

The

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Fibromyalgia Magazine

Support for the FM FaMily

My career has lost an E

by Connor Moffat -
Full Time Carer



Let medicine be thy food

by new columnist Emma Stark



My Career has lost an E

by Connor Moffat - Full Time Carer

You go to school, pass your exams, get a job and then spend the next couple of decades developing it into a career. You earn fairly good money, buy a car, rent a house, put a little aside each month, and finally meet a woman daft enough to want to be with you. Your life progresses in a decent if unassuming direction. All is well. Then suddenly all is not well. In fact your partner becomes seriously unwell. You continue to work, spending more of your free time looking after her. A diagnosis of M.E and fibromyalgia, along with a raft of other, more minor but accumulative conditions are diagnosed. Suddenly the love of your life is so sick she spends nearly 18 months wracked with pain, comatose in bed, unable to feed, clothe, or even wash herself. That's when you have to make a decision, and suddenly your career drops an E and you become a carer...full time.

Everything changes. Her life is a personal hell, and your life suddenly consists of learning all you can about these diseases, medication types, management techniques, all the while feeling a quiet despair grow at your inadequacy to be able to heal the woman you love.



Your life changes drastically. Your 8 hour working day is no more. Suddenly you are on call 24/7. Life becomes much more insular. You don't go out, other than doctors' visits, hospital visits, or the odd shopping trip for food and medication. She needs constant attention, help to the bathroom, help eating, help getting in to bed, help getting out of bed.

Your savings disappear, and as someone who has always worked, you suddenly face having to ask for help. Your partner is disabled. Help is available from the government. To access it there is a bewildering array of forms, questions, medical assessments,

rejections, appeals, court dates. Your partner has a so called invisible illness, and that has a world of stigma attached to it. The public, some doctors and the government system seems to feel disability involves missing arms or legs, horrible disfigurement or being in a coma or terminally ill. You have to learn to fight, to educate, to stubbornly insist 'this is real, this is harsh, and this has changed the woman I love irrevocably.'

Don't get me wrong, it took a while for the help to come, but it eventually did, and I am very grateful. We get DLA (tho we have just received the dreaded change to PIP letter, so the struggle may just start all over again.) We have a motability car, without which Sharon would be truly housebound. Occupational health jumped in and we were given a wheelchair, a rolator (a godsend for helping Sharon manoeuvre through our tiny one bed flat with some semblance of safety and control.) A wet room was installed as Sharon cannot get in and out of a bath or stand under a shower. I even get the heady sum of £62.10 a week as a full time carer, and it all helps!

We can survive, we can live, but even this comes with a price.

Certain newspapers cry out that disabled people just milk the system, spend six months a year in Florida and all drive around in BMW X5's that they get for free. They are all spongers, and are the reason the country is falling into wrack and ruin. We have first-hand experience of abuse, snide remarks and outright hostility...the oft quoted 'there is nothing wrong with her, she's got all her arms and legs' syndrome.

Being a carer is frustrating. I have been accused of being an unemployed layabout also just sponging off the system. The truth is between us we paid tax for pretty much 50 years. Sharon didn't ask for this life changing disability. I sure as hell know I didn't. And now we need help. The money is sufficient to live. We eat, we are warm and have a roof over our head. But despite what the media tells you we are not rich. Sharon's illness precludes virtually all 'normal' activities, but to make the money we receive work to have any standard of living we have sacrificed much. We have never been on holiday, ever. We have never eaten in a restaurant, we don't go to the cinema. We don't smoke, we don't drink, we don't socialise, the money just isn't there for frivolities. Pretty much everything we own is second hand.

I have went from having expendable income when I worked, to having to budget, to shop around, to buy the reduced goods...all the while hoping nothing major breaks or goes wrong in the house.

As a carer you become a ghost in a way. My friends have gradually drifted off; after all I could no longer spend time with them....you can't forward plan because Sharon is often too ill to be left alone at all. I don't go into the office each day, so there are no colleagues to interact with, to chat to, to be human with. People rarely visit because either Sharon is too ill to spend time with them, or you see them shuffling uncomfortably, issuing a few banalities and wandering off looking slightly relieved. My parents and sister live in the States. I can't afford the £90 for a passport, never mind the hundreds to fly out and spend time with them, so the months have become years since I saw any of them. Contact now consists of a few sultry emails a year. After all they have their own lives and problems to deal with.

Sharon spends a great deal of time in bed trying to fight the endless pain, or 'drugged up' on prescription medication in an effort to grab a few hours true sleep. But you can't go out because she might need you at any time, so you spend endless hours just sitting staring at 4 walls. You can't make noise because a gift of the illness is extreme sound sensitivity, so you sit in silence. You see no-one, you talk to no-one, and you do nothing, endless swathes of nothing. The rest of the time you are nurse, cook, cleaner, dresser, washer, hair dresser, inadequate makeup artist.

The two or three days a year I try to get away (for my own sanity) are a logistical nightmare, arranging for her mother, or a good friend to stay for the day, or even more rarely the night...and then hope when the months in advance day arrives she is not too ill for you to actually go.

Being a carer is lonely. Being a carer oft goes by unnoticed by the outside world. I often get bouts of depression and nostalgia for my old life. I more often get depressed at how little I can actually help Sharon, when she lies there crying, begging me to take the pain away.

But there is a huge silver lining for me. I love her, and I get to spend every day, every hour, every minute with her. When I am lying on the sofa trying to sleep because the pain I would cause her by accidentally touching her I know she is just a wall away. I get to see the rare good days, when a shadow of the old Sharon reappears. I get to be with her on the myriad bad days and know that I am maybe making things just a little better for her.

Being a full time carer is hard work. It is daunting. It changes your life and yourself beyond all recognition, and sometimes it is so wrenching you just want to give up and admit defeat.

It isolates you socially; it means there is never a throwaway moment, never a spontaneous action. Everything has to be planned. Everything Sharon does, however briefly will have long term consequences on her pain levels, her tiredness, her mood.

There is sacrifice, tongue biting, and ridicule. There is pain, sadness and endless frustration with almost everything. There is the anger when I take her out in her wheelchair and the comments start, or even worse they talk politely to me and treat Sharon like she is invisible, or learning impaired.

But there is love; there is the knowledge that I need her as much as she needs me, maybe more, because being a carer ends up defining what and who you are. To quote an old script 'it was the best of times, it was the worst of times' and I wouldn't change these times for the world.

It was the best of times; it was the worst of times'

Charles Dickens

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Ask the Doctor by Ginevra Liptan, MD

How long after stopping medications such as gabapentin, amitriptyline and solpadol - can you expect a pick-up in your metabolic rate? I put on a lot of weight during my time taking these meds, but despite dieting strictly now I am struggling to lose much. KL

Unfortunately, as you have discovered several of the most common classes of medications used to treat fibromyalgia can cause weight gain, including anticonvulsants such as gabapentin and pregabalin and antidepressants such as duloxetine and amitriptyline. There seems to be a component of both metabolic rate slowing and fluid retention, along with some other factors we don't understand well, causing the weight gain. This is why I always try to use very low doses of these medications to limit any issues with weight gain.

In answer to your question regarding time frame, after stopping the offending medication sometimes it can take up to 6 months to a year to lose the weight, and it can be very frustrating! Some options to consider are if persistent fluid retention or edema seems to be an issue for you, talk with your GP about trying a low dose diuretic. And try to boost metabolic rate by adding in some gentle movement therapy that gets your heart rate up.

What's the difference between polymyalgia & fibromyalgia? NS

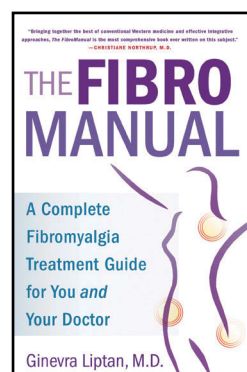
Though their names and symptoms have some overlap, these are actually two very distinct diseases. Patients with fibromyalgia have widespread muscle pain, fatigue and sleep disruption. There is a gradual onset to symptoms, classic blood markers of inflammation are normal and corticosteroids usually bring no relief. Polymyalgia rheumatica (PMR) is an inflammatory rheumatic condition that comes on suddenly, is characterized by intense aching and stiffness around the shoulders and hips, and blood markers of inflammation such as ESR and CRP are extremely elevated. Symptoms of PMR usually respond promptly to corticosteroids.

In part, the confusion stems from poorly chosen names. Both fibromyalgia and polymyalgia rheumatic contain the word myalgia- meaning muscle pain. For fibromyalgia, this is a pretty accurate description, as one of the biggest characteristics of this illness is that our muscles feel very painful and tender. In the case of polymyalgia rheumatic, this is a misnomer, as muscle tenderness is not a prominent feature and the tenderness around the shoulders and hips is due to inflammation of the synovia (joint lining) and bursa (fluid filled pockets that act as cushions between joints and muscles).

What is your thoughts on the benefits of vitamin/ mineral supplements? Thanks AL

If you spend any time on the internet or social media you will inevitably be barraged with information about vitamins and supplements. Trying to figure out which are truly helpful and which are just hype can be a really expensive and frustrating process. I often see patients struggling to keep up with complicated and expensive supplement regimens and work with them to streamline it down to the essentials. Specifically, I find those nutrients that support the healthy functioning of the nervous system (brain, spinal cord and nerves) and the digestive system are where supplements can give the most benefit in fibromyalgia.

The core, long-term supplements that I have all of my patients take are those that are well-known to support healthy functioning of the nervous system including B-vitamins, fish oil, Vitamin D, and magnesium. I also recommend probiotics (healthy bacteria like those found in yogurt) and digestive enzymes to aid in digestion and lessening of irritable bowel symptoms. More specific recommendations can be found in my book, The Fibromanual: A Complete Fibromyalgia Treatment Guide for You and Your Doctor.



About Dr. Liptan:

Ginevra Liptan, M.D. developed fibromyalgia during medical school. She is a graduate of Tufts University School of Medicine and board-certified in internal medicine. Formerly an associate professor at Oregon Health and Science University, she is now medical director of The Frida Center for Fibromyalgia, a fibromyalgia specialty clinic (www.fridacenter.com). The clinic is named for Frida Kahlo, the Mexican artist who endured years of chronic pain and is thought to have been a fibromyalgia sufferer. Dr. Liptan received a Gerlinger Foundation Research Award to study myofascial release for fibromyalgia, with results published in Journal of Bodywork and Movement Therapies. She has also published articles in peer-reviewed medical journals about fibromyalgia exercise and self-management strategies.

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

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Let medicine be thy food

by Emma Stark

Hippocrates made such an impression on medical history that his name is still very much associated with medicine today. He said "Let food be thy medicine, let medicine be thy food" and he couldn't be more right! I know, you've probably heard it all before and thought how can food possibly help as much as my medication? I'd like to show you all how!

Chronic pain has been my nemesis for the last 17 years, really peaking in the last 8 and resulting in me having to stop working two years ago, at which point I could barely move for pain. At that time, I had moved around a lot and been told by multiple GP's that I had multiple ruptured discs and trapped nerves. As ruptured discs are normally healed after three months, they suggested that I may need my discs shaved or replaced. Something I was excited about. I know, right? Imagine being excited about something like that! I really was, as it meant to me that I could get my life back on track. This operation could mean I might be able to walk, go to the loo without wanting to cry with pain, get back to work, be active again! I was on so many painkillers I'm surprised I didn't rattle, and yet I was still in agony and feeling ill all the time.

So, my consultation comes along, I get scanned, I'm all ready for the results and just wanting to get to the bottom line of when will I be fixed. "Your spine is very healthy" says the muscular skeletal consultant. "This is something I can't deal with, you need to see your GP, you've got a long road ahead of you." I suddenly felt like a fraud, my spine is healthy? How can that be, I'm literally crippled with pain, I'd already been tested for everything else. It was after this that my GP told me I have FM and M.E and that one day it might just disappear on its own. We will get you some counselling, that usually helps alleviate the symptoms she said.



This wasn't good enough for me, I don't like the unknown and I can't rest until I get answers. At this point I was swallowing 42 pills a day between

Gabapentin, Diazepam, Naproxen, Solpadol, Tramadol, Amytriptyline and Duloxetine and getting no better. This was after trialling just about every other pill out there and being told my last option was morphine. I was miserable with the amount of pain in my body. I'd wake up one day and my hands would be normal, the next they would be triple the size and I couldn't even feed myself as I couldn't grip my cutlery. I had to depend on my boyfriend for everything and it's tough breaking that barrier in a relationship. I could stand up for no more than 17 seconds and my legs would shake so much that if I tried to walk they'd often give way and leave me in a worse state. I didn't think I'd ever get better, I think we've all felt the same way at some point. When does it end? This is when I started my journey to find out all that I could and try to at least make life more bearable.

I'm a qualified nutritional therapist and a keen science enthusiast. There are a lot of answers out there if you are given the right resources and I'm grateful to have found all that I have throughout my learning and I'd love to share this with you guys! Food has really helped me, I'm fortunate enough to now be taking 1 pill a day which I still find crazy as I never thought in a million years I could cope without all 42. Thankfully, it's true; and I can now walk with the aid of my walker or my crutches, only around the house but it's a huge start from being bedbound. My legs no longer tremble, I don't get half as bad inflammation and I can now help improve my symptoms just by eating the right things. Sound too good to be true? Let me help! Each month I'll help get rid of some myths and explain why some things help and others don't. I'm also happy to answer questions that you have, everyone is different and there's no one size fits all.

Each month I'd like to cover how to help with each of the symptoms of fibromyalgia so you can start to change your diet gradually and learn what works and what doesn't work for you. Even though food is the best medicine, stress and other medication can also alter the effects of eating well. Reducing stress isn't easy but it's equally as important as eating well. For anyone on medication that isn't seeing the results they expect, get in touch and let me help. I'll try to cover what helps with certain medications over the coming months as well to help compliment your treatment and make you feel as well as possible.

For my first month's advice, I think pain is a good place to start! We all suffer from it a great deal and it can be debilitating not just physically but can be very emotionally draining too. Before I cover which foods will help, I think it's important to discuss the adversaries first. These are the things that rob you of your progress. Eating healthy, can for some of us; be quite a lifestyle change and I know that I've been guilty in the past of going "I've been good all day, so I deserve a treat." However, what we think can be a treat can rob your body of all that good you've done that day! I think knowledge is power and the more you know, the more you can help yourself. So, let me introduce you to anti-nutrients. These can come from –

- **Deep fried foods**
- **Refined sugar**
- **Additives**
- **Cans and plastic containers**
- **Alcohol**
- **Painkillers**
- **Antibiotics**
- **Pollution**
- **Environmental chemicals in water**
- **Excessive free radicals from smoking**

Anti nutrients can gradually create a toxic overload and rob your body of vital nutrients to function which can then lead to a host of different health problems and symptoms. Before even adding new things into your diet, cutting these things out can help with so many of our symptoms from pain, inflammation, depression, water retention, gastro problems etc.

Lots of small changes can add up to a big change. Drastic changes to your diet can give you a bit of an upset stomach and you'll feel the effects of a sugar detox so try and implement these changes a little bit at a time and see how you get on. First try and cut out the above and secondly, try and add some of the following foods into your diet.

Joint inflammation and pain is aided by foods rich in Omega 3 and 6, B Vitamins, Vitamin C and D, calcium and magnesium. It can also be made worse by adrenal stimulants such as tea, coffee, sugar and refined carbs so make sure you drink lots of water and herbal teas along with your new improved diet.

Top Foods

Omega 3 – Mackerel, swordfish, fresh tuna (not canned), salmon, sardines, flaxseeds, walnuts, chia seeds, shelled hemp seeds, sunflower seeds, egg yolks.

Omega 6 – Sunflower oil, corn oil, sunflower seeds, pumpkin seeds, walnuts, sesame seeds, pistachios, avocados.

B Vitamins – Watercress, squash, courgette, lamb, asparagus, mushrooms, cabbage, broccoli, tuna, chicken, salmon, peas, lentils, cauliflower, bananas, oysters, sardines, tuna.



Vitamin C – Broccoli, peppers, watercress, cabbage, cauliflower, strawberries, oranges, tomatoes, kiwi fruit, lemons, grapefruit.

Vitamin D – Herrings, mackerel, salmon, sardines, oysters, cottage cheese and eggs.

Calcium – Swiss cheese, cheddar cheese, almonds, brewer's yeast, parsley, corn tortillas, prunes, pumpkin seeds.



Magnesium – Pumpkin seeds, sesame seeds, sunflower seeds, wheat germ, almonds, cashew nuts, brazil nuts, peanuts.

There are lots of ways to enjoy healthy eating. I use Pinterest a lot to try and find tasty new recipes that make me feel like I'm having a cheat day while still sticking to healthy foods. Does anyone have any good healthy recipes that follow the advice above that they would like to share?

My advice here is general and suited to most symptoms suffered through fibromyalgia but as I said earlier, everyone is different. I offer an 8 week course for anyone looking for an individually tailored nutritional therapy program; otherwise, I'm always open to answering any questions that you may have, email me care of

starknutritionaltherapy@gmail.com

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



Fibro Fog? – Forget it!

by Karen Crosby

It is well known that one of the most common and mysterious symptoms of fibromyalgia is fibro fog!

Clinically known as cognitive dysfunction, it can have an impact on our lives in so many ways that I am going to give some tips on how to combat it!

Imagine someone who does not have fibro going for an interview! The anxiety of what they are about to do can make their mind go blank, and I think everyone has experienced this at sometime in their lives.

However, fibro sufferer's deal with this every day and it can be really difficult for our work, in social settings, even in the supermarket!

There have been studies and research as to why this happens and some of the findings are: -

1. Fibro sufferers do not have enough oxygen to some parts of the brain on some occasions, possibly caused by the problems with the nervous system bringing about changes in how the blood vessels work within the brain itself.
2. Other research (not fibro-related) found that chronic pain may affect the front region of the brain associated with emotion, and that this region is constantly active because the affected areas fail to shut off, thus causing the neurons to become over worked and affect the brain as a whole – like walking too far causes our legs to ache!
3. Another possible cause is the lack of level four sleep that fibro sufferers experience, this is the deep restorative sleep we all need to help us feel fully awake with an active brain, heal and regenerate all the cells in the body, and help keep us healthy.
4. Also the lack of the four hours we need of deep sleep obviously causes a lot of fatigue, and this does impair cognitive ability for anyone.

Short-term memory loss is the main problem with fibro fog: making fibro sufferers forgetful for everyday activities and difficulty with things like maintaining conversations.

Symptoms of fibro fog: -

1. **Directional Disorientation** – forgetting where you are even in familiar surroundings (this happens to me sometimes).
2. **Words** – problems remembering words, using the wrong word at the time and forgetting names (this causes problems for me when I see so many students).
3. **Short-term memory loss** – forgetting what has just been said, read or studied, and causing confusion because of being distracted.

4. **Multi-tasking problems** – sometimes I am doing three things at once and forget the first one I have started!

Top Tips to combat fibro fog: -

1. *Write things down every day, tasks that you need to do at home or at work and prioritise the most important things first. Don't make the list too long as this will become overwhelming, but tick things off as you complete them.*
2. *Avoid too much caffeine as this is a stimulant, do not drink caffeinated drinks within 3 hours of bedtime as this will contribute to sleeplessness and during the day will result in crashes and tiredness when it wears off!*
3. *Keep a strict diary of events and appointments so that you do not forget any, check your diary every day to make sure and write them on the to do lists, with a big red star at the time it is etc. Set your phone alarm to the time you need to set off for the appointment in case you forget.*
4. *Routines are important, as you go through the day, do the same tasks at the same time each day, things like cooking, cleaning, and have lots of breaks to avoid being overwhelmed.*
5. *It is all too easy to lose things, so put the keys in a basket on the table to avoid rushing around the following morning. Keep the house and workplace tidy with things always in the same place, and file things properly.*
6. *Start writing your shopping list as soon as you run out of something and add to the list as you go along, plan meals and write down any missing ingredients, as well as a list of what you will cook each day.*
7. *Don't do too many things at once, as this leaves you open to forgetting what you were originally doing and leaving things only half done.*
8. *Sleep – make your bed your sleep only place, go to bed at the same time and get up at the same time every day, even on weekends. This helps establish a healthy sleep pattern.*
9. *Breathing – as a yoga teacher and holistic therapist, I know the benefits of slow, deep breathing patterns, as this helps with sleep and de-stressing.*
10. *Keep the grey matter working with reading, problem-solving puzzles, crosswords or studying for a course, like our muscles, the brain keeps healthy by being used!*



How I work fulltime with Fibromyalgia

By Karen Lovegrove

Working and Fibromyalgia shouldn't be in the same sentence! The same as raising a family and Fibro.

Just to give you a little bit of history, 5 years ago, I was working fulltime as a registered care manager, working anything up 70 odd hours a week, and stepping in to deliver care when needed. It was nothing to shower an 18-stone man in my day to day duties. But I was struggling massively. My health was on the decline, mostly I think due to the stress of working so many hours, and the physical side of the job was taking its toll.



I had at this time been diagnosed with Fibro along with IBS, Reynaud's, TMJ, spine problems, high blood pressure, Costochondritis. Proctalgia Fugax and mobility problems due to a severe weakness in my left leg. I was attempting to work these long hours on every drug available to me, most were listing side effects as "May Cause Drowsiness!", this in its own right was enough to cause major problems with working over 70 hours a week. Along with this, as my life was slowing down dramatically I mourned my previous life, as a realisation washed over me, that although I had been diagnosed with non life threatening illnesses, they were chronic enough to change my life beyond recognition.

My mental health slipped, the end result was giving up my much loved job to a life of being at home. I was exhausted at the time, and it felt like I was in a very dark place. Fibro robs us of so much now it had taken away my only source of income, and my lifestyle. It had taken my ability to exercise, and walk my dog. I was unable to visit the shops without it becoming a military manoeuvre!

I ended up in a wheel chair for most of the time when outside of the house, and I also purchased a mobility scooter, for when we went out for the day. I live in a very isolated village, so seeing people on a daily basis was no longer an option for me.

I lived like that for several years, and threw my time in to helping others via the UK Fibromyalgia Private Group on Facebook. My pain most days was through the roof, and mostly I negotiated my time based around medical appointments and when my next pain killer was due. I think most of you out there can relate to this.

Whiz forward 3 years, to last summer. Out of the blue I receive an email, a London agency saw a very old CV I had forgotten about on a website. But the job intrigued me, up until that point I hadn't even considered that I would go back to work.

I set to work weaning off some of the drugs that were causing my major tiredness, I then managed to coax my GP in to another round of physiotherapy and hydrotherapy. I worked my socks off trying to grab back some of my mobility. It paid off, I felt a lot better off the meds and with a small amount of exercise.

Interview arrived, I nervously stepped in to the room, and amongst being vetted for the job I bought up the fact that I was a Fibro sufferer and explained about having good days bad days, as it happened my interviewers wife also suffered! I was offered the job!

That was motivation enough for me, so I worked doubly hard from then on to maintain my mobility and keep my pain under control.

Luckily I have an understanding employer, and yes there are some out there! I give my all on the days I can, and if I am not up to it the next they get it and understand. I managed to summon up some extra support at home too. All of this enables me to work, my active mind appears to have reached as near normality as it can, and my mobility although hasn't improved it remains the same, in that I am able to move around enough to get me through a working day.

Yes I am exhausted at the end of each day, yes I am sore and yes I am no longer held by the restraints of claiming benefits. I am happy in myself, and I love the work that I do in IT.

With planning, work is a possibility, I had myself written off completely!

- Plan a workable solution to your pain relief
- Be honest with your employer
- Keep as mobile as possible
- Work hard and actively on the days you can
- Rest on the days you are not feeling so good
- Try to remain flexible in your approach to work
- Build up to working full time, start with a few hours at first
- Enjoy it!



The Verdict on Nutritional Supplements: Yay or Nay? By Sue Ingebretson

Author of, *FibroWHYalgia* www.RebuildingWellness.com

Has anyone ever shared a natural health product with you expressing so much enthusiasm that you wanted to run the other way? This happens often in the chronic illness community. Or, have you ever been told that one particular pill, powder, packet, or juice will fix your health challenges?

I sure have.

Simple fixes are very enticing. Who doesn't want fast results?

Fast results are a good thing, to be sure. This one-product-fits-all philosophy also brings up another tempting idea. If you buy into it (literally and figuratively) your solutions are wrapped up in one thing. This means that you can stop the endless searching for "the fix" because you've already found it. And, it's easy.

I wish that it were all so easy.

My own health journey has taken a lot of twists and turns along the way. The biggest problem early on is that I had no plan, no direction, and no idea of what to do.

Of course, many people shared their opinions with me. They were eager to tell me what I should or shouldn't do. My doctor said that food had absolutely no impact on my health. My physician's assistant told me that the next step after a cane, a scooter chair, would be GREAT since I could then carry my grandchildren on my lap. My husband suggested a miracle calcium supplement -- a one-product-fits-all remedy -- from late night TV.

Of all of those suggestions, at least the one about taking a supplement had a kernel of merit. I definitely a lot to learn.



The world of nutritional supplements can be very confusing. Especially when you're first starting out. I grew up believing my job was to sit still in the doctor's office and listen. He or she tells me what's wrong then gives me a prescription to fix it. I tried that. It didn't work. Once I began to shift my thoughts and incorporate new ideas into my healing plan, my world expanded. I began

to take action on my own rather than wait for an outside source to tell me what to do.

This shift of responsibility may sound simple (and perhaps even silly) but it was a very big change for me. Taking charge of my own health was a completely new concept. The interesting thing is that as soon as I started to take charge, I started to see results.

Adding key nutritional supplements to my healing plan was just one part of the whole package. I don't make any claims about supplements fixing anything. Rather, they played a vital role in the whole healing process.

Over the years, I've synthesized my thoughts on using nutritional supplements. Here are five ways that I believe they can help lead to healing success.

1. They help you to feel empowered.

Seeking out supplements to try provides a great opportunity. The simple act of looking for and choosing natural remedies can help you feel empowered and in charge. Researching personal solutions (i.e., improved nutrition, adaptable fitness activities, etc.) allows you to put on your Team Captain's Hat. Creating a personalized health plan takes a team approach, and it's important for you to assume the role of Captain.

2. They're part of a larger plan.

Nutritional supplements are an important part of your personalized health plan. Healing success comes from creating a combination of treatments that work for you. Supplements are most successful when used in addition to a healthy regimen of nutritious foods and regular fitness activities. Supplements (by very definition) are designed to augment the efforts you're already making to rebuild your physical health.

3. They support the healing themes of consistency, self-awareness, and investment.

Would you ever plan on taking prescribed daily medications sporadically or not at all? When it comes to alternative treatments, the same principle applies. It takes consistency and diligence to see if something is working. It also takes self-awareness to assess how you feel. Being aware of your own symptom improvements will help you to make adjustments as necessary, and find solutions to build on your success. When I mention investment here, of course, it's obvious to think of money. Nutritional supplements, especially high-quality ones - can be very pricey. But even more important than the financial investment, I want to point out the

investment of your personal time and effort. It takes time to research potential treatments and therapies, so please be patient with yourself. Take the time you need with an open mind to try something new. You get to decide if it's beneficial or not.

4. They play a powerful role in the treatment of chronic conditions.

Oftentimes, we look at a particular supplement (especially ones with a higher price) and we calculate how much it would cost to use it for months or years down the line. This may be an unfair assessment. The use of supplements evolves in three distinct phases as the body begins to heal.

- Initial phase for supplement use - those to take (maybe in higher doses) for a short period of time. This is sort of like a crisis phase of treatment. A detox plan would be a simple example. This phase may last for a few short weeks or for many months. It depends on the supplements and the severity of symptoms.
- The sustaining phase for supplement use - don't short-change this one! Some supplements, for example inflammation-fighting remedies, need a longer term approach to see results. The complicated symptoms often found in chronic conditions may need consistent, long-term treatment. This may last for a year or more. The consistency of use in this period allows the body to heal and sustain the healing benefits gained over time.
- The maintenance phase for supplement use - those needed on an ongoing basis. While there are some nutrient supplements that are likely to be needed long-term, it's good to keep in mind that the body is always changing. Constant assessment of the supplements you use is necessary to be sure that you're getting ideal nutritional support.

5. They're a proactive remedy.

It's easy to fall into the pattern of listing your symptoms and feeling that nothing can be done. Symptoms come and go and so does the intensity. Taking care of your body (every day!) through a variety of means, including nutritional support, is a positive, nourishing, and affirming way to treat your body. By taking nutritional supplements when needed, you're supporting your body with vital nutrients while taking an active role in helping your body to heal.

Have you found these five ways to be true?

Let's not forget that there are objections to supplement use, too. How do we know they're pure and contaminant free? How do we know if their results are truth or hype?

How do we know where to start?

My suggestion for these questions is to follow the recommendations of a person, practitioner, or professional who has your trust. Of course, do your own due diligence to see if the manufacturer's practices meet your own standards. But, beyond that, just do your best. There is no "perfect" product and there is no such thing as a one-product-fits-all approach.

Another concern for me as a nutritional therapist is to see clients who tell me that they don't eat vegetables because they believe their supplement is a replacement. Supplements aren't intended to replace living, whole, natural, nutrient-dense foods. They augment a healthy diet and do not serve as a substitute. Unfortunately, some companies market their supplements in this way. They want to appeal to those who'd rather swallow a capsule or drink a shake than eat a salad. While these supplements may provide short-term results, the long-term benefits will lack in other ways.

Getting back to when I was critically ill, I had no idea that I was completely malnourished and nutrient deficient. I hate to think about what would have happened if I hadn't learned more about nutrition. I had no understanding of the impact that my nutritional ignorance played on my body. I consumed processed foods and often skipped meals.

I'm grateful for the intervention of others. When I started my healing journey, a wise natural health nutritionist guided me toward some nutritional supplements to help me along the way. Was that my whole journey? Of course not. But nutritional supplements played a powerful role in my personal healing story, and they continue to do so into the present.

What say you? Of course, my experience leads me to give supplements a resounding YAY. What will be your experience?

Sue Ingebretson (www.RebuildingWellness.com) is an author, speaker, certified holistic health care practitioner and the director of program development for the Fibromyalgia and Chronic Pain Center at California State University, Fullerton. She is also a Natural Health Editor for the ProHealth.com fibromyalgia website community.

Her #1 Amazon best-selling chronic illness book, FibroWHYalgia, details her personal journey from chronic illness to chronic wellness.

Would you like to find out how stress is impacting your life? Sign up for Sue's free Is Stress Making You Sick guide.

(<http://rebuildingwellness.com/stress-guide/>)



Fibro Parenting: How to Talk to Your Kids About Fibromyalgia by Brandi Clevinger

Kids are full of questions. Why? How? When? Why? Where? How come? Why? Yes, I purposely put why multiple times because that's the most common question with kids.



Really, any answer you give a kid is shortly followed with, why? Their minds are beginning to register the world around them outside of their home, and the questions they ask are their tools to figuring it out. As parents and caregivers, we encourage this type of questioning. It means they are learning and growing, and isn't that what we want our kids to do? Of course.

But what if those questions were directed at you about your illness? What if those questions of why, how, when, where, and how come were asked repeatedly about the same subject day in and day out? The prodding questions leave you feeling guilty, confused, and maybe even angry. Would you still encourage it?

Let's throw this factor into the mix: On top of all those questions about your condition, you don't have sufficient answers. In fact, you don't even know where to begin with your answer. There is so much information you could repeat to them, but it's not the reality of your day-to-day living with the pain and other symptoms. And those symptoms can vary each hour and day to day as well as the intensity or pain. What would you do then?

I'll tell you what I did. I either deflected their questions, acted as though I didn't hear them, or said, "I don't know." None of those answers were the best choice, but at the time, I didn't know what else to say. For one of the few times of my life, I was at a loss for words. It pained me to see the confusion in on their faces each day, but again - I didn't know what else to say.

I remember the time before and shortly after my diagnosis, the never-ending questions from my kids about the lack of interaction or physical activity I had with them. They were just innocent, curious questions

about their mom, but each question was a little stab of pain. How was I to share with them the generalization about my illness when I knew very little? And if the complexity of the illness was confusing to me, how were they supposed to wrap their little minds around it? As stated before, how could I translate my daily struggles and experiences with them in such a way they could understand? It seemed like a hopeless situation. It and only compounded my struggles with fibromyalgia.

Knowing what I know now, I would tell my past self that my choices of deflecting, ignoring, or saying 'I didn't know' was not the way to handle it. In fact, those responses only led to them asking more questions. I created an endless loop of questions by not answering their original questions.

So, how did I break that endless loop and talk to my kids about my illness?



I sucked it up and just did it. I told them about fibromyalgia and how it was affecting my body. I told them the basics and how that limited my physical activity. I stressed that it was not their fault and that I was doing my best to stay healthy so I would have less painful days. Sounds easy enough, but there were more feelings before I started the talk with them. Before the discussion, I was worried about them asking questions that I couldn't answer. Or they would feel guilty, somehow, about my illness. Or - worst yet - what if they didn't understand anything I was saying? Eventually I figured anything was better than not talking, I prayed for the best and just went with my instincts.

The conversation went well and much better than I anticipated. I used small, easy words for them to understand in a casual voice so as not to alarm or distress them. We hugged while talking and answering their questions. It went smoothly, for the most part. If I had to do it all over again, I would do it the same way with no regrets.

We discussed this topic in my Facebook Fibro Parenting group, and parents had great ways they talked to their kids about fibromyalgia.

A few ways included the following:

Bringing up the subject casually and letting the discussion lead itself through the kids' questions or comments.

Using Ravyn's Doll by Melissa Swanson to lead into the topic. Melissa does an amazing job exploring the subject of fibromyalgia and the invisibility of the illness through her new book, Ravyn's Doll. Using vibrant colors and adorable characters, children learn that sickness does not always come in the form of symptoms you can see. This teaches kids about compassion and understanding which are perfect for invisible illnesses.

How Many Marbles Do You Have? By Melinda Marlott: This is like the spoon theory, but uses marbles instead of spoons. It is easy enough for kids to understand about the use of marbles in relation to being tired and not being able to do certain activities.

Allowing the kids to attend doctor's appointments and making them a part of that discussion.

For older kids, providing reading material that is not too overwhelming with information can help and provides a path to a discussion about fibromyalgia.

Before launching into the discussion of fibromyalgia, ensuring kids that fibromyalgia, although it has no cure, it is manageable and is not a terminal illness. Kids tend to worry more than we realize, and it's important to ease any distress they may have regarding your health.

Letting them know it's not their fault you're ill and you are not able to always participate in the physical activities; however, watching a movie together or other less physical, quiet activity is fun with them, too.

In summary, here are six simple tips to talk with your kid(s) about fibromyalgia:

ONE

Use a casual voice with easy to understand words while embracing them so they feel your security. Limit the information so as not to overwhelm them.

TWO

Ensure them that even though fibromyalgia does not have a cure, it is not life threatening, and manageable to a certain degree.

THREE

Using visual aids such as children's books (as referenced above) to introduce the topic and guide the conversation.

FOUR

Include them on your treatment preferences and let them know how they can help you (using indoor voices, helping with chores, giving gentle hugs, etc).

FIVE

Encourage questions and any thoughts they may have about it. Even if you can't answer a question, tell them you are still figuring it out and will let them know. Include them if there is a way they can help find the answer.

SIX

There are other ways to have fun with them that do not always include physical activity. Suggest snuggling with them while watching a movie, reading a book, or playing a game on a mobile device.

However you choose to talk with your kids about fibromyalgia, just talking to them can make a difference. Leaving them in the dark, as I did for quite some time, only leads them to ask more questions or even ask themselves if they are to blame. Include them in your life, even the part that is fibromyalgia. This will, more than likely, encourage them to talk with you about other subjects they are concerned about. Keeping an open-door policy with your child improves communication within your family and encourages them to be more compassionate and understanding.

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

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

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



Fighting off illness with Fibro

By Naomi Harvey

Any normal person with a bout of illness has about 5 stages they go through,

- **Feeling a little rough**
- **At deaths door**
- **Some improvement but still rough**
- **Nearly almost fully recovered but maybe a little lethargic and weak, some back sliding while body regains full health**
- **Back to normal**

When we add in any life long chronic illness, immune system disorder, or any health battle a simple cold can mean weeks or months of recovery time, and sometimes, just sometimes we never fully regain the abilities we had before the illness.

Anything from a common cold, to the flu to norovirus can leave us in a state for months on end, where as a "normal" person would be back to normal after a couple of weeks. There are plenty of things we can do though to give ourselves the best chance of coming out of illness without too much of a pay back to our already existing conditions.

Vitamins and Boosters - If you already take vitamins and boosters as part of your health regime you have already given yourselves an added boost. If you don't then its never too late to start. Folic acid, vitamin C, Zinc, Echinecea, to name a few. For what ever illness you have its good to research and find ones that can help give you an extra chance of fighting it off.

Eat well - The last thing you want to be worrying about when struck down with added illness is eating properly, but it is at this point when it is vital to ensure you eat right and as healthily as possible. If you aren't able to cook for yourself get someone in to do it for you. Shop online and make sure you include all the good healthy food, like vegetables, fruit and comfort foods.

Rest - This is beyond vital to any one who is sick but extra important if fighting chronic illness, you will tire faster, mush faster then normal and if you try to push past it then you will only hinder your own recovery and drag out your illness. If it takes days you must use those days to rest and recover and not blame yourself for any of it

Steam - Steam can help clear out any blockages in the sinuses making breathing easier and allowing you to rest fully and comfortably for some time, giving your body the chance to start to recover. Adding herbs to the seam can also help promote the bodies defences and let you detox, herbs like lavender and sage make a very good addition, boosting healing and giving your body the extra strength to fight off toxins.

Plenty of fluids - No matter which illness you have on top of your chronic condition it is always vital to maintain a healthy balance of fluids in the body, when dehydrated some symptoms of cold and flu can be exasperated. You must keep up your fluid intake while ill especially if you have been expelling them.

Keep clean - While the last thing you want to do when ill is clean it is important to keep on top of your cleanliness to prevent infecting others or spreading your own illness around yourself. Put used tissues in the bin, clean each cup, bowl, or cutlery in the wash each time. Don't reuse and don't leave things around, minimise your own and others exposure to the germs as much as possible. Keep your body clean as well, change your bedding and pyjamas regularly if have been feverish or bed bound, if you can't get help to. Shower regularly washing away the germs as much as possible.

Change of scenery - The last thing anyone really wants to do when feeling ill is to go out of the house, the effort of this is difficult even on our good days for those with chronic illness, but sometimes even a change of room or atmosphere can make a huge difference. Simply go to another room for a while, sit in the garden if possible. But the change of air makes a big difference as it gives the body a chance to clear the system. If you can't leave the bedroom then air it out, open doors and windows to get a through breeze.

Know when to ask for help/seek a GP - As any chronic illness sufferer knows we put off going to the GP as much as we can, we become deb hands at knowing when we should or shouldn't go for our "normal" conditions, but when we add in a cold or flu it becomes confusing as to what "should" be OK to get through and when we need the extra help. I know I usually put a "simple" cold off as long as I can and then usually end up with a chest infection and asthma issues because I stubbornly think I know best. A "normal" illness though for us can be so debilitating that if we do try to push through the wrong one then we can make things soi much harder to beat in the long run.

None of us are immune, no matter how many vitamins/ medications we are taking at the best of times so don't be afraid of a little cold, just know how to fight it for the best chance you have and when to seek help. No illness is "little" when chronically ill.

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

FIBROMYALGIA

FACT

OF THE MONTH

The comorbid conditions of fibromyalgia may be characterized as existing upon a continuum of painful conditions, sharing key symptoms or simply co-occurring with FM [1, 2]. It was showed that one of the most commonly comorbid category is "other diseases of the musculoskeletal and connective tissue," where 45% of FM claimants had at least one claim [1].

Some disorders such as hypertension, respiratory and other chest disorders, back disorders, abdominal pain, irritable bowel disorder, depression and other mental diseases and neoplasms were reported in fibromyalgia more frequently than other conditions [1, 3, 4].

Now it is clear that the bête noire of fibromyalgia, one of the most common comorbidity in fibromyalgia, is a psychological illness. Indeed, fibromyalgia patients experience psychiatric comorbidities in 30-60% [2]; this rate increases when the rate of lifetime psychiatric disorders (commonly depression and anxiety) is considered. As often debated, mood disorders may aggravate and complicate the management of fibromyalgia, but the nature of the causal relationship between these two conditions is unclear [5, 6].

Several analyses revealed the high levels of comorbidities and resource utilization of fibromyalgia claimants [3, 4, 7, 8, 9, 10, 11, 12, 13, 14,). Commonly visited specialists such as radiologists and mental health practitioners, rheumatologists and internists may further reflect unsatisfactory diagnosis and medical care for both physicians and patient. The cost of patient management in all levels of care is high because of the extensive work-up and disappointing treatment [3, 7].

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Foggy Moments

We asked our Facebook group what's the daftest thing you've done or said due to brain fog?

GB- I was doing some strawberries for after my tea. Cut the stalks off and put the strawberries in a bowl, then put some yoghurt on them, and went and sat down. I bet you've guessed what I'm going to say - a lovely dish of strawberry stalks with yogurt, strawberries in the bin!

GB- After coming to the UK for my daughter's wedding I was taken to the airport to get back to France - 2 days late! I was so sure I had the date right - quite a costly mistake, especially as my luggage was overweight too!

RT- Put boiling water on cereal. Yesterday!

CW - This page makes me feel better about myself. I'm always forgetting to put a tea bags in and sitting get down with a hot mug of very weak milk! Once I even put my mug of tea in the fridge and sat down with the bottle of milk. The last thing I remember doing is asking hubby if he wanted a Kunky Chit Chat that one has stuck now and is our name for a Chunky Kit kat!

PM -When hubby and I have dinner at home and I need to clean up in the kitchen before I eat I always tell him "don't wait, start." One day I told him "don't start, wait." I came in to see him patiently waiting for me and asked him why he hadn't started eating yet .I also look for my glasses and find I'm either wearing them or have them hooked on my top! I do a similar thing with pens and always seem to be holding them

SH- I've tried opening the front door with the key the wrong way round and was getting quite irate when the hubby eventually said turn the key round. Have found my glasses in the washing machine and then spent the next hour looking for them. My youngest still teases me over that one. Have put shampoo in bath instead of bubble bath. The list is endless but it helps my family and I keep our sense of humour with this illness

SC- I am always getting my words muddled up. The other day I asked hubby to put to some tea in the booster and have asked him to put the line on the washing. I have tried to get into the wrong car a few times and the other day I asked my daughter if she was taking my grandson to watch Finding Dora. I am also always looking for my glasses and I either have them on or they are on my head or looking for my keys when they are in my pocket. The best yet has to be the day when I very nearly

went out with no top on and only realised when I opened the front door that I was stood there in my bra... now that would have been an eyeful for the neighbours

SG- Oh you just reminded me! a few months ago I was walking towards my car and spotted a hole near the front light. I studied it for a while wondering how on earth it happened and why I hadn't noticed it before - it was quite big. I was there 5-10 minutes looking at my car quite perplexed. Then I went to the driver door and wondered why I hadn't noticed the colour of the thing that pops up when you open it, it never opened and I stood back and looked up and down the road feeling really weird then noticed a couple staring at me, standing by their front door, before they said "can I help you?". I looked at them, looked back at the car and said "oh sorry, this isn't my car is it?"!!!! It wasn't even the same colour; mine is blue/grey - this was silver, it was a totally different car, and my front light has been taped because I smashed it on my wall getting out of the drive! I never even thought that there should actually be a load of tape where the hole was that I studied for so long!!! lol what an idiot I must have looked - it actually spooked me quite a bit and the burly toothless couple that were staring at me weren't too impressed either!





Forum News By Claire Collopy

I love the friendly, caring, supportive online community on the UK Fibromyalgia forums.

This month I asked the forum:

What positives has fibromyalgia brought to your life?

I shared that I had not been well lately, I had nearly a week off work with a fibro flare, so it's easy to focus on the negatives of life with this condition. But, I don't want to let fibro take away my smile and positivity. So, I was thinking about the positives:

I now know how strong and resilient I really am.

I now appreciate life's little pleasures - for me, happiness can be found on a cold Sunday afternoon, wrapped up in my slanket, snuggling with my cats, a movie on the TV, and a warm mug of hot chocolate in my hand.

I discovered the meaning of true friendship - I appreciate those friends who are still here for me.

S responded: Mostly self-discovery:

I have more willpower than I thought

I have a higher pain threshold than I thought

I can do more than most healthy people can when I set my mind to it

I am more bloody minded than I thought

Apart from that, it's been pretty rubbish, really.

L replied: It's very hard to think through all of the trauma from having chronic health and what things I've lost but!.... sitting here thinking and looking at things I didn't before I feel brings a positive like:

Nature! When I can I walk my dog up to the fields. The fields stretch for miles and miles and there's a bench I sit on. I look out at the fields, the trees, the clouds, the sky and wildlife. How quiet and peaceful it is. It's the best thing for me and always helps lift me out of a bad day and helps my moods.

L also shared: Fibromyalgia has taught me to take time out for me. Time to self-care. Realisation that stuff can wait. Learning what I can do, and what I shouldn't do. As you said Claire, friends! I now can very clearly, differentiate between real friends, and acquaintances. It has also taught me to let go of the

anger that I felt towards those who I thought were friends, but have been forgotten by them.

Lots of positive things, for self-growth.

A then shared: Hello. Well after finally accepting it and learning how to live with it, these are the positives FM has brought to my life: listen to my body, take time to rest without feeling guilty (not always, I have to admit, I sometimes still feel guilty about having a rest on a Saturday afternoon when everybody else is running around sorting things out), enjoy the good days yay :-), healthy eating - a big positive for me! and also the fact that I can actually take more pain than I ever thought I could! Be strong everyone and have a good night sleep! xx

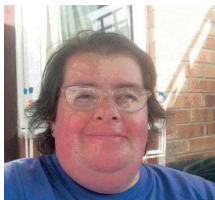
Can you help answer other members' questions about Fibromyalgia? Do you have any questions of your own?

Come and join the discussions on the UK Fibromyalgia forums:

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



BRENDAN KEELEY



ARE YOU A LARK OR A NIGHT OWL?

By Helen Watts

I have always struggled with mornings no matter how well I sleep I still find mornings hard but very happy to be out quite late in the evening and then still be up at gone midnight so I'm definitely an owl but I wondered if others were larks or owls so asked the Facebook group members.



'MM' replied "I'm an 11.00 to 15.00 person so I'm not sure what that makes me!"

'SCM' commented "good question, same as MM I'm 11-1500 with added exhausted pigeon in the mix".

'VM' said "Owl. Completely. But scared of the dark, so it doesn't work out so well!"

'SH' stated "Definitely not mornings, I avoid appointments then as much as possible. But then I prefer to wind down properly in evenings to help me sleep better so can't do late nights either! Plus an afternoon out breaks up the day and helps me keep my sanity for that day by interacting with real people".

'ED' said "I'm a lark sounds weird I know".

'CNJ' replied "I used to be a Lark. I'm definitely not an owl. What would you call someone who fights to wake up in the morning and fights fatigue at about 1700? Maybe I'm just a lazy worm".

'SS' stated "Owl I'm afraid".

'CB' commented "I'm very much an owl. Often happy to be up a bit later but cannot shift my butt out of bed in the mornings, which doesn't help when my 4 yr old daughter decides 6.30 is time to get up and trash her bedroom looking for barbie!".

'CD' said "A lark, I'm ready for bed by 9. Up early cos I cant usually sleep!".

'TB' replied "I always go to bed when my little ones goes to sleep, chill , read , whatever for a couple of hours, do my relaxation /meditation, then fall asleep, by 2am I'm awake, no matter what time I go to sleep its 2am . I may nap on and off during the night for 10

mins , then I get up at 6am . I'm awake enough in the morning but body is drained. I usually write during the night when it's quiet and I don't get distracted. By 3 in the afternoon I am done in".

'JD' stated "I'm definitely a Lark, always up around 4.30 - 4.45 am. every day".

'GB' said "I'm an Owl. I've tried going to bed earlier, and occasionally will manage to sleep, but most of the time I'm still awake late and then can't sleep. Nearly every morning I stay in bed until about 10.00 am, or later".

'RJR' added "I am an owl sometimes I stay awake til 5 am then sleep most the day away".

'HR' replied "I was a Lark who became an owl then had hard core training to become a Lark again for school runs and a quality of life, not to mention a body that was much healthier!".

'TH' commented "I'm a Lark, always have been. If it's not been done by early afternoon it doesn't get done".

'KP' added "I'm a lark up at 5.30 in the week without fail by early evening I'm done and drained, I like to be up early and get sorted".

'PJ' replied "Have you seen the meme "I'm not a lark or an owl, I'm some kind of exhausted pigeon!" well, that's me!!! I don't sleep well so I'm always up late but I'm also up by 6.30/7am".

'LP' commented "I don't sleep well - I wake up a lot in the night - but I'm a lark up at 5.10am or 5.25am every day".

'DB' said "I'm an owl ... wide awake at night and absolutely shattered when I wake. Takes me till lunch to start waking properly. Not good when I'm up at 7am".

'HB' replied "I'm an owl, although the pigeon really does sound like me".

What a great mixture of larks and owls and the odd pigeon! Which view most aligns with your day, are you up and busy early or are you at your best in the evening? Why not come along to the Facebook group and join the discussions.

Helen Watts



ASK BRIAN

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

Dear Brian

Two years ago, I suffered a prolapsed disc. I needed an operation. During the course of that operation on my back, I developed a spinal infection. My back pain became much worse and I have also had a loss of feeling down my right leg and right foot. I also have had pains in my legs and a severe psychological reaction. I was despairing because of the pain.

Brian, I appreciate that this is not a Fibromyalgia case, but it does involve intense pain and what is your advice?

Hayley

Dear Hayley

This sounds like it has been an awful experience for you. My suspicion is that at the time of the operation you may not have been given antibiotics or sufficient antibiotics to prevent the infection in your spine. We will need to investigate this, but it was probably negligence if that happened. The infection will have caused your back pain and we would need a neurologist to comment on whether, if there was a failure to provide antibiotics, that was also responsible for the loss of feeling down your right leg and foot and for the pains in your legs. It may well have been and would have caused you depression.

I would not be surprised if you are still in pain, your mobility remains reduced and you are not able to work. You will have needed and may still need care and assistance from your family and hydrotherapy for pain relief. We can explore all these aspects.

This will be a substantial claim if I am right about the lack of antibiotics.

Brian

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Grosvenor House
Agecroft Road, Manchester M27 8UW
Tel: 0161 737 9248 • Fax: 0161 637 4946

THE FIBROMYALGIA EXERCISE COLUMN



Low GI Foods by David Jenkin

You may have heard the terms “low GI” or “slow release” foods before, but possibly never knew what these terms meant? Let’s start with the ‘GI

part’, this stands for Glycaemic Index. This is an index chart of foods scored by whether they raise blood glucose levels quickly, moderately or slowly. Different carbohydrates are digested and absorbed at different rates, and the Glycaemic Index is a ranking of how quickly each carbohydrate-based food and drink makes blood glucose levels rise after eating them.

Low GI foods are therefore more filling, because energy is transferred from the food, to you, more slowly, you do not need additional food for additional energy intake. So this really helps to cut down on snacks and portion sizes for weight management. Low GI foods are also much better for your concentration and fatigue levels, as high GI foods peak and trough your energy levels, giving you an energy surge followed soon after by an energy crash. Low GI foods are obviously much better for you too if you are diabetic, or in a risk group for type 2 diabetes (aged over 40 years old, have a parent or sibling, history of high blood pressure, or if you are overweight – especially around the middle).

Low GI foods include: aubergine, broccoli, garlic, cabbage, green vegetables, lettuce, onions, mushrooms, red peppers, and tomatoes (all scored at 10 out of 100). High GI foods to avoid are chips and puffed rice (both 95 out of 100), honey, mashed potato and rice (90), and cooked carrots, cornflakes, baguettes, popcorn and rice cakes (85). Some foods that may be have a higher GI than you thought include: broad beans (80), watermelon (75), turnip (70) and melon (65).

I want to conclude by advising you that high GI foods are not necessarily unhealthy, they may well contain vitamins and minerals and be low calorie. By the same token some low GI foods are not especially good for you and are not low calorie (walnuts 15, peanuts 20, dark chocolate 22). So GI is just something to be mindful of, if you can choose a food that you know to be good for you, and is also low GI, then make it a power food for you this year!

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

<http://tinyurl.com/o9s6bw8>

Or alternatively you can email the magazine at office@UKFibromyalgia.com

or myself on davidjenkin@hotmail.com

and we can assist you in purchasing your copy.
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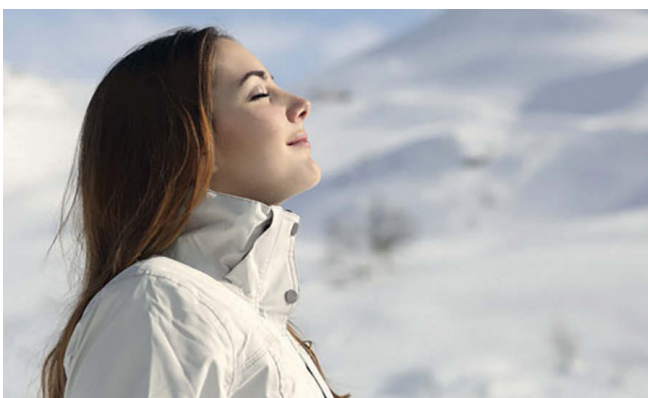
Remember to Breathe!

By Linda Hall

www.audiomeditation.co.uk

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

Breathing is so automatic that most of the time we're unaware of it even happening. And because it's something we do on autopilot, we tend not to notice the poor breathing habits we've adopted. Like me, you probably hold in your breath when you are nervous about something or performing a tricky task. Whilst this is perfectly natural and not damaging in itself, it can become a problem if the habit generalises out into your day-to-day life. The way you breathe has an impact on your well-being and reflects your emotional, mental and physical state. For instance, fast, shallow breathing, interspersed with frequent holding in of the breath, (forgetting to breathe), is likely to be an expression of your nervous system being caught in the 'freeze' state of the 'fight, freeze or flight' stress response. The age-old advice, "Remember to breathe!", has solid roots. The act of slowing the breath and exhaling fully, helps release physical tension and clear the mind because it triggers the body's Parasympathetic relaxation response, whose primary function is to restore, repair and renew.



Born to breathe from your diaphragm

Let's take a look at the process of breathing. You were born to breathe from your diaphragm - a flat, elastic muscle sitting above your digestive organs below your lungs that draws air in and out like a bellows. The action of breathing is assisted by other muscles in your body, primarily your intercostal muscles located between your ribs. The muscles involved in breathing become tight and less flexible through prolonged periods of stress,

causing breathing patterns to become shorter and shallower. Chronic illness, lack of exercise, depression, anxiety thinking patterns, stress of any sort, discomfort or pain, all shorten the breaths' cycle.

Breath awareness for stress management

Fast, shallow breathing adds to your body being in a state of distress and feeds into your autonomic nervous system's fight, freeze or flight response. Ideally, you are looking to open up any tight breathing patterns and allow your breath to slow, relax and deepen, so that you breathe from lower down your lungs when you are at rest, as if from your belly.

Part of the body's natural relaxation response

The good news is that, as your mind and body relax, your breathing will naturally begin to relax too. And, the more your breathing relaxes, the deeper your mind and body will be able to move into the 'relaxation response'. It's best not to concentrate too hard on your breathing as this may make you over-vigilant or anxious. Rather than judge the way you are breathing, merely notice its ebb and flow and let it slow and deepen in its own time. Just as relaxation cannot be forced, your breathing needs to be allowed to open up naturally in stages.

A powerful resource

Becoming aware of your breath acts as a powerful anchor to the here and now. As well as a means for releasing physical and mental tension, breathing provides a way to manage difficult feelings and allow them to be expressed safely. You can use your breath to ground and steady yourself; energise and empower yourself; self-soothe; manage pain and much, much more! Breathing is an amazing resource that we'll continue to explore in this column in future issues.

To help you adopt healthier, more relaxed breathing patterns, try incorporating the following mindfulness exercises into your daily life.

Mindfulness Breathing Exercises

Pause every now and then during your day and:

Notice if you are holding on to your breath: Allow your shoulders and belly to relax. Breathe out fully, in a sigh if it feels right.

Notice any shallow or fast breathing: Allow your shoulders and belly to relax. Sit back and allow your breath to slow down and become fuller.

Notice if any anxious thoughts are affecting your breathing: Come back to the present moment and become aware of your surroundings; feel the ground beneath you and the air on your cheek. Savour the air as it enters your nostrils. Breathe out where you've been in your head.

Notice if it doesn't feel like you have enough personal space: Sense the horizons outside and breathe in from these horizons. Breathe the light and spaciousness into you.

Notice any holdings or tension in your body: Breathe out down to your feet and imagine or sense everything your body doesn't need to hold on to flowing out of you into the ground. As the out-breath softens and releases, allow the body and mind to soften and release.

Notice if the mind is racing ahead or busy: Come away from your thoughts and slow the breath down, focus on the sensation of the air entering your nostrils and leaving again. Sit back and ground yourself through your body's connection with the surface beneath it.

Notice the islands of rest at the end of the out-breath: Allow yourself to rest in these spaces every now and then.

Notice the steadiness beneath you and breathe it up into your body to recharge and steady yourself.

Practise Belly Breathing: Place the palms of both hands on your belly, with your elbows and arms relaxed, (it's best to do this when you are lying down, or sitting comfortably supported), and slowly breathe into your belly and out again from your belly. Allow your hands to gently rise and fall as your belly fills and empties like a balloon. Belly Breathing teaches you how to slow your breath and breathe from your diaphragm rather than the upper part of your lungs. It can be a good way to induce relaxation. There's no need to try hard, allow your breath to ebb and flow gently without over breathing.

Before sleep, say "I let go of the day" as you breathe out. Allow everything you no longer need to hold on to from the day to flow out of you.

In the morning, on waking, breathe in from the horizons outside. Welcome the day and re-charge yourself. Breathe out what you no longer need to hold on to from the night

Meditation Exploring the Breath

Sit back and ground yourself

Allow your breath to ebb and flow naturally

Notice the sensation as the air enters your nostrils, goes deeper and leaves again

Become aware of the expansion of the in-breath and the release of the out-breath

Explore the receiving of the In breath and the release of the Out breath

Breathe in from the furthest horizon

Release fully as you breathe out

Sense out to the space around you

Notice the spaciousness and allow your breath to slow down and become more spacious

Explore the pauses at the end of the out-breath

Allow yourself to rest in the rise and fall of your breath

Notice what happens when you allow yourself to go with the breaths' flow. Close.

I hope you've enjoyed this article and found it useful. I wish you a good month. Happy breathing and go well!
Linda

audiomeditation.co.uk

More on Exploring the breath:

Listen to my audio 'The Power of Breathing'.

Available in CD or MP3:

<http://bit.ly/2jUrK0d>

Read my article 'The Breath of Life':

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

Watch my YouTube 'Breathing' video meditation:

<http://bit.ly/2e8THY6>

To help you keep on track



Breathe out fully - Breathe slower

(Stick your Post-It reminders where you'll easily catch sight of them: the fridge door; your computer; the mirror; the back of the loo door; the front door; your bedside table).

Practical Guidance

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

www.TheMeditationProgramme.com

Conscious Process is also available as a multi-media on-line course:

<http://bit.ly/1PrhORp>

Visit my on-line store for relaxation, meditation and personal growth CDs and MP3s. Mindfulness, creative visualisation, positive thinking, sleep inducer, meditation courses, blog and articles
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BRIAN BARR
SOLICITORS

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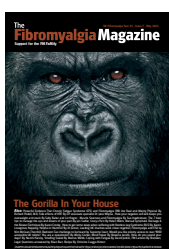
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Christine's Recipe

More than 500 scientific studies have shown that people who consume soy on a regular basis have a lower incidence of chronic disease – including heart disease, which is the UK's biggest killer. One reason for this is that soy, a complete protein, contains isoflavones, which can lower blood cholesterol. For post-menopausal women it is useful, too, because it contains plant oestrogens. As a result, hot flushes, irritability, depression and so on are reduced. However, as soy acts as a hormone in the body it can interact with the delicate balance of thyroxine, the hormone produced by the thyroid gland. Moderate consumption of soy is therefore recommended, whereas high consumption should be avoided.



Chicken wings with honey and soy (serves 2)

6 chicken wings
1 tsp vegetable oil
3 tbsp soy sauce
1 tbsp water
1 tbsp honey
1 tbsp sesame seeds

Preheat the oven to 190C/gas mark 5. Heat the vegetable oil in a small ovenproof frying pan then fry the chicken wings for 2-3 minutes on each side, until golden. Remove the pan from the heat and add the soy sauce, water and honey. Transfer to the oven and cook for 10-12 minutes, turning the chicken wings once. Arrange the chicken wings on a warmed platter, scatter over the sesame seeds and serve.

Chilli soy tofu (serves 2)

500g/1lb 2oz fresh tofu
1 small red chilli, sliced finely
2 spring onions, trimmed and sliced finely
3 tbsp soy sauce
2 tsp sesame oil
1 tsp oyster sauce
2 tbsp fresh coriander

Fill the base of your steamer with water and bring to the boil. Drain the tofu and place it on a heatproof plate that will fit inside the steamer. Steam the tofu for 20 minutes, then drain off the excess water and carefully transfer to a serving plate. Heat the soy sauce, sesame oil and oyster sauce together in a small pan until hot. Pour the mixture over the tofu, scatter with the red chilli, spring onion and coriander leaves and serve.

Steamed fish with ginger and soy (serves 4)

4 pieces of white fish (cod, haddock, plaice, etc)
2 tsp sesame oil
2 tbsp light soy sauce
1 tbsp white wine
1 clove garlic, crushed
2 pieces fresh ginger, sliced thinly
2 medium onions, finely chopped
800g spinach, roughly chopped

Line a steamer with baking paper then place the fish in a single layer into the steamer. Mix the oil, soy, wine and garlic in a bowl and pour the liquid over the fish. Scatter onion and ginger on top. Now place the steamer over a pan of simmering water. Steam for about five minutes, or until the fish is cooked through. Meanwhile, stir fry the spinach in a lightly oiled preheated wok until wilted. Serve by placing the fish on top of the spinach. Spoon any excess liquid over the fish to finish.

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



Worldwide Research

tDCS seems to reliably improve the symptoms of fibromyalgia.

Pilates training improves pain and quality of life of women with fibromyalgia

Losing Brain Matter – the Fibromyalgia Way

A Diagnostic Challenge: When Fibromyalgia Coexists with Ankylosing Spondylitis

A Letter to my Loved Ones (What I Wish You Knew)

20 Minutes of Moderate Activity May Help Ease Inflammatory Conditions

Ultrasound Therapy for Fibromyalgia and Lyme Disease

Investigating Subjective Experience and the Influence of Weather Among Individuals With Fibromyalgia

How to Cope With Fibromyalgia Fog

Group celebrates 15 years helping people with condition which baffled doctors

7 ways to support someone with fibromyalgia

by Frances Coleman-Williams

It can be tough coming to terms with a chronic illness diagnosis.

And when you do get that diagnosis, it's important to get the right professional support.

But perhaps even more importantly, the support from friend and family is vital to manage day-to-day.

I suffer from fibromyalgia, a condition that causes pain all over the body. Although its symptoms are debilitating, what causes the condition is unclear.

I've had mixed results from the rheumatologists, physiotherapists, etc. but my true rock has been my husband.

He supports me when I'm crying in pain and when the fatigue saps me and makes me grumpy.

Here are some of the ways you can support someone who suffers from fibromyalgia too.

1. Learn about fibromyalgia

Most people don't know anything about the condition so get googling.

Some good sources include NHS choices and Fibromyalgia Action UK.

This can help you and the person you're supporting gain an understanding of what happens and equip you both to manage the pain and be survivors.

Couple embracing on couch in vacation home man kissing woman's forehead

2. Help them find a regime that helps

A number of treatments need to come together to manage fibromyalgia.

Medication helps but other things include massage, paced exercise and keeping warm.

It can take time to find the regime that works so it can help to discuss the options and adjust over time.

When you're suffering, it can be really hard to see the wood for the trees so having someone else who can see the bigger picture and perhaps suggest alternatives can be helpful.

3. Remind them that it's OK to stop

I get incredibly frustrated that my body can't do what it used to do and I'll often push myself and become completely exhausted.

My husband has to remind me that stopping is not

failing – it's looking after myself and this is OK.

I have to schedule in rest days and I have to be reminded not to do housework etc.

Woman sleeping

4. Support them to keep going

It can be very hard to get the balance right.

When the pain and fatigue hit, it can take every ounce of determination to keep going.

It's important not to give up or stay in bed.

A vital part of management is regular exercise so a supporter will encourage the sufferer to keep it up regularly.

5. Do the little things

It's surprising how touching it is when someone else runs me a bath or heats up my wheat bag when the cold is attacking my joints.

6. Take time for yourself

Supporting someone with any chronic illness can take its toll on you.

It's OK to take a break for yourself and when you come back, you can support them with renewed energy.

7. Stay positive

Yes, fibro is a chronic, debilitating condition but it's not the end of the world and everyone involved needs to stay focused on the fact that it can be managed.

I have found that having the right support is the difference between fibromyalgia controlling me and me controlling my fibromyalgia.

<http://metro.co.uk>

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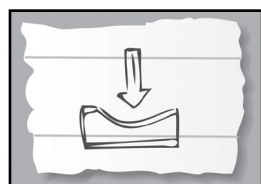


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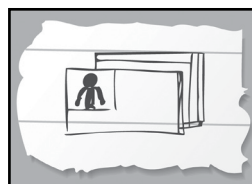
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Ms Gill Galyer	Newark, Notts - Ring between 11am and 4 pm Monday to Friday 01636 526160
Bede Francis Thomas	West London - 020 8840 7759 -Not mornings
Mrs Viv Norrie	Angus & Mearns Fibromyalgia Support Network (Montrose, Scotland) Monday & Friday 5pm to 7pm 0844 887 2389 or e-mail: am-fm@hotmail.co.uk
Margaret Evans	Cardiff - 02920 258526 - 12noon-6pm weekdays
Ann Adams	Ring Anytime 01304 382335
Yvonne Singleton	Fibromyalgia support group - South Wales - 01639 681468
Pamela Buckle	Warwickshire - 01789 765587 - Tues/Wed/Thurs 17.00-22.00
Janice Dipper	Winchester Fibromyalgia Support - 0844 887 2608 winfibrosupport@gmail.com
Mrs Ulla Deichelmann	Redruth, Cornwall - 01209 213123 - 10am-10pm ulla.deichelmann@btinternet.com
Bexhill & Hastings	Bexhill On-Sea, East Sussex - 0844 887 2425 Tues 10am-12pm
Mandy Wordsworth	TEL: 0113 2795936 - Leeds. Contact anytime.
Janette Leeds	Fibromyalgia Support Group - 0844 887 2371 - 11am-5pm
Alan Smith	Rhondda Valleys - 01443 433027 - Please call 6pm to 10pm
John Allen	Swindon & area Wiltshire Fibromyalgia information & support 01793 751920 (answer-phone phone buddy etc support) highfly29@hotmail.com (emails preferred) 21 Heberden House, Cricklade, Wilts SN6 6AS
Maddie Seacombe	Bristol - Tel 07790130403 - best time is 3pm - 8.30pm.
Claire Hilton 4	3 Alexandra Road, Thornton Cleveleys (nr Blackpool) Lancs FY5 5DB Tel 07912 792250 Any day 11am-6pm shelbyeatenton@hotmail.com
Linda Holder	Luton, Bedfordshire - 01582 570240. Phone chats or meetings phone in the afternoon.
Mrs Teresa White	Bracklesham/Witterings/Selsey Support Groups West Sussex telephone support/group meetings/social lunches 01243 670 783 any pm or evenings
Denise Shotter	Guildford and Bordon monthly meetings 08448872358 5-7pm email denise.guildfordfibro@yahoo.co.uk
Diane Jaques	Burnley, Lancashire - 01282 701390 after 7.30pm Mon-Fri if you would like to chat
Diane Leak	Darlington Friendship Group - 1st Wednesday of the month 12pm-2pm. Upstairs Café of the Darlington Dolphin Centre.
Mrs Jane Wallace	Bursledon Hampshire Contact number: 08448872409 Email: bursledonfibrofriends@gmail.com
Mrs Natalie Hicks	Chorley Fibromyalgia Support, Lancashire - Contact number: 01257 275145 Please leave a message if no answer. Email: nataliehix@gmail.com
West Kent	Fibromyalgia in Tonbridge Support Group meet in TN10 bi-monthly. Tel: 0844 887 2429. Email: fibromyalgia.tonbridge@hotmail.com
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Paul Peccioli	Happy to take calls from anywhere .I assist in PIP & Blue Badge Form Filling dealing with local District Councils and DWP problems. A listening ear and support and am able to aid those with a variety of other problematic areas. I take calls from 08:00hrs till 21:00hrs 7 days a week. 0844 887 2591
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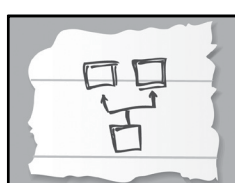
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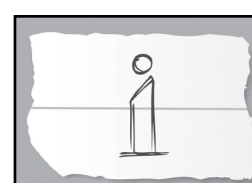
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