I can't wear tight clothes, eg, jeans, tights or close fitting tops"

SW "I get this but only occasionally on my forearms and wrist area. It's a bit like having sunburn rubbed for me. I can struggle with wearing bras at times because the pressure on my shoulders/ ribs makes them start aching but I see that as different to the burning skin thing"

HJM "I'm really sensitive to touch sometimes, especially my arms, legs and shoulders. I can't let my pets or anybody touch me at those times. I often get random pains like pins or something sharp digging into me at random times. I prefer tighter fitting clothing however it does hurt me so when I'm indoors I just wear pyjamas. My glasses hurt the back of my ears too so I have to keep taking them off and I feel every bump in a mattress so it takes forever to get to sleep"

SB "I get this, I find when it's bad I live in a loose pair of pjs. Even the towel when I have a shower hurts getting dry"

JH "I can't wear anything tight, glasses, hats, scruncies all hurt, I sit on memory foam and have my cushions under my arms, can't have my blanket on my feet, can't sleep with 1 leg on top of another or arm on arm.I feel sounds and can't stand noise and even rubbing my head can hurt"

DG "I get this most of the time. Hugs hurt or when someone touches me in a loving way as they daren't hug me. I have to now wear loose clothing as they hurt and buy bigger sizes. I struggle wearing a bra as have pain round ribs and shoulders, wearing one often makes the pain increase and can take days to calm down, even with painkillers. I also can't sleep with one leg on the other or put my hands on my legs"

MRF "I often can't have cuddles from my children, or have them sit on my lap - it breaks my heart! I can't wear jeans most of the time, instead I have loose trousers. Drying myself with a towel after a shower hurts, and so sometimes I use the hairdryer. Even brushing my hair hurts my scalp, so try to avoid it as much as I can, it's just horrible"

RH "Tickets in clothes are like pin pricks. Even bedding can be too much to the skin. I met someone on a fibro management course that said he spent his days at home in his boxer shorts because clothes hurt so much"

NK "Yes but not constantly, mainly my legs"

SM "Yes I have this, it is for me the worst symptom of fibromyalgia. I was diagnosed back in 2006 but I used to just have it mainly in my legs and ankles especially at night, but now it can affect my whole body, it feels like severe sunburn as if my skin is red raw, I can't bear anything touching my skin, I can only wear very soft light weight clothing, even having a shower is impossible some days, the towel can be very soft but on my skin it feels like sandpaper. I can't brush my hair as I even feel it on my scalp, on the rare occasion that I go out to visit my mum, I have to get changed as soon as I get home, My husband and I can't cuddle anymore some days we can't even hold hands as his body heat is just too much for me. It wasn't until last week that I realised there was a word for it"

DE "Yes it's like your skin hurts, slightest touch is like being burnt. Especially bad during a flare up"

JN "Yes, not all the time but very painful to the touch when it does happen"

BW "I have had this on the inner part of the top of my arm, in my armpit radiating out toward my back, on my cheekbone, chin and the area around my thumb joint. Felt like sunburn/razor burn. I couldn't tolerate any clothes apart from my pj's, and having a shower was agony. Went on for a week, and found absolutely nothing to relieve it. Hoping it was a one off"

SF "Oh yes, painful to touch, especially my upper arms, back, shoulders. Also becoming more sensitive to clothing, Everything I buy has to now be of supersoft fabric. My skin feels like it's on fire. When it's really bad I use Aloe Vera gel along with Arnica gel, that helps to soothe the burning pain"

JC "Tactile Allodynia is one of my worst fibromyalgia symptoms as, other than fellow sufferers , no one understands it . How can you be feeling pain from a simple pinch on the shoulder in passing"

SM "I'm not super sensitive to the touch of clothes or water. It does however hurt when I'm squeezed or manipulated on most parts of my body"

JDF "I suffer with this on my scalp and tops of my thighs at times the slightest touch is really painful with my thighs. Once I'm dressed my clothes don't hurt just when I'm touched but with my scalp I can't even touch it or brush it it's just too painful"

SB "I need my clothes to be soft and loose fitting, can't bear to be tight an squeezing, if have to wear tights it can be agony, so now mostly wear Maxi kaftan type dresses so can wear socks, slipper socks. If going out in cold then knee high stockings which come off minute I'm home again. Some days can't comb hair as it hurts"

TB "Yes it was one of my first symptoms I didn't know what was wrong. Very embarrassing when people used to hug me and I flinched"

ST "When in flare I feel as though majorly "sunburned" and can't bear to be touched. Can't wear anything heavy or tight"

OB "Labels in clothes drive me crazy & touch as well as wind on my face"

SH "Clothes drive me crazy, any thing touching me when having a flare up is unbearable, I wear loose clothing too"

SG "I wear thin cotton clothes to help me with this. But often someone will touch me and it feels like a major injury. Sometimes my scalp is that bad I can't brush my hair"

EK "I have huge problems with this, used to wear jeans all the time but now it's just jazzy leggings all the way"

It looks like we all have problems with this, maybe we need our own fibro clothing range of super soft clothes and no harsh labels. Have you found any ways round these problems? How have you educated those closest to you on touch and how it makes you feel? Whatever your views come along to the Facebook group and join in.

Helen Watts

This month's contributions came from our closed Facebook Page - why not try it yourself?

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

CherryActive for Fibromyalgia.

CherryActive is a natural cherry product, which has been shown to help reduce inflammation and muscle soreness and improve sleep patterns. It is made from a unique variety of cherry called the Montmorency, which contains high levels of natural compounds, including anthocyanins and melatonin, which are thought to promote the anti-inflammatory and sleep improvements.

CherryActive cherries are grown, pressed and bottled, avoiding excessive heat to preserve their natural properties. No preservatives or other unnecessary chemical additives are used. CherryActive has won several natural health awards and is taken by thousands of customers, including those suffering with fibromyalgia, with very good results.

CherryActive is available in a concentrated juice format, which you dilute with water and as a low calorie, convenient capsule. Nutritionists recommend fibromyalgia sufferers take 30ml of the concentrate diluted in a glass of water or two capsules, with a meal, daily.

CherryActive has been sold since 2006 and is a top seller in health stores across the UK and Ireland.

Readers of this newsletter get a 15% discount off all orders, with discount code FMS2019 from website www.active-edge.co.uk

Here are some emails the company has been sent over the years from Fibromyalgia sufferers:

I have found CherryActive juice to be a refreshing drink, which reduced my pain levels somewhat after one week. I have now been taking the juice for three months and my sleeping pattern has also improved. I do not wake up so many times through the night and I am grateful for the extra sleep. I will certainly continue to use the product.

Lucy Graham

CherryActive really does help my Fibromyalgia... particularly the fatigue. I can't praise it enough. Thank you.

Sharon Edwards

I suffer from fibromyalgia, and since I began taking CherryActive each day, I have hardly had to take any pain relief at all. I don't know how I have managed all the years before without it and I will certainly be taking it going forward.

Joanne P Shore

I am sorry to sound like a "born again" CherryActive junkie but I cannot tell you the wonderful difference this is making to my (and ipso facto my husband's) life. I cannot wait to spring into my GP's surgery clutching a bottle of CherryActive and explaining what has brought this miraculous change.

Wendy Northover

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


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60 days
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Peripheral Neuropathy by Karen Crosby

Pathy – means disorder, and neuro relates to the nerves.

Peripheral in this case means affecting the nerves outside of the brain, and mainly relates to hands, arms and feet.

In people with fibro, this kind of pain may actually be the main reason they suffer with fibro in the first instance, and the reasons that have been found for this are: -

1. The nerves connecting the body and brain are responsible for the physical sensation of pain, and when there is a problem in this area like in fibro, this leads to pain that does not make sense.

2. When we injure ourselves, the nerves send signals to the brain, which the brain then sends back to the area and pain is felt, so if we hurt a hand the pain is instantly felt in the area, which tells us in real time we are injured.

3. As fibro is a nerve pain condition, the signals get crossed, confusing this system and thus we feel pain when there is no apparent injury.

4. A study by a Harvard-affiliated hospital in Massachusetts on fibro patients, found half of the patients studied had small nerve fibre neuropathy. This is nerve pain caused by damage to small nerves carrying pain and touch signals to the brain, and the study found that some of these patients with this problem were showing to have less of these small nerve fibres than people without fibro.

The above information points to the fact that fibro pain may actually be neuropathy in some cases.

However, not all fibro patients have small nerve fibre neuropathy, so this does not explain their symptoms, but it is now known that fibro has its origins in the wrong signals being sent for pain when no pain should be happening.

There are several types of Peripheral Neuropathy: -

Sensory Neuropathy
Damage to the nerves carrying temperature, touch, pain and other sensations to the brain.

Motor Neuropathy
Damage to nerves controlling movement.

Autonomic Neuropathy
Autonomic means involuntary, so our bodily processes like bladder function, digestion, and blood pressure have damage to the nerves controlling these.

Mono Neuropathy
Mono means one, and this is damage to a single nerve outside of the central nervous system (carpel tunnel syndrome is an example of this).

I know that fibro sufferers do get symptoms of Sensory Neuropathy, as I am one of these people.

The symptoms of this kind of neuropathy are: -

1. Tingling (pins and needles) in the affected area, which I have had a lot and have spoken to others who have also had this.

2. Numbness, burning and sharp pains, particularly in the feet. This is interesting to me, because I get this all the time, and because I have an old fracture injury just under the toes of my left foot, I always put it down to that, until I had it in the other foot! This is really painful!

3. Allodynia – feeing pain from very light touch.

4. Sensory ataxia – loss of balance and co-ordination because of less ability to know the position of the hands or feet (teaching Yoga means this is an embarrassment for me)!

Motor Neuropathy

The symptoms of this kind of neuropathy are very familiar to most of us: -

Muscle cramps and twitching, muscle weakness or paralysis (thankfully I have not had the latter for many years, but I did suffer mild temporary paralysis at one stage).

Peripheral Neuropathy is found with many health conditions, some serious and some not, but what I have researched now makes sense to explain how our nerve impulses are affected in fibro and how this is all connected to this type of pain.

With this neuropathy, it is mainly the hands, arms and feet that are damaged, and in the UK alone an estimated 1 in 10 people over 55 are affected by some degree of peripheral neuropathy.

This could be because of other medical conditions that may come on later in life like diabetes, hypothyroidism (underactive thyroid gland), chronic kidney disease, lymphoma, rheumatoid arthritis, and many more.

With fibro however, chronic pain is a daily struggle, and it makes sense that pain, because of scrambled nerve signals, means there are strong links with this type of neuropathy.

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FIRZONE
FIRZONE

How to set up and run Fibromyalgia Support Group - The Treasurer's Role

By Julie Barker - Chairperson

This edition we are going to have a look at the treasurer's role and a simple explanation of keeping the books up to date.

First, I want to give a shout out to a new friend of ours, Tina Morris. Jane our group treasurer and I met Tina on a 'Tai Chi for Beginners' instructor training course in February, in Nottingham. She runs the Fibromyalgia Action Group Nottingham and is a very experienced Tai Chi for Health instructor. She has had an incredible journey of recovery and owes it mainly to the Tai Chi for Health. If anyone shows Positive Fibro Attitude, it is Tina! Hopefully we will be doing some joined up events in the future.

Jane Gordon
Treasurer

So back to business! Anything to do with maths or accounts is just not my thing. It's strange but looking back to BF (Before Fibro) which is quite a task having suffered for the past 34 years, I was top of the class in maths. It wasn't until I had the flu bug that instigated everything that I had problems. Since then, I have failed and had to retake every maths and accounts module that I have needed to do. So, I have brought Jane in to help co-write this article to ensure it all makes sense.

When Jane came along it was a massive relief for me as she is the company secretary for a landscape and design business and is responsible for all things financial, so we have had an immaculate set of accounts since the beginning. The trouble is she won't let me spend any money!

('Trouble is' I proofread these articles, and I feel the need to say that, as treasurer, I think that it is more than reasonable to veto most of Julie's spending!! - Jane)

I think I have been very sensible! World domination is not cheap you know! lol

Individual groups might deal with their money differently, but the concept is still the same.

The Treasurer's Role

The Treasurer is an officer of the committee and is responsible for managing and safeguarding the group's finances and capital. They should ensure there are proper budgeting systems in place and try to make the rest of the committee stick to them!

Keeping financial records needs someone who is organised and meticulous at keeping records. The finances for our group are relatively straightforward, so no accounting knowledge is required, but it does make life easier if you have someone experienced, who is willing to take on the position.

Bank Account

The first thing any group should do is open a bank account in the group's name. To safeguard the account, it is good practice to have at least two non-related signatories to sign off expenditure, one should be the treasurer, who can then watch and make online transactions, reconcile bank statements and liaise directly with the bank.

Accurate Records

To support the treasurer's role, it is good practice to keep a record of attendance and income at weekly meetings. The income can be balanced to the attendance register and at Fibro Active we include donations, fundraising and miscellaneous items, so we know into which pot to pay the income. Then it doesn't matter who takes the money at the meetings as long as it balances on the sheet.

The attendance sheets help to keep accurate financial records by supporting the evidence of the income and expenditure. These records must be kept for 7 years.

All income should be banked regularly; this helps to keep track of the funds and reduces the risk of holding onto large amounts of money. All income must be banked and recorded accurately. Any expenditure should either be payed as soon as possible via cheque or bank transfer, so it shows a paper trail. For very small amounts for milk etc you could hold a petty cash float that has already been accounted for. A petty cash book is advisable to keep records of payments and receipts.

Jane states that 'as the treasurer, can I just add that I keep two handwritten daybooks, one for cash and one for the bank account; these are kept up to date on a weekly or even daily basis. The bank daybook, with the use of online banking can be reconciled to the bank at any time. As we take mainly cash at our group meetings and tai chi sessions, all cash is processed through the cash daybook, so we have no need for a petty cash book as well. I also keep monthly records of all income and expenditure on spread sheets, this is an easy format for providing information to your auditor, as it can be copied and encrypted to a flash drive.

This is a secure and easy way to provide details of your yearly accounts, although paper copies of any purchase receipts, sales invoices and grant income may also be required.

It's probably worth mentioning at this point that some banks offer free accounting software, this is usually a fairly basic programme, but can be useful, amongst other things, for easy bank reconciliation, record keeping, producing sales and purchase invoices and some reports including trial balance.'

Keeping the accounts up to date

With regular money coming into the group it is best practice to stay on top of things by keeping the accounts up to date. The treasurer should be able to give you an idea on the state of the accounts at any one time and produce a financial report for the committee meetings, as the management committee as a whole is responsible for the group's finances. This makes it more important to be able to produce financial reports in the proper format, so people like me can follow and understand the information, these reports can then be sent to funders, or members on request.

It is also helpful to be able to discuss these reports, to enable other committee members to see what we really have to spend. Funding grants usually have a specific purpose and time limit, which needs to be adhered to. A reserve fund for any rainy-day issues is a necessity, what might look financially healthy now, may be halved in a couple of weeks when grant money has been used for it's purpose.

Year End Accounts

All this talk of income and expenditure is exacerbating my fibro fog, but we haven't finished yet! That is why I am so grateful to Jane, as she also needs to produce a set of year-end accounts. For us this is a relatively simple balance sheet showing income and expenses. However, we also keep separate records of all our grant funding, this enables us to keep a careful eye on spending and makes it easier to provide accurate information for any reports that we are required to submit to our funders.

The year-end accounts, if you are a registered charity need to be audited, this is a requirement by charity law. However, if you are an unincorporated organisation you do not have to have the accounts audited. If you have got a contact that would be willing to do them for you, it is favourable to have them audited, especially if you are applying for grants from larger funding pots.

The Treasurers Report at the AGM

The year-end accounts are also produced and presented at the annual general meeting. Presenting the accounts at the AGM also provides evidence that the income is being used correctly and in line with the group's objectives. There should also be a record of the group's capital expenses, such as our gazebo, tables, chairs, electronic devices etc. and separate data to keep track of who uses it and when.

Next year's budget

Keeping everyone involved in how the money is spent is really important for ensuring that everyone is in agreement knowing where the money is going. According the Recourse Centre 'Budgeting is a crucial way to stop your group running out of money unexpectedly or ending up in debt.'

After working hard throughout the year fundraising and writing funding bids it's nice to find out if the budget I have for the next financial year leaves me with enough cash to allow me to continue the quest. The trouble is Jane still won't let me spend any money!

In the next article we will be hearing from our group members. I want to find out what impact Fibro Active has, had on our members and share their stories for Fibromyalgia Awareness Day.

PLEASE HELP.

PETITION TO PARLIAMENT

https://petition.parliament.uk/petitions/236693

New research shows that medicinal marijuana has the potential to revolutionise pain management for fibromyalgia sufferers, yet the current rules do not allow G.P.s to prescribe it for fibromyalgia. Fibromyalgia affects 2%-5% of the UK population, which means that at least over one million people could benefit in a relaxation of the Misuse of Drugs Regulations. Please sign our petition to ask the government to debate the following motion:

UK Fibromyalgia asks the government to relax the current legislation to allow general practitioners to be able to prescribe medical marijuana to sufferers of fibromyalgia and all other patients with similar chronic pain conditions.

Thanks to your help we now have over 13,000 signatures. If you have not yet signed it only takes two minutes and has the potential to change all our lives. If you have signed it please ask your friends and family to sign it and share the link on social media

Thank you

ASK BRIAN

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

I was a victim of a serious unprovoked assault last year which resulted in life threatening injuries. Whilst these injuries have now healed, I have mild PTSD and I have developed Fibromyalgia. I can no longer work. The police charged the person responsible but I was too scared that there would be repercussions if I went to court to give evidence against them. Is there anything I can do to be compensated for this injury which was not my fault and has caused me to lose my job?

Elliot

Dear Elliot,

I am sorry to hear you were a victim of a crime. There is recourse to compensation via the Criminal Injuries Compensation Authority (CICA). You should usually make a claim within two years of the incident occurring. The CICA have set compensation figures for specific injuries and you may also claim loss of earnings if it can be shown on the balance of probabilities that you being unable to work is a direct result of the injuries you sustained in the assault.

The CICA do not always accept claims where the injured person did not co-operate with the prosecuting authority in bringing the perpetrator to justice and the fact that you did not give evidence at court may hinder your ability to make a claim. However, the CICA will consider each claim on a case by case basis and so it is worth submitting an application to them. The process can be lengthy, stressful and often requires the input of independent medicolegal experts so you may wish to contact Solicitors, such as ourselves, who regularly submit and manage CICA claims for their clients.

Brian

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MIND FULL
by
Kayleigh Roberts
& Christine Harris

Confrontation

Confrontation can be as easy as clarifying how you feel about something to having an out and out argument with somebody. When we confront we don't want to turn it into blame.

On Truth, Brene Brown says we have the choice to be true or lend a lie. On a more radical note, she says we have the choice to accept or reject a lie. Truth and dishonesty do not live in a vacuum. As with every way we relate to one another, it's a mutual exchange, a symbiotic relationship, in which giving and taking are equally important. You have the choice to accept or reject a lie.

But what does truth have to do with confrontation? The need for confrontation arises out of conflict. Conflict comes from misunderstandings and overstepped boundaries. Usually, at least one party never got the memo on what's going on or didn't see the boundary line before tripping over it.

Part of our responsibility to ourselves relies on holding others accountable and upholding our personal and ethical boundaries.

Seek Balance. How can we find a happy balance, where we can address issues that are important to us without the uncomfortable situation of creating a bother? Why is it our culture supports blatant white lies as a means of not hurting someone's feelings? When we are not true to ourselves we may delay an upset, while also delaying the solution we want.

Confrontation is not Arguing. Confrontation addresses both how you feel in a situation and how you seek a solution that works best for both parties. A common misconception equates conflict to an attack. We want to focus on what we have in common and find ways to reach each other's goals, be it a peaceful home or a functional, caring relationship.

Give the Benefit of the Doubt. Assume the person is on your side and wants to work towards a mutually beneficial solution. Creating an attack will only lead to a heated series of counter attacks.

Approach Each Conflict with Sympathy and Compassion.
Everyone has difficult days. Conflicts arise out of timing and people misfiring their frustrations on friends, family, or co-workers. It may be difficult, but try to put your hurt feelings aside and ask "Are you alright?" Hear them out. Let them know how they are speaking to you, and how that makes you feel, which may sound like "You seem upset, and you're raising your voice at me. I care about you, but the way you are speaking to me makes me feel uncomfortable. Let's work this out."

What do you want? Try to focus on positive suggestions and the vision of what you want to see, instead of what you don't want someone to do. If you want a child to stop yelling, it's easier to ask them to "Come here. Why are you yelling?" than to yell "Stop!" which both sets the example of what you don't want, and fails to lend a better option. Suggest a positive, mutually beneficial boundary.

Get on with it. If you are going to do something you dread that must be done that will not go away without you doing something, it's better to get on with it. There's an illusion that avoiding conflict makes life easier, but on the contrary, tensions, ambiguities, and conflicts have a way of building on each other with time. If anything should be avoided, it's allowing stagnant energy to accumulate within the relationship. Avoidance extends the anxiety of the necessary conflict resolution process.

What if? Go deeper into it. The worst case scenario is usually still better than living in fear. The regret built up over never trying may be harsher than the possibility of failure. When you fail, you have the option to try again. When you dread, you remain in a state of cowardice, watching as the monsters grow larger.

Stay in touch with your feelings. A nervous feeling doesn't necessarily mean danger. The anxiety can be excitement, stand for a great adventure or a soul-searching journey towards an epic truth. Perhaps this feeling is the exhilaration for standing up for your true self, and in turn, for your friends, and for the world you want to create.

What are you really afraid of? The best way to end your fears is addressing them.

Avoid Avoidance. Slay the monster instead of building it up in your head.

Face Fears Head On. Put your head up, relax your shoulders, and confront what is bothering you.

Build Your Strength - 1) Write down how you feel and objectively describe what happened. (We never really know what another person is feeling so keeping the attention on our own experience is valid.)
2) Write: "I feel _____ in _______ situations" 10 times down the page. Then use 3 slow, deep breaths to relax yourself. Now, quickly and unconsciously fill in the blank spaces.
3) Pause and breathe again while reflecting on your completed responses.
4) Observe gently and without judgment!

Be sure to check out our Next Article on The Art of Confrontation: A Step By Step Guide.

www.ChristineHarrisTherapy.com Let's connect!

Sleep Is Vital For Good Health - In CFS and FM

by Dr. Sarah Myhill, MD

The need to sleep is of paramount importance in CFS/FM patients, and "you must put as much work into your sleep as your diet," says Doctor Myhill, who specializes in nutritional and preventive medicine. Before considering drugs, she advises her patients to manage the physical essentials - "pressing the right buttons" to put your brain to sleep, helped by low-dose natural preparations such as melatonin and valerian root.

The Physiological 'History' of Sleep

Humans evolved to sleep when it is dark and wake when it is light. Sleep is a form of hibernation when the body shuts down in order to repair damage done through use, to conserve energy and hide from predators. The normal sleep pattern that evolved in hot climates is to sleep, keep warm, and conserve energy during the cold nights and then sleep again in the afternoons, when it is too hot to work and hide away from the midday sun.

As humans migrated away from the equator, the sleep pattern had to change with the seasons and as the lengths of the days changed. People needed more sleep during the winter than in the summer in order to conserve energy and fat resources. Furthermore, during the summer humans had to work long hours to store food for the winter, and so dropped the afternoon siesta.

But the need for a rest (if not a sleep) in the middle of the day is still there. Therefore, it is no surprise that young children, the elderly, and people who become ill often have an extra sleep in the afternoon - and for these people that is totally desirable. Others have learned to power nap, as it is called, during the day and this allows them to feel more energetic later. If you can do it, then this is an excellent habit to get into - it can be learned!

More Sleep in Winter, Less in Summer

The average daily sleep requirement is nine hours, ideally taken between 9.30 p.m. and 6.30 a.m. – that is, during hours of darkness, but allow for more in the winter and less in the summer.

Light on the skin prevents the production of melatonin, which is the sleep hormone essential for a good night's sleep. Therefore, the bedroom should be completely blacked out and quiet in order to give the best chance of quality sleep. Even people who are born blind still have a day/night rhythm - it is light landing on the skin which has this effect. Just closing your eyes will not do it!

After the First World War a strain of 'Spanish' flu swept through Europe killing 50 million people worldwide. Some people sustained neurological damage, and for some this virus wiped out their sleep centre in the brain. This meant they were unable to sleep at all. All these poor people were dead within 2 weeks, and this was the first solid scientific evidence that sleep is more essential for life than food and water. Indeed, all living creatures require a regular 'sleep' (or period of quiescence), during which time healing and repair takes place.

You must put as much work into your sleep as your diet.

First, Get the Physical Essentials in Place

- We are all creatures of habit, and the first principle is to get the physical essentials in place.
- A regular pre-bedtime routine. Your 'alarm' should go off at 9:00 p.m., at which point you drop all activity and move into your bedtime routine.
- A regular bed time – 9:30 p.m.
- A busy day with the right balance of mental and physical activity.
- Not having a bed fellow who snores.
- Small carbohydrate snack just before bedtime (such as nuts or seeds) helps prevent nocturnal hypoglycemia, which often manifests with vivid dreams or sweating.
- Perhaps restrict fluids in the evening if your night is disturbed by the need to pee.
- No stimulants such as caffeine or adrenaline inducing TV, arguments, phone calls, family matters or whatever before bed time! Caffeine has a long half life, so none after 4pm
- Dark room - the slightest chink of light landing on your skin will disturb your own production of melatonin (the body's natural sleep hormone). Have thick curtains or blackouts to keep the bedroom dark. This is particularly important for children! Do not switch the light on or clock watch should you wake.
- A source of fresh, preferably cold, air.

- A warm comfortable bed. We have been brainwashed into believing a hard bed is good for you, and so many people end up with sleepless nights on an uncomfortable bed. It is the shape of the bed that is important. It should be shaped to fit you approximately and then very soft to distribute your weight evenly and avoid pressure points. TempurR mattresses can be helpful (if expensive), as are water beds.

Address Other Factors Known To Disturb Sleep

Address Other Factors Known To Disturb Sleep

1. If your sleep is disturbed by sweating, then this is likely to be a symptom of low blood sugar.

2. Another common cause of disturbed sleep is hyperventilation, which often causes vivid dreams or nightmares. However, I often use a benzodiazepine ["minor tranquilizer"] such as diazepam 2-5 mgs at night, which reduces the sensitivity of the respiratory centre.

3. If sleep is disturbed by pain, then one must just take whatever pain killers are necessary to control this. Lack of sleep simply worsens pain.

4. If one wakes in the nights with symptoms such as asthma, chest pain, shortness of breath, indigestion, etc., then this may point to food allergy being the problem with these withdrawal symptoms occurring during the small hours.

5. Some people find any food disturbs sleep and they sleep best if they do not eat after 6:00 p.m.

If you do wake in the night, do not switch the light on, do not get up and potter round the house, or you will have no chance of dropping off to sleep.

The Hard Part: Getting the Brain Off to Sleep

Getting the physical things in place is the easy bit. The hard bit is getting your brain off to sleep. I learned an astonishing statistic recently, which is that throughout life, the brain makes a million new connections every second! This means it has a fantastic ability to learn new things – which means it is perfectly possibly to teach your brain to go to sleep. It is simply a case of pressing the right buttons.

Getting to sleep is all about developing a conditioned reflex. The first historical example of this is Pavlov's dogs. Pavlov was a Russian physiologist who showed that when dogs eat food, they produce stomach acid. He then 'conditioned' them by ringing a bell whilst they ate food. After two weeks of conditioning, he could make them produce stomach acid simply by ringing a bell. This, of course, is a completely useless conditioned response, but it shows us the brain can be trained to do anything.

Applying this to the insomniac:

1. First, he has to get into a mind-set which does not involve the immediate past or immediate future. That is to say, if he is thinking about reality then there is no chance of getting off to sleep - more of this in a moment.

2. Then he uses a hypnotic (see below) which will get him off to sleep.

3. He applies the two together for a period of 'conditioning'. This may be a few days or a few weeks.

4. The brain then learns that when it gets into that particular mind-set, it will go off to sleep. And then the drug is irrelevant.

However, things can break down during times of stress, and a few days of drug may be required to reinforce the conditioned response. But it is vital to use the correct 'mind-set' every time the drug is used, or the conditioning will weaken. I do not pretend this is easy, but to allow one's mind to wander into reality when one is trying to sleep must be considered a complete self-indulgence. It is simply not allowed to free-wheel.

Self Hypnosis to Form a Conditioned Reflex Pattern

Everyone has to work out their best mind-set. It could be a childhood dream, or recalling details of a journey or walk, or whatever. It is actually a sort of self hypnosis. What you are trying to do is to "talk" to your subconscious. *This can only be done with the imagination, not with the spoken language*. [For a step-by step explanation, see the final section of this article - "Self Hypnosis - Like Learning To Drive With A Clutch" – which offers excerpts from a book on self hypnosis.]

I instinctively do not like prescribing drugs. However, I do use them for sleep, in order to establish the above conditioning and to restore a normal pattern of sleep, after which they can be tailed off or kept for occasional use.

Indeed, viruses can cause neurological damage (for example polio) and this could involve damage to the sleep center. So often CFS patients in particular get into a bad rhythm of poor sleep at night, which means they feel ill for the day, which means they get another bad night. They are half asleep by night and half awake by day. Furthermore, their natural time for sleep gets later and later. They go to bed late and if they have to get up at the usual time, chronic lack of sleep ensues. Indeed, there is now evidence that the biological clock is dependent on normal adrenal function and we know this is suppressed in CFS. So often some medication is needed to facilitate sleep. Most CFS patients react badly to drugs in normal doses.

The Personal Sleep Support 'Starter Pack'

I like to use combinations of low dose herbals, natural remedies and prescribed drugs to get the desired effect. Everybody works out his or her own cocktail which suits. This may have to be changed from time to time. I like to supply a 'starter pack' for patients, which has a selection of hypnotics [as outlined below, the supplements melatonin and valerian root, and the over-the-counter sedating antihistamine NytolR) to try so they can work out their best combination…

I am always asked about addiction. My experience is that this is rare, especially if drugs are used as above to develop a conditioned reflex. One has to distinguish between addiction and dependence. We are all dependent on food, but that does not mean we are addicted to it. We are all dependent on a good night's sleep for good health and may therefore become dependent on something to achieve that. This does not inevitably lead to addiction.

Addiction is a condition of taking a drug excessively and being unable to cease doing so without other adverse effects. Stopping your hypnotic may result in a poor night's sleep but no more than that. This is not addiction but dependence.

Beginning With Natural Preparations to Help Sleep

These all work differently, and so I like to use low dose combinations until you find something that suits. Choose from the following, and start with:

Melatonin 3 mg (one tablet) 1 to 3 tablets at night. [Melatonin is a supplement available over the counter in America. In the UK melatonin can be prescribed and is also available from the Internet.] Some people just need 1 mg. CFS/FM patients have a poor output of hormones from all their glands - namely the hypothalamus, pituitary, adrenals, thyroid and also the pineal gland. The latter is responsible for producing melatonin, the natural sleep hormone. It seems logical to me therefore to try this first…

Melatonin is a hormone produced by the pineal gland. It signals the time to go to sleep and its production is often faulty [especially] in CFS. Levels are slow to rise and slow to fall and this may well explain why these patients tend to drop off to sleep late at night and wake late in the morning. It is like having a form of chronic jet lag.

Melatonin is made from serotonin (the "happy" neurotransmitter) which in turn is made from 5HTP [5-Hydroxy L-Tryptophan, a supplement which studies indicate works by supporting production of healthy levels of serotonin]. This may be why 5HTP is helpful for sleep disorders.

The only precaution is that one or two of my patients have become depressed with melatonin, so be aware of this. On the container it also states melatonin should be avoided in autoimmune disorders… [and certain other conditions including epilepsy and leukemia].

There is a test to measure melatonin production. The Melatonin Profile test measures salivary melatonin levels over 24 hours. Particularly Chronic Fatigue Syndrome patients have poor or delayed melatonin output, so they are unable to drop off to sleep quickly. If this test shows a deficiency of melatonin, then melatonin supplements are indicated.

Valerian root 1 to 4 capsules at night. This herbal supplement is shorter acting and can be taken in the middle of the night.

NytolR (diphenhydramine 50 mg). This is not a supplement, but a sedating antihistamine available over the counter. The dose is 1 to 2 at night. This is longer acting - don't take it in the middle of the night or you will wake feeling hung over. [It is "potentially dangerous" taken with alcohol.]

Prescription Drugs, Starting With Sedating Antidepressants

If there is no improvement with a combination of the above, or if there are intolerable side effects, then I would go on to a prescribed drug. I usually start with one of the sedating antidepressants, such as:

Amitriptyline 10 mg to 25 mg I would start with 5 mg initially. Most CFS/FM patients are made worse and feel hungover with "normal" doses.

Dothiepin. I do not prescribe dothiepin now because a study suggested that this had an increased risk of cardiac dysrhythmias compared to other tricyclic antidepressants.

Surmontil 10 to 30 mg at night.

Short acting temazepam 10 mg. This is useful but recently has been made a controlled drug. so doctors are understandably twitchy about prescribing it. It is controlled because some drug addicts were taking the gel and injecting it into themselves. Nowadays I tend to use instead zaleplon (SonataR) or medium acting zopiclone (ZimovaneR) 7.5 mg.

Diazepam is helpful if sleep is disturbed either because of hyperventilation (it reduces the respiratory drive) or for muscle spasms (it is a good muscle relaxant).

Different people will respond to different combinations of hypnotics. For example, one person may take a melatonin and two valerian at night, plus a zaleplon when they wake at 3:00 a.m. Somebody else may be best suited by 10 mg amitriptyline at night with a NytolR. Don't be afraid to try combinations - there are no serious side effects that I am aware of with any of these used in combination. However, don't change more than one thing at any time otherwise you (and I) will get confused!

One of my patients has found [a wrist band that presses on the acupressure point in the wrist] very helpful.

If Your Find Your Dose Creeping Up...

If you find your dose of hypnotic is gradually creeping up, then this may be because you have become less disciplined about establishing the conditioned reflex. Go back to the basics as above.

When your normal sleep pattern has been restored you can begin to reduce or tail off completely your hypnotic medication - but only if good quality sleep can be maintained. If your sleep begins to suffer, you must go back on the medication that worked before, because the need to sleep is of paramount importance in CFS/ FM patients.

Self Hypnosis – "Like Learning To drive With A Clutch" Continued from Sleep Is Vital For Good Health - In CFS and FM by Dr. Sarah Myhill, MD*

The following is lifted from a book on self-hypnosis which works for some:

We know that the hypnotic state is characterized by extreme responsiveness to suggestion. You can use this information for conditioning yourself in self-hypnosis. Here is a standard procedure to follow.

1. Lie down in bed, ready for sleep initially with your eyes open (the room needs to be dark). Mentally give yourself the suggestion that your eyes are becoming heavy and tired. Give yourself the suggestion that as you count to 10 your eyes will become very heavy and watery and that you will find it impossible to keep your eyelids open by the time you reach 10. If you find that you cannot keep them open and have to close them, then you are probably under self- hypnosis.

2. At this point deepen the state by again slowly counting to 10. Between each count mentally give yourself suggestions that you are falling into a deep hypnotic state. Give yourself suggestions of relaxation. Try to reach a state where you feel you are about to fall asleep. Give yourself the suggestion that you are falling more deeply down into sleep. Some may get a very light feeling throughout the body; others may get a heavy feeling.

3. Let us assume that your eyes did not become heavy. Then repeat the procedure. You can count to 100 if you need this period of time to assure an eye closure. The closing of the eyes is the first sign you are in a receptive frame of mind. Let us assume that you get the eye closure. Take a longer count to get yourself in the very relaxed state. Once you achieve this you should be able to respond properly. The difficult bit is not allowing your brain to wander off into other areas. You must work hard at concentrating on the counting and the responses that achieves.

4. If you respond properly, give yourself the "post-hypnotic suggestion" that you will be able to put yourself under later by counting to three, or using any specific phrase you desire.

5. Continue using it every day and give yourself the post hypnotic suggestion every time you work with it, that at each succeeding session you will fall into a deeper state and that the suggestions will work more forcefully with each repetition.

Each time that you work towards acquiring the self-hypnotic state, regardless of the depth that you have achieved and whether or not you have responded to any of the tests, give yourself the following suggestions: "The next time I hypnotize myself, I shall fall into a deeper and sounder state." You should also give yourself whatever suggestions you desire as though you were in a very deep state of hypnosis.

You may ask "If I'm not under hypnosis, why give myself the suggestions?" You do this so that you will begin to form the conditioned reflex pattern. Keep at it. One of the times that you work at achieving self-hypnosis the conditioned response will take hold... you will have self hypnosis from that time on.

It is like learning to drive a car with a clutch. At first you must consciously go through the process of putting your foot on the clutch and shifting gears. Usually there is a grinding of the gears and you feel quite conspicuous about this, but gradually you learn to do this almost automatically and you gain confidence in your driving ability. The same is true of hypnosis. As you work at your task, you gradually get the feel of it and you achieve proficiency in it.

*** Dr. Sarah Myhill, MD, is a UK-based CFS specialist focused on preventive healthcare, nutrition, and patient education. This material is reproduced here from Dr. Myhill's patient-information website (DrMyhill.co.uk) R Sarah Myhill Limited, Registered in England and Wales: Reg. No. 4545198. This article first appeared in the Family Magazine in May 2007.**