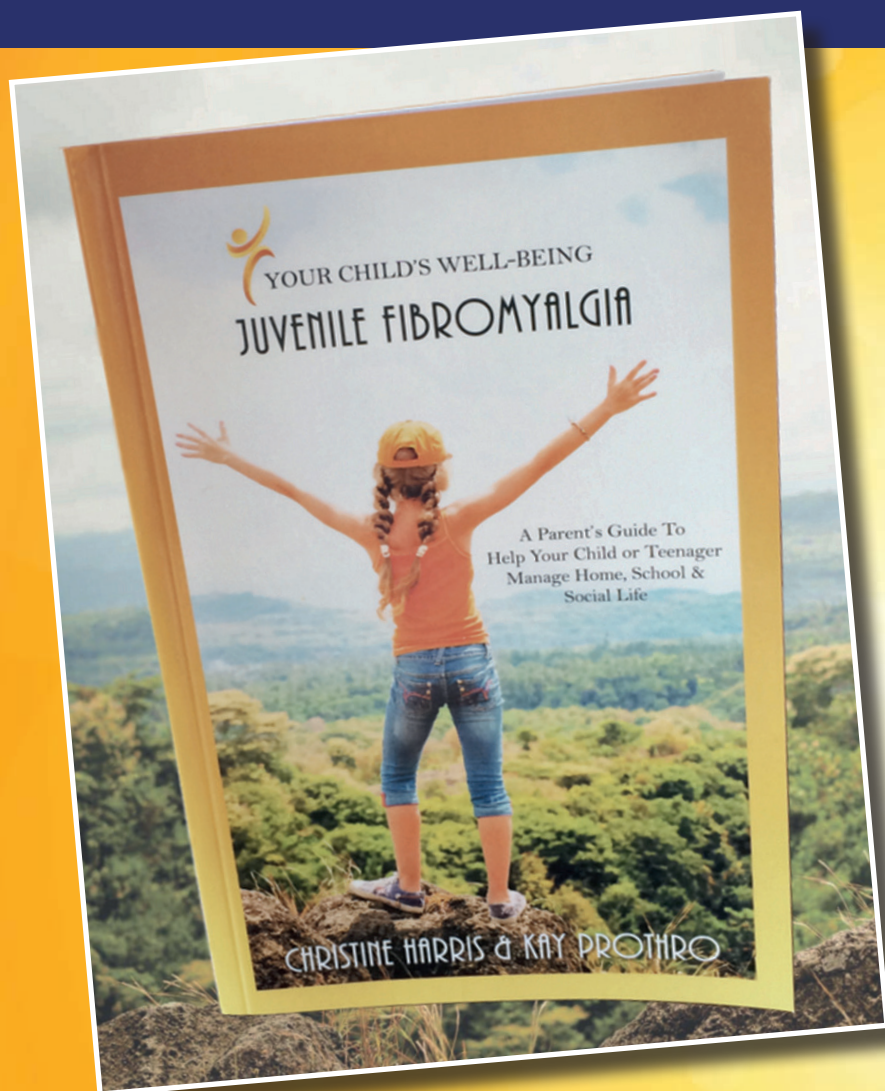


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Exclusive extract
from:
**Your Child's
Well-Being:
Juvenile
Fibromyalgia**
By Christine Harris
& Kay Prothro

**Welcome to
the summer**
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Exclusive extract from-Your Child's Well-Being : Juvenile Fibromyalgia By Christine Harris & Kay Prothro



START AT THE BEGINNING: You Are Not Alone

We read or hear every day of the many people facing difficult life experiences, especially where a child's well-being is concerned. The most important thing to remember—and possibly the hardest to achieve—is staying positive. Remember that you are not alone. You have a team of doctors and nurse practitioners in your camp. You may even rely on the skills of a nutritionist or an herbalist or an acupuncturist. You are surrounded by a close, caring circle of family, and friends. You and your child will find a workable resolution together, and you will find a greater and stronger sense of yourselves and your family.

As a parent, you become pro-active when it comes to helping your child who is in pain. You will likely have to explore such recognized syndromes and conditions as Depression, Chronic Fatigue Syndrome, Lupus, and Multiple Sclerosis (to name a few) before coming to Juvenile Fibromyalgia Syndrome [JFMS], simply because those symptoms and conditions are far easier to diagnose. Your focus remains on being positive, energized, and centered, never ceasing to find your own direction and strength in order to be an informed advocate for your child and your family.

One pediatric rheumatologist has said that the definition of Fibromyalgia is "full body pain" which causes muscular-skeletal discomfort, fatigue, sleep disturbance, moodiness, and mental foggy. Fibromyalgia, like other childhood chronic conditions, makes it very difficult for the child to participate in school. For instance, missed school days disrupt the communal continuity of class discussions and lead to a backlog of homework assignments for which your child already has little energy to complete. Having to manage Fibromyalgia on a day-to-day basis also impacts your child's ability to form friendships and participate in age appropriate social activities because her low stamina will not permit her to be as active or stay out as late as the others in her age group. Depending on the degree of severity the

child experiences, she can feel very lonely and isolated from her peers, causing depression and anxiety which only feeds into Fibromyalgia flare-ups. (Flare-ups are when all the symptoms are magnified and intensified for a period of time; we write more about flare-ups in Chapter 4.)

At times, your child may feel hopeless and believe her situation will never end. It begins to feel like her life is passing by and nothing ever seems to change. At those times, the child needs an understanding and knowledgeable adult to talk to her and be her support system.

One of the problems with Fibromyalgia is its elusiveness. It's like the Scarlet Pimpernel—"you seek him here, you seek him there, you seek him everywhere." There are certain factors which seem to contribute to the development of Fibromyalgia pain. It is commonly believed by the medical profession that the following characteristics may leave a child more vulnerable to Fibromyalgia:

- sensitivity to pain
- experiencing tremendous stress
- exhibits problems in psychosocial development
- has difficulty in relationships with both family members and peers and/or
- must deal with parents who are challenged by their own life stresses and problems

Most families have a similar beginning experience with Fibromyalgia. The child has repeated bouts of some group of symptoms. Some children experience chronic sore throats, fevers accompanied by fatigue, and body pain. Other children experience sleep problems, extreme fatigue, and feeling emotionally dispirited. Symptoms can repeat over time and can occur in various combinations that may show up differently with each flare-up.

General practitioners (GPs) and pediatricians do their best to treat the symptoms. When the treatment does not result in long term success [meaning a long period of wellness], they will usually start referring the patient to a specialist. Often the ear, nose, and throat consultant is called in to make further assessment. Other times a referral to a neurologist is made. Many families report that by the time a diagnosis of Juvenile Fibromyalgia is made, their child has been assessed by three to five physicians.

Generally, until a child is about twelve years old, she will not be given a diagnosis of Juvenile Fibromyalgia but instead the description of their symptoms will include the words "myofascial pain" rather than a formal diagnosis. This might be because physicians tend to err on the side of caution rather than prematurely diagnose.

Does Your Child Have a Diagnosis?

Until a formal diagnosis has been made, your child's treatment and school life may be as chaotic as the symptoms she is having. It is a good idea to involve everyone who deals with your child, and keep them involved by talking openly and honestly about her situation. Let them know that you are looking for their support and cooperation. Keep track on your family planning calendar if your child is missing days of school or practice sessions in her after school activities. This is important information that will be helpful either to health practitioners and/or the school in the future.

Figuring out what is happening to your child if you do not have a confirmed diagnosis, or even if you do, is one of the frustrating elements of Fibromyalgia because the symptoms vary from person to person. The treatment approaches vary. The medications are varied. The alternative healthcare options are extremely varied.



How To Talk Openly About Your Child's Diagnosis

It does not help that most people do not seem to know exactly what Fibromyalgia is. You may find yourself constantly explaining when you are met with the question, "She has Fibro-What?" Or "Yeah, I think I heard something about that. What is it again?" Suggestion: keep your explanation simple. It takes energy from you to provide the explanation. You need to pace yourself for your own sake and for that of your child and your family.

Adopting and repeating the same, simple explanation is an energy-saving way to explain Fibromyalgia to others. The phrase, "full body pain," is something that most people will easily be able to understand. And it is pretty

much how the American College of Rheumatology (ACR) defines Fibromyalgia. Their definition of Fibromyalgia has been updated. The first definition involved an examination of eighteen specific tender points in the human body. The ACR required evidence of body pain in a minimum of eleven points. Susmita Kashikar-Zuck, Ph.D., Professor of Pediatrics at The Cincinnati Children's Medical Center says, "The American College of Rheumatology guidelines no longer require a tender point exam. The widespread pain in many body areas and associated symptoms of ongoing fatigue, sleep disturbance, and cognitive difficulties is enough to give the diagnosis once other potential medical causes are ruled out." About the only other piece of information you might want to add is that "the symptoms come and go." This is a simple explanation that will save you from having to discuss too many details.

Feelings About the Diagnosis of Fibromyalgia

It is normal to experience a variety of feelings after your child or teen has been diagnosed with Fibromyalgia. You may feel angry, go into denial, feel sad or scared or frustrated. All this and more is normal because you are in the midst of feeling grief over the loss of your expectations as well as the uncertainty of what your child will have to endure. Most parents expect that life will throw their child challenges here and there and that the child will grow up to be a fully independent adult with the help and guidance that a loving parent can provide. The diagnosis of Fibromyalgia or any serious condition may send you into a spiral of grief.

The grief process will be easier if you are gentle with yourself and allow yourself a safe place to express your feelings. Writing your feelings in a journal or diary, reaching out to supportive friends, family, counselors, and spiritual teachers, are all good ways of working through the different feelings that will come up for you. There are many support groups available, and the Internet is an easy way to find them. There are groups to be found on the Internet at Meetup.com, as well as many social media groups via Facebook, etc. (See Appendix for additional resources.) Your community and/or hospital center may also have local support groups.

Remember that your child is going to react to how you are feeling. Therefore, working through your own feelings on your own time is a priority. Trying to be stoic is not going to help you or your child. Working through your feelings is important because children easily pick up on parents' moods and feelings, and they need the best from you at a time like this.

Building a Stronger "You"

Being a parent requires strength, the full body kind, not just being emotionally strong. It is in everyone's interest that you increase your strength. By becoming physically strong, you will increase the energy needed to help yourself and your child.

Your endorphin levels will increase, and increased endorphins will help fend off the emotional dips which are a natural part of the Fibromyalgia territory for both parent and child. Working out, cycling, Pilates, yoga, Tai Chi, or just getting your heart rate up for 20 minutes every other day will help you balance your mood and your energy. Your patience will increase. And (from a mental health point of view) you will be expressing your feelings and thoughts via your body.

Building a stronger "you" can be very simple and affordable. Walk up and down a set of stairs. Run in place. Ride a bicycle. Shoot hoops or play volleyball with the neighbors in your back yard. Dance. The list of what you might be doing to bring your heart rate up is endless. Of course, if you have medical issues, you will need to consult your healthcare provider before you embark on any fitness program. The point is that since you are your child's primary caregiver, you will need to take care of yourself first. As is so often mentioned, this is the part of your journey where you need to put the oxygen mask over your own face first and then your child's (as in an airplane). It is really important that you care for yourself as if you were the best parent for yourself.



About The Authors



**Christine Harris,
LCSW, LISW-CP, DCC**

Christine Harris has been providing psychotherapeutic services for individuals (adults and children), couples and families for over 20 years either in a face-to-face setting or as a distance counselor using video-conferencing. In addition to maintaining a private practice, she has also worked as a consultant for a wide range of organizations including hospitals, senior citizen agencies, brain injury, and disability centers, pediatric care programs, and programs providing specialized care for challenging illnesses like HIV+, AIDS, and cancer.

Upon completion of her Master's of Social Work degree at New York University, Christine continued her traditional professional development by further studies in Family Therapy, Gestalt, Cognitive, Psychodynamic, Guided Imagery, Autogenic Relaxation, and Focusing.

To learn more about Christine and her work, visit

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www.yourchildswellbeing.com.



Kay Prothro, LCSW-R, ACSW

Kay Prothro has been working with patients and clients on human potential and human development issues for over 35 years. As a Menninger-trained psychotherapist in private practice in New York City, Kay specializes in working with

Adults, Adult Development, and Couples Therapy. She has spearheaded many innovative health programs nationally for groups, families, couples, and individuals.

Kay works with her clients by focusing on finding strategies relating to mind-body-spirit wellness and healthy conscious living. Her primary areas of focus include interpersonal and family relationships, life-challenging illnesses, grief counseling, aging, life transitions, and stress management.

After completing The Menninger Post Graduate Fellowship Program, Kay furthered her education at the Institute for Life Coach Training and the Blanton-Peale Graduate Institute. She originally trained as a psychodynamic psychotherapist and has since become known for consolidating transpersonal, integral, and cognitive behavioral perspectives into her work.

To learn more about Kay and her work, visit

www.JustImagineNYC.com and/or

www.yourchildswellbeing.com.



Ask the Doctor by Ginevra Liptan, MD

What are the best alternative therapies for pain management as I prefer not to take medication and am finding it hard to cope at times.

The most effective fibromyalgia pain-reliever I have found—both personally and for my patients—is a form of manual therapy called myofascial release, in particular the style taught by John F. Barnes. Myofascial release therapy involves using very slow but sustained gentle pressure to separate tiny adhesions in the muscle tissue and fascia, and this lessens muscle tension and breaks up knots in the muscle. Two European studies found that myofascial release therapy was effective for reducing fibromyalgia pain, and that it gave long-lasting pain relief even at one month and six months after the last session. To find a therapist trained in this technique go to www.mfrtherapists.com.

The good news is that myofascial release is also something we can do for ourselves! A recent study showed that a regular program of self-myofascial release lowered pain intensity and lessened stiffness. To start, you can simply lie on the floor and place a small, soft ball (around the size and density of a large orange) under any tight and painful muscle areas. Then allow your body to sink onto and around the ball for a few minutes to provide the right amount of sustained pressure to allow the fascia to release. To learn more about how to give yourself myofascial release go to www.fridacenter.com/tools/

Creams derived from natural products can also provide local relief for painful muscles in fibromyalgia. The best part is that topical treatments tend to be very well tolerated with few side effects. One herbal homeopathic cream that I have found helpful is MyPainAway Fibro cream. It includes arnica to reduce muscle pain, echinacea to reduce inflammation, along with other herbs targeted to reduce nerve pain by improving microcirculation around pain-sensing nerves. Capsaicin creams are another natural option for pain relief. These contain the active component in chili peppers that usually cause a burning sensation. I know it sounds like this would cause more pain, but in fact the low levels of capsaicin in these creams block pain by temporarily depleting the

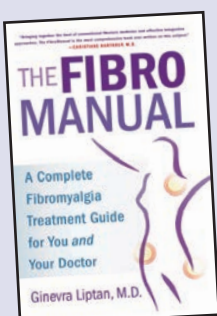
nerves of certain chemicals that transmit pain impulses. Application of this cream three times daily was shown to significantly improve pain scores for fibromyalgia in one study done in Spain.

I'm wondering if any research is happening with regards to cannabis pain relief in fibro?

Yes, there is quite a bit of research activity on cannabis for pain relief in fibromyalgia and many other chronic pain conditions. Earlier this year marked the start of large study based out of the Netherlands on the effects of inhaled medicinal cannabis on fibromyalgia symptom. This is a well-designed study that is double-blind, placebo controlled and uses standardized, pharmaceutical-grade medicinal cannabis.

Can fibro affect proprioception? Or should I put this down to hypermobility.

About half of people with fibromyalgia report balance problems, ranging from mild to severe. In particular, we have a hard time maintaining balance when asked to do a secondary cognitive task—like subtracting sevens backward from 100 while walking—but tend to score normally in seated tests. We don't know exactly why this happens to us, but it may be a result of poor signaling from the muscles and joints to the brain; the brain gets confused about where the body is in space. This confusion stems from an impairment in proprioception, meaning knowing the sense of the relative position of one's own parts of the body. Proprioceptive signals are sent to the brain from particular nerve endings in our muscles, tendons and joints. One theory as to the cause of impaired proprioception in fibromyalgia is that a brain that is distracted by constant pain signals has less capacity to devote to activities like maintaining balance. Interesting that you mention hypermobility as well. Patients that have excessive joint hypermobility in addition to fibromyalgia (and they quite commonly co-occur) seem to have an even worse time with balance and proprioception.



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.



How to Avoid Stress when you need it most - Part II

by Karen Crosby

After last month, the article on avoiding stress was in part my own coping mechanisms and partly what I have learned in my stress management diploma, and what I teach in my workshops.

Now I have moved to a different life, into the highlands of Scotland to begin the next phase of my life in a quiet, beautiful place. This has been a dream for as long as I can remember but realising it with my fibro was not easy.

An international author Susan Jeffers wrote: - "feel the fear and do it anyway" and wrote a great book about turning your fear about new things into positive and fulfilling outcomes. This is really indicative of how I began to change my life journey.

The message I want to give to you all is that if you have a dream, don't be afraid to follow that dream by putting in place anything you need to (this may take years) to realise your potential in life!

I have found in the past that I let my fibro hold me back in so many ways, in my working life, my relationships and my attitudes, but time and a little dash of wisdom has made me realise that thousands of people with much more major hardships than me have gone on to do wonderful and profound things with their lives!

This prompted me to do my yoga teacher training, all my holistic training, and my stress management qualifications and after 8 years of study I am finally doing what I love!

During the house move, I found myself working too hard for too many hours during the day, and falling exhausted into bed at night, and there is only so long a person with fibro can do this without consequences! When I arrived in Scotland I had some time to myself before we got into our cottage to relax a little and do some walking, which re-charged the batteries a little but not enough for the onslaught of getting the furniture in and unpacking so many boxes it was exhausting!

I started to really feel depleted, depressed, and really weak, so I put on the brakes, restricted myself to 3 or 4 (small) jobs a day, and rested the rest!

Now I am almost there and taking my time, as there is no rush or deadline for finishing the unpacking!

I must say absolutely without reservation that it was all worth it to be in my beloved Scotland and following my dream to be here!

If you have a dream, no matter how big or small, here are some tips on how to realise that dream no matter how it scares you or how unattainable it seems: -

1. Find out information – information is crucial to see how you can work towards your goal. It may be re-training, doing certain qualifications, or simply speaking to people!
2. If you feel you are not getting anywhere, take advice from someone who is doing what you want to do, it can be anything like volunteering for charity, helping others in your area like the vulnerable, elderly, or setting up a discussion group or a book club, the more advice you can get from like minded individuals the better, this is how you gain the best ideas!
3. Speak with the local council for job/training/volunteering information as they will put you in contact with the right organisations or point you to someone who will.
4. Look at the inter-net, this is sometimes frustrating but more often than not very helpful, and helps with any research into your chosen subject/ideas.
5. Take baby steps; don't rush headlong into anything as it sets you up for regret! Write down how you can begin your journey with a realistic attitude and temper your ambitions to your abilities.
6. Talk to family, they will be honest and encouraging at the same time, but don't let any of them put you off!
7. Start each day being grateful for all you have in your life, the food on your table, the people you love, the sunshine and anything else to begin your day uplifted!
8. Be patient! Remember Rome was not built in a day!
9. Climb out of your comfort zone, you may find it liberating and it will give you confidence to keep going!

Remember,
keep
plugging,
take your
time and
have faith!



Rugby Fibromyalgia Support Group 10th Anniversary

Rugby's Fibromyalgia Support Group has just celebrated its 10th anniversary. Founded in 2007 by Mary and Maurice Clarke, today the Group has over 30 active members, attracting people from Rugby and the surrounding areas of Warwickshire, South Leicestershire and West Northamptonshire. Members' ages vary from teenagers to people approaching their 90s. As is usual for fibromyalgia, the ratio of men to women is 10% men and 90% women.

The Group stimulates members to take part in a range of activities which not only help to cope with the condition but enable members to make new friends and socialise. There is an active telephone support line, and befriending and home visiting can be arranged for housebound members. The group has, thanks to fund raising over the years, been able to establish a variety of educational and support services for members. It runs Hydrotherapy sessions at a local special needs school and has an extensive library of useful books, magazines and DVDs which can be borrowed, as well as producing a Newsletter. This is distributed every two months by email, or by post for those without access to the internet. It provides details of upcoming events, hints, tips,

quizzes, a funny joke, and the latest information on fibromyalgia, including research into the condition, advice in general, and help and suggestions on ESA and PIP form filling. The group also has a website and a new Facebook page – details below.

Hilary Brocklehurst, leader of the Group says "We meet in the centre of Rugby in a disability friendly building with free parking, on the second Thursday of each month in the evening. We offer friendly advice on an individual basis as we are all managing to get by with the condition. Some meetings are just social get-togethers, whilst at others we have visiting speakers. The main thing to remember is that we all have fibromyalgia and so we relate to and support each other, especially at times of stress, or anxiety."

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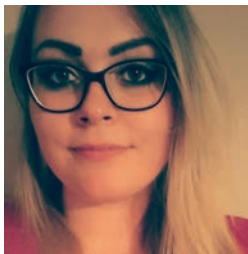
Website:

www.fibromyaliarugby.wordpress.com

Facebook

www.facebook.com/groups/1834696306852372/





Nature Vs Nurture

by Emma Stark

How much of our health and wellbeing is in our hands? How much does food really come into it?

It's been shown that fibromyalgia can run in families and you can be more likely to be diagnosed if you have a history of fibro in the family. This isn't an uncommon concept, it's quite normal for certain illnesses to carry a hereditary aspect, and I'm sure we can all see some common themes running in our own families. I've never met anyone who doesn't have something running through their families. But why is this? Would it surprise you to know that only 5% of us are genetically unhealthy? Only 5% have a chance of getting an illness through genetics but even so, it doesn't mean that you're destined! Through numerous factors we can help control our health. No surprises that one of the main factors is food! The choices we make every day impact the future generations.

Epigenetics is something I find amazing, understanding how your genes are expressed can help you change your life. I'm a strong believer in that knowledge is power, and it's much easier to make changes if you know why these changes are important to your body. Take me for instance, I've been told I'm more likely to have a heart attack as both my parents had heart attacks young. My family has been plagued with heart problems, but why? What is it that makes my family so unlucky? Can I do anything to change this? After speaking to my Doctor about this and studying disease prevention I've found that the things we do each day impact us way more than we realise. And the reason for things running through families is because of habits! Now I'm not saying it's everything, there are some diseases that it makes no difference what you do, you can still pass on. However, we all have habits and routines and beliefs within our families. For you to break the cycle you need to be different.

When I was younger we used to have a tradition of a big fry up on a Sunday morning, sausage, egg, bacon, French toast, potato scones, black pudding all cooked in fat in a frying pan. In our family, this was a treat and something to be excited about, when really, now I can't

think of much worse. I mean this was just one small thing, we had so many other terrible unhealthy habits which all seem normal when that's what you're used to. It's hard to see the harm in anything to do with a tradition, especially when it's linked to happy family times. It's not just at home either, habits at work can be just as dangerous. I've found that in most work places you're never far from temptation. Especially at work celebrations and being the odd one out, or helping make a change can be tricky.

Now I'm not saying everyone should stop what they are doing and all change everything. Just now that you understand the impact, you can help reduce the risks. For example, if you have a risk of cancer you would avoid known carcinogens and try and live as healthy a lifestyle as possible. This might involve breaking lots of habits

but in turn significantly reduces your risks. Let me explain..... we are all born with a unique set of genes inherited from our parents (Nature). How these genes are expressed depends on many factors. What we eat, where we live, what medications we take are all examples of (Nurture) how we can turn certain genes on and off. The word "epi" comes from the Latin for in addition to/above because genes are turned on or off, up or down based on epigenetic markers.

**Did you know –
Eating one portion
of processed meat
per day increases
your risk of
diabetes by 51%**

We are led down a path of temptation every day! You can't walk down the street or turn on the TV without having all things unhealthy advertised. We live in a time of convenience where it's perfectly acceptable to eat lots of processed foods and sugar, to smoke, drink in excess and so on. Each in turn taking a toll on our health. Most people don't see the consequences of their actions until they get a wake up call. Being diagnosed with a new health condition or seeing someone close to you suffer often makes you take stock and start to reevaluate your life. But why wait for things to get too late? It's taken for me to be diagnosed with fibromyalgia and m.e to start really being careful with how I eat and to review my lifestyle choices and I wish I done it sooner!

At first it might feel like a chore but once you start to see the health benefits of your new lifestyle, you're opinion changes soon after! It might not seem so, but how we live each day has a huge impact on our health.

Not just for ourselves either, studies have shown that epigenetic markers can be passed down from around five generations. Explains the similar diseases running through families.

It's not all doom and gloom! The reason I wanted to explain epigenetics is because its easier to make healthy changes when you know why! There's not enough information advertised to us about how we can not just improve health, but in some cases preventing and curing disease. We know that junk food can be bad but if we really knew the real extent, would we eat and live how we do? When studying disease prevention you see a theme throughout the data. In more developed countries where convenience food is a plenty you will see high levels of cardiovascular disease, cancer, autoimmune diseases, diabetes and so on. In less developed countries where plant based foods are consumed more, these diseases are almost non existent in comparison!

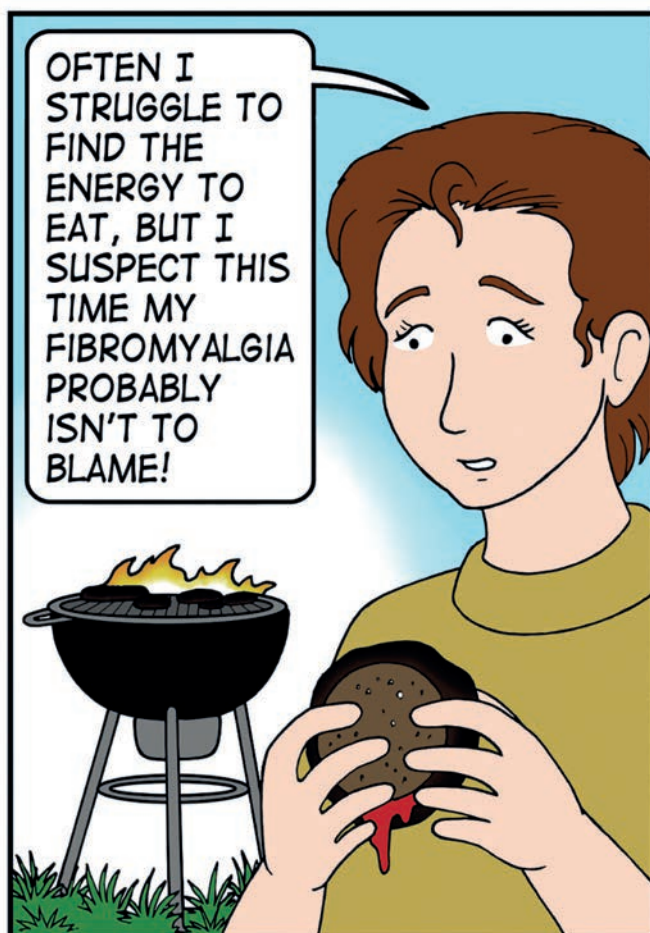
There is a concept floating around brought about by scientists that fibromyalgia symptoms are often linked to poor nutrition, intolerance and deficiencies. It makes sense when you see the symptoms of which! Why suffer when we can be in control?

As per my previous articles, carrying out a body detox and finding out any nutritional intolerance can help make a significant difference to your health. Adapting a lifestyle that's nourishing for your mind and body will help change epigenetic markers over time and begin to reverse multiple symptoms. By making small changes

each day, eating less processed foods, giving up all things artificial, limiting refined sugar and eating a more whole foods based diet you will improve your health tenfold! The best way to approach it is not to think of it all as a diet but a new way of living. For me, everything used to taste better with cheese! Now I find myself being more adventurous with flavours and good quality ingredients and enjoying food even more.

Going forward I'd like to go more into detail about what individual changes we can make to our genes and how we can switch them on and off. If anyone has anything in particular they would like to know get in touch! Are you always gaining weight even though you're constantly on a diet? Do you find your stomach a mystery? Get in touch and I am happy to help! I'd love to hear if anyone has started seeing positive results from changing their diet and what they found works.

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.



BRENDAN KEELEY



Welcome to the summer

By Naomi Harvey

In general the heat is wonderful and we see all the beauty of summer around us. People in general also seem a lot happier to have the warmth and we can all top up on our vitamin d levels. It seems to add hope to the world as well as corny as that sounds. Then we get to those of us caught in the web of chronic illness, the changeable weather makes things very uncomfortable for us and we all have increased issues depending on what type of day we get each time, so what can we do to try to limit our reactions to the ever increasing heat?

The heat for me has always been the worst to cope with, with the cold I can bundle up and layer things but the heat feels like a harder battle each time. Given that part of my conditions makes me constantly have a low grade fever this isn't surprising. There are a few things we can do for ourselves though to help limit the bodies reactions to the heat, be it as a sun worshipper or not.



Air Conditioning

One of the best purchases I made a few years ago was my air conditioning unit, its only a small single room one and cost around £60 (they are usually around £100 now) but can be wheeled to the room I wish, and yes I have 2 one for each floor in house, but do a very good job of managing to keep a stable temperature in the house. Except for the room I need the vent pipe to go through but that's because I broke the pipe a few days ago, opps.

Pros – Pros – Regulate the temperature at any given time/ room, full control of the base level in any room can adapt to choice, relatively cost effective in the long run. Cheaper than most people think and not huge great window machines most people expect from air conditioning.

Cons – Can be expensive to run if budgeting but solar panels on hot days can negate this. Needs access to a vent area/pipe, this can get hotter if not set up correct or

you knock the pipe out. Bulky machines can take up a fair bit of space so make sure you allow for that in the rooms decided for use. Need emptying of water build up every few months depending on use so if live alone need to be aware you may need to bend to it at times. Can be hard to find for sale but google is your friend. Makes a low humming from the fan noise and clicks on the temperature turn over, after a short time though this is drowned out in your head and I find it quite soothing.

Fans

The majority of us have fans in the home, and most of us use them in the bedrooms to help keep us cool enough to sleep. I know many people even need the sound of a fan now to get to sleep they need them so often to help regulate temperature.

Pros – Lightweight usually can be moved easily, can even be handheld. Available most places especially in the summer months. Can be pretty cheap to purchase. The oscillating ones can help move the air around multiple areas.

Cons – Rarely actually cool the air around them just move it around, so rarely do much to cool off unless you are sat right in front of it. Can be very noisy/clicks and no matter the type I never could get used to the noise they make. Can run heavy on electricity so may be more expensive over time. They break quite easily especially if knocked over. Can be dangerous for small fingers, depending on the type of fan.

Cooling Sprays

Cooling sprays can be pretty much found anywhere these days, from aerosol ones to water based mists that contain an alcohol scented spray to help trick your body into cooling itself off. Ranging in price and ingredients most of us can find one that may help when out and about. Depending on your skin type or preferences though its worth a little trial and error to find one that helps you to keep cool in the heat. If you have sensitive skin though, especially common with chronic illness then please be aware that these sprays may do more harm than good.

Pros – A fast result from the spray means we can feel more comfortable quicker. Portable able to fit in bags/ pockets and useable anywhere. Variety means we can find the right one for us in scent/feel. Costly as can be picked up for £1 or more depending on your choice.

Cons – Can affect skin if sensitive. Alcohol based ones can leave the skin feeling like its tingling or burning. Only a short term fix really as only lasts until the spray dries on your skin.

Cooling bed products

There is a huge range out now of products to cool the bed down, and a million more "life hacks" to do it yourself. Given that most of us spend most of our time in bed or using pillows/blankets then we need to be able to regulate heat there. Nowadays we can buy anything from "Chillows" a specially designed gel cooled pillow, to sheets of cooling gel to go under the sheets on our beds. There is even a fan that is designed to be placed under the bottom sheet on a bed to give a constant layer of cool air beneath us as we sleep. No one can sleep comfortably when you feel hot and sticky so cooling off the bed in any way will always help. Life hacks like freezing the sheets before bed, adding cold packs to the bed before getting in etc. can help.

Pros – Devices make the cooling of the bed easier. Freezing the sheets we already have is a cheap alternative to buying specific products to do the job. If we can sleep more comfortably then we get more rest and feel better able to face the other issues in our lives.

Cons – Can be very expensive, still trying to find the money for a Chillow. It seems that there's only two options really for the bed, hot or cold, would like a way to maintain a steady temperature that's not too hot or cold. Freezing the sheets sounds a good idea until you realise you then need to put those sheets on the bed ... daily ...

These are just a very few of the options we have to keep warm without getting into the whole clothes, personal items debate. Its good to remember that cotton fabric breathe better and lighter colours can also help but since most of us live in lightweight soft cotton pyjamas I think we are pretty much ok on that score. Cold showers if you can take the feeling of the cold on your skin provide only a temporary fix though. Your body will also cool down quicker if you have enough fluid in it to sweat so increasing your water intake in summer months will certainly make a difference. Caffeine based or alcoholic drinks work the opposite way though so try to avoid to much of them.

Stay safe, stay cool and enjoy the summer. For me I will be hiding in doors with my air conditioning until the autumn comes and brings warm breezes back to me.

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

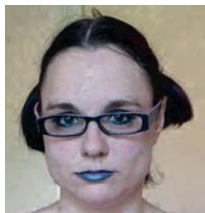
Start a Group Subscription to the Fibromyalgia Magazine for your Fibromyalgia Support Group and save money.

If you can find a minimum of two people to subscribe to the Fibromyalgia Magazine then you can save money. A group subscription is sent to the secretary's address and the magazines are then distributed at the meeting. We save on postal costs by sending one parcel so that we can pass that saving on to you.

If you subscribe through your group the individual cost is only £19.50 for the year instead of the usual £34.95. You need to give your cheques to the group leader payable to UK Fibromyalgia and he or she will set up a group membership for the group.

Ring 01202 259155 to find out more.





The Benefits Agony Aunt

by Nim McCoan-Thornhill

ESA & PIP Problems

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

This month we are looking at the complicated arena of means tested ESA, and how to make initial ESA and PIP claims.

Please could you help me as I am now becoming more and more confused. I receive ESA & PIP. The ESA have asked for an annual review of savings and any property and so on. Could you advise me in what I am allowed in personal savings. Confused.

Dear Confused,

I am not surprised that you are confused, as this area isn't entirely simple.

There are two classes of ESA; Income Related ESA, and Contributions Based ESA. Your income and savings should not be taken into account when you are on Contributions Based ESA. So if you believe that you are, I recommend contacting the DWP to tell them that they have made a mistake.

However, I am presuming that you are probably on Income Related ESA, since you have been asked to complete this review.

Income Related ESA is means tested. Both your savings and capital, and that of your partner, are considered. Capital includes property owned, stocks, shares, bonds, etc. The lower limit is £6000. The upper limit is £16,000. If your total is below £6000, you should receive full ESA payments. If your total is above £16,000, you are unlikely to receive any ESA payments, but should still receive National Insurance credits. If your total is in between the upper and lower limits, the amount of ESA payment you receive is adjusted accordingly.

Your PIP income is not included in the means testing. Nor is income from Child Benefit or Attendance Allowance, should you be receiving these. Also, any income from permitted work is not included.

I hope this helps.

Dear Nim

I have recently given up my job because I was feeling too ill to manage anymore. The doctor has diagnosed me with M.E. and Fibromyalgia, and said that I can get the dole when I'm ill. I don't know what the illnesses mean, and I don't know how to claim the dole. Please help me.

Jasmine from Ilfracombe

Dear Jasmine

I believe that "the dole" technically used to refer to what is now Job Seekers Allowance. When someone is too unwell to work they cannot claim Job Seekers Allowance. However, you may be able to claim Employment & Support Allowance (sickness benefit), and / or Personal Independence Payment (disability benefit).

My personal advice is to gather as much medical evidence as you can, as quickly as you can, before making any applications. The reason for this advice, is that the DWP (Department for Work & Pensions) give you a short time limit once you start the application processes. Medical evidence is things such as letters from doctors and specialists, blood test results, ECG / ultrasound results (the results from any tests that show your illness). A letter from your previous employer, if you left on good terms, describing how you struggled, can be useful too; as can a letter from a partner or someone else with whom you live, describing your daily struggles at home.

If you are up to understanding the complexities of how ESA and PIP are assessed, you may want to look up the "descriptors" for each of them. If you understand these, you can offer some guidance on what the letters written by your previous employer and your partner should include. However, if you do find it too complex you may wish to have someone look over the letters for you. You can find someone to help at Citizens Advice Bureau, DIAL, and MIND (there are other organisations, too – Google can help you find them). You may wish to seek help throughout the whole process from such an organisation if you are completely overwhelmed.

When you have some evidence, and feel ready to make an application, ask your GP to provide you with a sick note. This will start the ball rolling with the process of an ESA application. If you want to make both applications at the same time, you will need to phone the DWP and request a PIP application form. The number to use is 0345 850 3322. Alternatively, you could wait until you have been awarded ESA, in order to use the award as additional evidence towards the PIP application. Bear in mind though, that it can take months to be awarded either!

In regards to understanding Fibromyalgia and M.E., there are some fantastic websites and Facebook groups around. There are also often Fibromyalgia support groups in most areas. If your GP has not referred you on to specialists already, ask them to do so. The sooner you get help, the better.

I hope this helps.



Let's celebrate! The power of supporting each other by Karen Lovegrove

Fibromyalgia can be such an isolating condition, we lose friends, we skip going out at the last minute, making

arrangements to go out can feel like military manoeuvres!

Even going to a face to face support group can often get cancelled due to how we are feeling on the day. But what about those niggling questions we have, new ailments and the worry of eventually losing all contact with the outside world? Nearly 20,000 of you now, based in the UK and abroad have come together to support each other, online, in a place where it doesn't matter if you're still in your pyjamas, feeling dreadful and can't leave the house, where you feel safe to ask others questions, similar minded people who have been where you have been.

This month I asked the Facebook community to share their experiences and good news stories, this is what some of the members came back with...

"...When I was experiencing homelessness a couple of years ago the support from this group and fellow admins was amazing xx Thank you to you all I will also add I've made some very dear friends through this group you know who you all are xx"

"...The group has been a lifesaver to me, when I first got diagnosed, I hit the web to find more information and answers and I stumbled across a website called UKFM and it helped me with so much information. Then scrolling through I saw it had an fb group so I joined in the hope to be connected to at least a few who knew what this illness was like. To my surprise there were thousands! It's now become my safe haven. I've made fantastic friends and have learnt so much more than I would have searching through google. All the Admins are lovely, caring and sympathetic and they're absolute angels. Even when I'm needing to rant - I can rely on everyone to help and make me feel better and not alone. Thank you UKFM FB group just for being your amazing selves xx"

"...When I got diagnosed my GP said to go away, look online and come back a week later to see what I thought about diagnosis. I did that and realised that's what I have. I discovered the UK Fibromyalgia website, from there the forum and then on there they mentioned this group. Learnt loads very quickly and have been supported with several other issues since, especially regarding other health issues as there's always someone who's been through the same."

"...When I was first diagnosed I was in a bad place, came across this site, joined and the admin team supported me through it all, private messaging when concerned. Priceless"

"...I have suffered with fibro for 27yrs but I can say honestly say there were so many things I didn't understand - or fully understand - until I joined here. This group is amazing. Some people give amazing support, some have a fantastic sense of humour, some are really knowledgeable on

medical things or benefits etc. Loads and loads of loving and caring people. You're all ace and I really appreciate the friends I have made. Too many to name."

"...I was diagnosed in 2004 there really was nothing about FM no one had heard about it.

I joined this Facebook page 3 and a half years ago, as a member.

then became a admin for a couple of years, within this time I was in a car accident.

Between the accident and 5 months before Drs realised that I broke my neck resulting in operations 4 months of been in hospital, and having an added new diagnoses of Addison disease to come home with. Throughout the whole of this time the group especially the fellow admins were totally amazing. support was truly out of this world. I thank each and every one of you for all of the combined knowledge love and support that makes this group special."

"...Before joining this group I was really struggling and feeling lonely. I had recently left my marriage of 22 years, as well as my ex was an alcoholic, and I had been judged by a lot of people. I never wrote a post on this group but gained in confidence by chatting to the duty admin and commenting on posts. At that time, I talked to Karen and Jo-Anne and Elaine a lot.

This group means the world to me. Even though I am quite quiet you have supported me a lot through good and bad times. I'm now part of the Admin team and married to a man who treats me like a princess. I have some lovely friends now and I'm looking forward to meeting them in the future."

"...Without knowing it I have had Fibro for most of my life, after an accident when I was 13. I didn't know anything about Fibro and it was only when I was 59 that I was diagnosed. I didn't realise that a lot of my symptoms, which I had assumed were 'normal', meaning that I was a wimp for not coping with pain and lazy for not being able to fight the fatigue, were in fact part of an illness. Only since finding this group have I realised that I'm actually quite tough and a fighter. Even my depression, which hits me from time to time, is something that Fibro sufferers get, has been a bit easier to cope with (although I am suffering from being on the edges of the black hole at the moment). The people I've met on here are like me, with the same frustrations, wishes, regrets, and desires and so have given me a sounding board and an outlet. Thank you one and all"

Need some online support? Come find us on Facebook - <https://www.facebook.com/groups/UKFibromyalgiaPrivate/>

Or our FM dedicated forum -

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

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One stop shop for all things Fibromyalgia



Fibro Parenting: 10 Tips for a Cool Summer, Part 2

by Brandi Clevinger

This article is continued from last month's article: 10 Tips for a Cool Summer Part 1. Go check it out if you haven't already!

6. Enjoy the Nights

My husband and I have a massive yard which the kids and their friends refer to as 'the field.' During our family's Spring break this year, my husband and I worked each day for several hours in the backyard fixing it up. We wanted to start enjoying it more than we have in the past.. We added a garden, repaired the patio, trimmed the woods, and built a fire pit. Since then, our backyard festivities have been a huge success. Each weekend our backyard is filled with our friends and the kids' friends listening to music, roasting marshmallows over the fire, and playing in the "field." We plan on our summer nights being the same with a few added activities.

Some activities for these summer nights will include glow sticks and flashlights from the local dollar store. The internet has tons of ideas for glow sticks, to include glow sticks in bubble solution, making fairy lights in a glass jar, glow in the dark bowling or ring toss. Most of these ideas are super easy to prepare. The flashlights will be for "flashlight tag." If you're like me, and you somehow skipped your childhood and don't know what this is, I will explain: Each kid gets a flashlight to find other kids hiding. Once a kid is "tagged" with the light, that person is out. My husband played this as a kid and always enjoyed it. Once my kids learn how to play, I'm sure they will have just as much fun and love it as he did.

Another fun idea that I discovered over Spring break was fire packets that turn your campfire different colors. I found and purchased packs of ten online. Simply toss the unopened package into the base of the fire, and the flames turn green, blue, purple, and other colors. They last about ten minutes each, so a pack should easily get you through one night. All the kids were fascinated and entertained with it. I must admit the adults had fun with them, too.

7. Expect Flare Days

No matter how much fun you have this summer, there will, inevitably, be a flare day. A flare is when the body experiences an increase in symptoms, or has heightened pain. The flare can last a day, week, month, or longer. There is no way to make it better other than old fashioned time and rest.

No matter how much fun you have this summer, there will, inevitably, be a flare day. Prepare for the flare days while you feel okay and never feel guilt during the flare.

During a period of a flare, you may experience episodes of guilt. Guilt for not being able to play with your kids. Guilt for not taking them somewhere. Guilt for not being able to clean the house or whatever else you'd like to do and simply cannot. The guilt list can go on and on, but do one thing when you start to feel this way – stop it. Whether your flare lasts a day or a month, do not play the guilt game. It does not help you in the least bit and will only deepen your depression, worsen your pain and/or stress your body more than it already is.

To help ease the pain and still make the day fun for your kids, prepare a flare list and/or flare box. A flare list is a running list of activities you only do when you have a flare, and can be done with little movement (remember you are to be resting and taking it easy on your body).

Activities can include:

- a special movie with snacks
- board games
- playing electronic devices
- coloring/drawing



A flare box, like a flare list, only comes out on a flare day. It contains special little treats that the kids can have during your flare day, and can be used together with your flare list. Items in a flare box can be purchased from the dollar store and should be collected throughout the year.

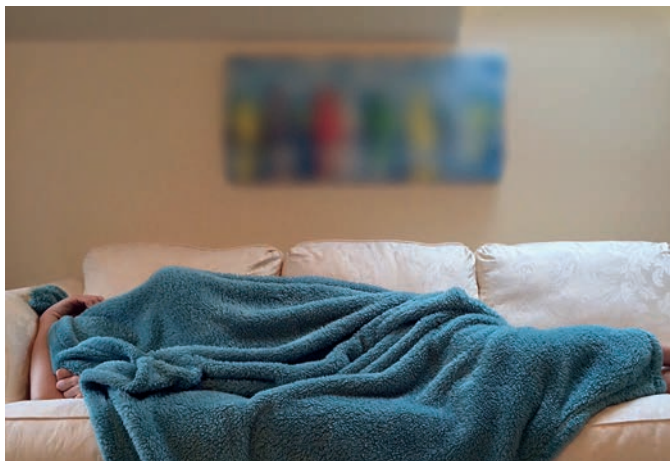
The box can include:

- coloring books
- crayons, markers, colored pencils
- travel size games
- action figures, or
- crafts

Don't limit what's in your flare box or on the flare list to the examples above. Let your kids suggest ideas or you can browse the internet for ideas. As long as you're resting, the possibilities are endless. The key here is to have these ready to go BEFORE you have a flare, so you you're not stressing out when the time comes.

8. Daily Resting

As stated in last month's edition 10 Tips for a Cool Summer Part 1, each day should have a routine. Not a schedule of specific times and activities, but a rough draft of the day so your kids know what to expect each day. Just as it's important to have breakfast, brush your teeth, or clean up your toys after playing, it is equally important to have a daily rest period. It doesn't mean you must take a nap, but if you want to and are able to do so, please take a nap! More importantly, resting time means taking a time out –with your kids – to refresh the body from the day's activities.



For me, I hit the exhaustion wall around 2:00 each day, and if I don't rest I will be spent until bedtime. If, however, I'm able to lie down for a little time to recharge my battery, it's easier and less stressful to make it through the rest of the day. Sometimes I fall asleep, but not always. Either way, my mood changes less drastically, and my senses are not easily overwhelmed, and I'm not snippy with family and friends. This is especially helpful for those nights we spend outside discussed above!

During resting periods, encourage your kids to rest with you. Read a book with them, watch a short show together, or just talk. This is a great opportunity to bond with your kids, and you never know what they might want to say to you. Give them your ears while the rest of your body rests. It will thank you later!

9. Meal Planning

If you're like me, the last task you want to tackle after a day in the sun is dinner especially if it involves cooking over a hot stove. And if you don't have dinner planned, add to the stress figuring out what to eat, finding the ingredients, and spending the next thirty minutes to an hour cooking it. That's a fast way to kill your afternoon and your fun day. What if you're having a flare? Or you have an onset of symptoms during the day? What then?

Easy answer: meal planning. During a day when you feel up to it, make a mean plan for the coming week. This should include the shopping list. Plan meals that are easy to make, and take advantage of slow cookers, or instant pots. The bonus to a slow cooker is that you can throw in everything in the morning and set it to cook for

the day while you are out AND there's no hot stove! This saves you time, money, and headache. Freezer meals and batch cooking are also time savers in the kitchen.

Sometimes plans fail, so what options are there? Have a 'be your own chef' night and let the kids make whatever they want for dinner. If that's not an option, sandwiches, breakfast foods, or microwaveable dinners are always winners. For more help with meal planning, be sure to visit my website.

10. Keep It Simple

Last, but definitely not least, remember to keep it simple. Your days don't have to be elaborate or filled with costly activities for your kids to have a good time. They won't remember how much money you spent on their games or activities, but they will remember how much fun they had playing with you. Those are the moments to strive for.

Be sure to check out the first part of 10 Tips for a Cool Summer in last month's edition. For all the activities listed above and more, please follow my Summer Fun Pinterest board at

<https://www.pinterest.com/beingfibromom/summer-fun/>

Next month's article will be about traveling with kids and fibromyalgia. Do you have any advice or tips?

Please email me at brandi@beingfibromom.com and it could be featured in the article!

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.



ASK BRIAN

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

Dear Brian

My daughter has been diagnosed with Fibromyalgia for 7 years now. She has been trying for the past 8 years to get medical retirement from the Civil Service. The stumbling block is that she is only 42. They agree she is unable to work, she has medical reports stating that she has widespread Fibromyalgia and will be unable to work at her job in the future. They say this is permanent. However, the doctors for the Civil Service state that "they do not take such a pessimistic view as the treating specialists". Their medical report state that the condition is not permanent. My daughter is now presenting her final appeal to the Pensions Ombudsman. Do you have any advice or evidence that we could put before the Ombudsman?

Dear Carole

The general view seems to be that there is no cure for Fibromyalgia, but with appropriate treatment the symptoms can improve. Ultimately, this is a medical issue. I suspect firstly that the medical experts who have seen your daughter and are treating her have a far greater knowledge of Fibromyalgia than the doctors provided by the Civil Service. Secondly, this is not just a debate about Fibromyalgia in general it is fact-sensitive to your daughter's particular circumstances. If she has had unpleasant Fibromyalgia for many years, such that she has been unable to work all that time, it seems highly improbable that she will suddenly get back to work at some date in the future.

The Pensions Ombudsman has a difficult task where the medical evidence is split. He cannot hear the experts and test the evidence in the way that a Judge would in a Court room. He may simply find that there is medical evidence supporting the position taken by the Civil Service (even if there is contrary medical evidence) and therefore find in favour of the Civil Service.

I hope that your daughter's appeal to the Pensions Ombudsman is successful. If not, there is always the possibility of bringing a legal case, although they are not easy.

Brian

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THE FIBROMYALGIA EXERCISE COLUMN



One Step at a Time by David Jenkin

One of the biggest reasons people are reluctant to take on an exercise and healthy living programme is what they perceive as the size of the task. People view the prospect of getting fit and healthy as too much to hope for or simply don't know where they would begin.

The fact of the matter is, getting fit is NEVER too much to ask for, and getting started is easier than you might think. Just changing one thing about your lifestyle is sufficient to get the ball rolling in the right direction. Whether that be drinking more water instead of fizzy drinks, switching from regular coffee to decaffeinated, cutting out snacks after 6pm, or even something a little more active like going out for a walk at least once a day, anything you start doing for the better is enough to make subtle changes to the body.

Other simple nutritional goals might include: switching to wholemeal bread, pasta and rice; eating more vegetables and salads, downgrading milk to skimmed or 1% fat, choosing a yoghurt (and similar products) with lower sugar levels, cutting out/reducing junk foods, cutting out/reducing treats and eating small amounts of food and more frequently.

Lifetime and health goals might include quitting/cutting down smoking, cutting down alcohol intake, undertaking some cardiovascular exercise e.g. a walk, swim or cycle once a day, performing some stretches once a day, or wearing a pedometer and just trying to increase the number of steps you walk each day.

Whatever it is you choose, and wherever you begin, changes do not have to be wholesale from the off, you can gradually better your position with small changes, one step at a time, and in time, these will begin to snowball into a much bigger result for you. So start thinking of things that you could change, and get the ball rolling, you will be amazed at how much better you start to feel.

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

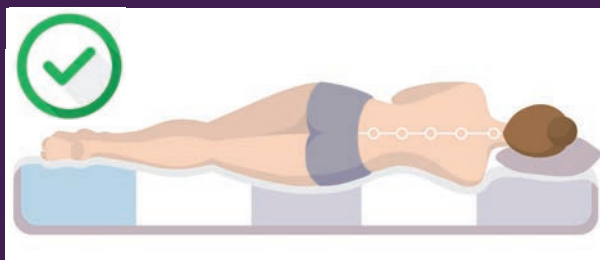
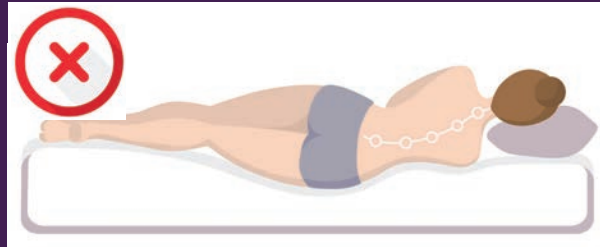
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Adjust Your Submodalities!

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.

“We are a resonating system in process rather than a stable, solid mass”

Randall McClellom

When you re-organise your body posture, routine or surroundings – it's very likely you'll feel different in some way. The reason for this is your external environmental, together with your habitual activities, have a direct impact on the internal environment of your thoughts and emotions. Doing the same thing day-after-day in the same way, at the same time and in the same place, trains your body to expect the experience it's had before and automatically elicit the same response. Change things around a bit, and you may be pleasantly surprised at the positive effect on your health and well-being!

The power of association

Painting the room you occupy most in your house a different colour, putting a new picture up or moving the furniture around can alter your mood and state of mind. Your body's organic way of learning is through the power of association. The 'Pavlovian Response', is the reason why you salivate when imagining biting into a lemon or unwrapping your favourite sweet. This natural 'association-making' extends to how you feel emotionally and psychologically. For example, if you've been chronically depressed or anxious whilst spending your time in a particular place and stuck in the same routine, it's likely that your surroundings and your routine may be contributing to your feeling that way. Your body has 'learned' to associate the depression and anxiety with your environment and what you've been doing. The simple adage: 'A change is as good as a rest' holds much wisdom! Introducing a little spontaneity into your daily routine and tweaking the decor may, very possibly, help to ease discomfort, lessen your stress levels and lift your mood.

An internal reference system

You can fine-tune things further by adjusting these associations at an even more subtle level. It's likely you may not have heard of submodalities and the role they play in how you experience everything on a day-to-day

basis. The concept of submodalities arose during the 1970's out of the field of neuro-linguistic programming. Research showed that we make sense of the world by coding our internal experiences at a subconscious level through our five main senses of sight, sound, touch, smell and taste. Everything that's ever happened to you has been recorded in this way as a sort of reference system through which your current experiences are filtered – which determines the way you think and feel about things in the present.

How submodalities work

Submodalities are the finer distinctions of this coding. For example, we may describe an image as large or small, bright or dim, black and white or colour. A sound may be quiet or loud, high pitched or deep. A texture may be soft or hard, smooth or rough to the touch. A smell may be pleasant or unpleasant; a taste sharp or sweet. We also experience everything in relation to us in space. Things may feel near or distant, all around us, in front, behind or to one side, above or below us. We routinely code everyday situations, people and things by their submodalities; thus, someone or something we find distressing might be represented as being large, close up, loud, discordant, jagged, and jarring in colour.

Changing your experience of something

It's possible to alter the way you experience something (and the impact it has on you) by simply changing the way it's coded within you. For instance, changing a submodality from hard to soft, or close-up to far away, can make a tangible difference to how you feel. Meditation is a useful way of helping you to do this; for instance, if you allow your mind to soften and sit back, and your thoughts to become hazy and distant, you are altering the submodalities of your mental state in a positive way that will trigger your body's relaxation response. You may already be familiar with the pain management technique of viewing physical discomfort as temperature that can be adjusted, ie: from hot to cold, or sound that can be turned down.

As always, it comes down to awareness providing choices. Through being present to how you experience the moment, you give yourself the opportunity of changing that experience. During meditation, you can play with sub-modalities such as lightness and softness, nearness, distance, colour, substance, texture and anything else that helps you relax and feel more at one with yourself. It's also a handy everyday tool. When I had M.E. some years ago, I regularly struggled to complete a short morning walk round the block with my dog. One day, aware of the amount of energy the exertion was taking, my legs

leaden, I imagined they were light and strong and that my body was sitting back on automatic pilot without needing to put any effort in at all. I found that doing this made the walk easier and less effortful. Through changing the way the experience had been represented internally, I was able to continue to give my dog those precious ten to fifteen minute walks she needed without it being such an onerous task.

Adjusting the submodalities for feelings and physical sensations

Pause in what you are doing and notice how you are feeling

Notice if you feel comfortable or uncomfortable, happy or unhappy, relaxed or tense, content or ill at ease, or something else.

Check inside and explore the submodalities of that feeling:

- Where is it located?
- What shape does it have?
- What sort of texture?
- What colour? Is it bright or dim?
- What sound? Is it soft or loud?

Now adjust each of the submodalities you've identified, changing the location, shape, texture, colour and sound in a way that feels appropriate. For instance, it may feel right to change the way something is represented from hard to soft, square to round, loud to quiet, rough to smooth, or near to far.

If you want to go one step further you can substitute the submodalities of your current state for the way you'd like to be by doing the following:

After identifying the submodalities of your current state:

- Think of how you'd like to be instead
- Imagine yourself being that way
- As you do so, identify the submodalities of the desired state
- Now swap the submodalities of your current state for the submodalities of the desired one

Adjusting submodalities for people and situations

If you have an issue with a person, place or a situation, explore the submodalities of how that person, place or situation is coded within you, then adjust the submodalities until you feel more comfortable and the issue feels more manageable.

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

Linda

audiomeditation.co.uk

More about the mind/body connection:

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

www.youtube.com/user/AudioMeditation

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

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

Read my article: 'Mindfulness In Everyday Living':

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To help you keep on track



This month's Post-It Reminder: How can I change things around?

(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

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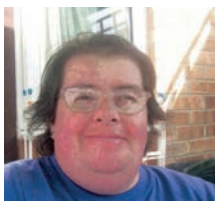
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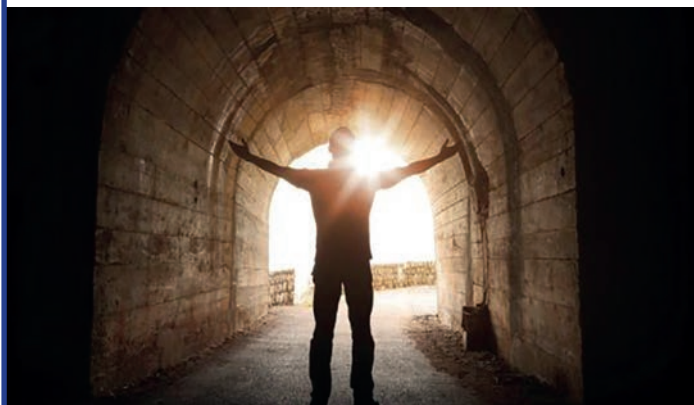
FLARE UPS

By Helen Watts

Part and parcel of living with Fibromyalgia are flare ups that can often come from nowhere and take varying amounts of time to ease. Many folk have developed coping strategies to get through times of flare so I asked the Facebook group members to share their ways of dealing with them.

“MD” replied “To help me cope I now have an image in my mind that I have created. It’s what I want it to be and it gives me comfort in my mind, I have told it what I want it to look, smell, talk, feel like. I can go to this place in my mind and feel a comfort. I have even decided what this image can say to support me. It’s like a big hug that doesn’t hurt like real ones do. Sounds crazy but thinking about my image I created takes my mind from the pain I’m in to a degree and I get some help from it”.

‘PJ’ said her top tips were “Lots of pain killers, as much rest as I can, use any walking aids I need, get my head down and ride it out!! Oh, and takeaways and plenty of water but no caffeine or alcohol (or chocolate/sweets etc) for at least a week longer than the flare ending”.



‘BF’ commented “During a flare (which I’m in now) I try to think positive otherwise I’d bring myself down. I’ve had so many I know that there’s always light at the end of the tunnel, may it be a day, a week or a month. I try and rest as much as I can and ask for help (everyone who knows me knows I don’t ask for help unless I’m at rock bottom). I always try to be kind to myself, for example I won’t get annoyed because I can’t Hoover - it’ll still be there when hubby gets in from work, if I want a chocolate bar, I’ll have a chocolate bar. These may sound simple but this is how I personally cope”.

‘DD’ said “Having just come out of a really terrible flare up I have decided to prepare my strategies in advance for next time. My husband tries to understand but it scares him when it happens. I’m writing a list of things he will need to do in a flare, because I can’t do them for myself. Things like detailing my meds, making the room dark, checking I have water, heated lavender bag for my neck, helping me to the loo, even just sitting with me and holding my head. They are all little things but I can’t explain when I’m in a flare so he will need a checklist”.

‘ED’ commented “When I’m in a flare I rest up as much as I can and take regular pain relief. When I’m well I batch cook so I’m not struggling to cook meals etc when a flare strikes”.

‘AH’ said “When in a flare I am exhausted and have found all I can do is sleep. I have also found it really helps not to get dehydrated. I have my favourite dvds/Netflix on. I always have easy to prepare food in the freezer for that time. The hardest thing to learn has been to tell my husband and son so they know to leave me alone”.

‘KSH’ added “I listen to my relaxation app or dream I’m at my beach hut with the sun shining and waves lapping up on to the beach. I really believe that when you’re in pain you end up in more pain because we tense up and hunch over more. By laying flat with a pillow beneath my knees I then deep breathe it all away. I try not to take painkillers unless I have to, that way they work better”.

Lots of great coping strategies here. Pop over to the Facebook group and share your flare up tips.

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



How to set up and run a Fibromyalgia Support Group: Part Two -The Programme



By Julie Barker - Chairperson Fibro Active and Tracey Peel - Secretary

In the first article, we looked at partners who helped us launch the group, the hurdles we came to along the way and the development of the groups aims. In this article, we will look at how our weekly programme evolved from identifying members needs to funding requirements.

Following the Launch of Fibro Active on March 3rd 2016, a date was set for the first meeting on Tuesday April 26th. Although numbers were low at the launch I still had hope that we would grow and Kev and I sat and bounced ideas around for an initial six-week programme.

It is very easy for a non-sufferer to judge activities based on what an average person is capable of doing. It is also easy for a sufferer to sit in their own bubble and believe that no one can be as ill as they are and that increased activity leads to increased symptoms and pain. I knew from personal experience that we must be careful but also that the more inactive we are the more deconditioned we become, pain increases and mobility decreases. By starting with bite size steps and positive thinking we hoped to promote a healthier and more active lifestyle. I'm not quite talking '*my body's a temple*' but by making small, easy to cope with, positive changes we could gently improve our health and well-being in a secure and friendly environment and in ways that our bodies could cope with. Even though I have gone up 2 dress sizes since I started the group! Of course, this is not entirely the fault of the group but we do have some members who like to share their incredible homemade bakes over a cuppa and a chat and it would be rude not to join in!

We knew from the beginning that the programme had to cater to everyone's capabilities and address a wide range of issues that go hand in hand with any long-term health condition. We felt it had to give each member a sense of achievement and hope as well as being inclusive. Some of our members have been forced to give up work and that brings along with it a whole host of new problems outside that of the illness itself. For those who can no longer work breaking their isolation and giving them new experiences and achievements is crucial to improving their life. We also had many members who had been given very little explanation of their illness by their practitioners. Some had only been given a prescription and a web address to research it themselves! Some members are confident when using the internet and had already researched their symptoms, but for others we were their first venture onto the internet and we needed to teach them how to access our Facebook page. Also, we all suffer in unique ways some rely on carers others are independent. Some can walk or jog, others need to use walking aids, wheelchairs and mobility scooters. Some are unaffected by poor

lighting and background noise whereas others have difficulties with sensory overload and cognitive problems. Our starting point in the early days was based around key areas of support needed for the individuals. We had no budget, however Kev had contacts. The programme looked like this:

Week 1	Introduction and ice breakers
Week 2	Short walk at the local park followed by café with Kev as walking leader
Week 3	Healthy eating, fun light exercise and smoothie bike with Kev
Week 4	Strictly No Falling With Age UK Derby and Derbyshire
Week 5	Boccia delivered by Village Games
Week 6	Citizens Advice

Of course, with any venture there are always difficulties to overcome. The programme was booked. Consent forms printed, refreshments sorted what possible could go wrong? I will spare you the details but the key areas I learnt was the following:

- A lot of the member's initial remarks were that due to lack of explanation from practitioners they were still in denial that they had FM and/or ME/CFS. Comments like "I don't look as ill as that member maybe I shouldn't be here" needed to be addressed through education and increased understanding of the conditions.
- The levels of anxiety in many members was a lot higher than we initially expected.
- Members were worried about losing their benefits if they were caught attempting a gentle walk.

On the positive side; everyone was loving it! Because the main aim of our group was to move away from the cuppa and a moan format and instead focus on things we can do there is always a buzz of positivity at the end of our sessions.

We asked the group what they would like to see on the programme and we built a bucket list of: Tai Chi, CAB, Welfare Rights, Occupational Therapy etc.

After the first 6 weeks we were still waiting for funding to come through. We had to leave the CVS and beg free rooms at the local council run leisure centre when there were no bookings and we did a few more gentle walks and a cuppa at a café. Without funding we were having to make the programme up on a weekly basis depending on available venues.

Members were stagnant we had 20 Facebook members and 6 attending weekly sessions. One or two newbies were starting to attend but we were stuck between a rock and a hard place as we needed to recruit new members but we didn't know where we would be each week. Unfortunately, due to other commitments Kev had to withdraw his support at the weekly sessions and this added to the pressure. In Summer, our membership began to increase and we heard good news we had been awarded funding. With confirmation of funding in place Kev was able to go back to the CVS and negotiated room hire. They kindly agreed to give us use of the room and we could pay them back as soon as the funding came through.

Key people from other support organisations had contacted me during the summer offering their services and I was able to start putting together a programme starting in September. The group spent the summer holidays planning the way forward, designing a logo, leaflets and formalising the group with an inaugural meeting.

The funding finally came through in September but unfortunately, came too late to enable us to block book the room for the next twelve months as another group had booked the 1st Tuesday of every month. So, in the true spirit of our group we turned this negative into a positive and planned gentle walks, café visits and meals on those dates. Also, members who struggle with anxiety and find unfamiliar or crowded places difficult knew that if they chose to attend one of the Fibro Active offsite sessions they would be meeting familiar faces, they would get regular Facebook updates leading up to the session so they could check who would be going and there would always be someone willing to offer them a lift and support them in attending.

We now have a full and bespoke programme to meet the needs of everyone in the group.

Alice from Relate delivers work shops around acceptance and loss, family dynamics and anxiety. Alyson from Arthritis Care has delivered a pain workshop and is delivering a 6-part 'Living with Long Term Illness' course over 6 months.

Tracey, the Secretary and I met with Mandy from Live Life Better Derbyshire in January and she signposted us to their free online resource that sets out a 12-week education in healthy eating programme that we could deliver ourselves. This was amazing!

Chris from Impact Physio delivers Tai Chi for Arthritis every alternate week at each branch. Fabulous for mindfulness and movement and falls prevention. This was a on the bucket list but has taken a year to arrange.

Diane on behalf of Wash Arts have been funded to deliver a further 10 arts sessions after the success of a joint spring prints project.

Helen from Erewash Borough Council has just come on board to run an 8-week wellbeing course for the Ilkeston branch and she is a qualified walking leader for our walks.

Amanda Letts who specialises in nutrition and chronic illness has put together a monthly group presentation as part of our new project that was launched in June affectionately known as 'Fibro Lites'. She will also be looking at 1-2-1 support for complicated cases.

By April just gone, our programme is full for the entire year and we were having to tell organisations we are not able to accommodate them until 2018!

Many of our weekly group members struggle to access other services because of issues such as fatigue, mobility and/or anxiety we were suddenly in the unique position of being able to bring those services to them. We are getting long term support for our members all under one roof without them having to travel to multiple appointments and venues.

In the next article we will be looking at the power of Facebook communication, the hub of the group, how it has helped the group grow and where to advertise you are here.



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by David Jenkin

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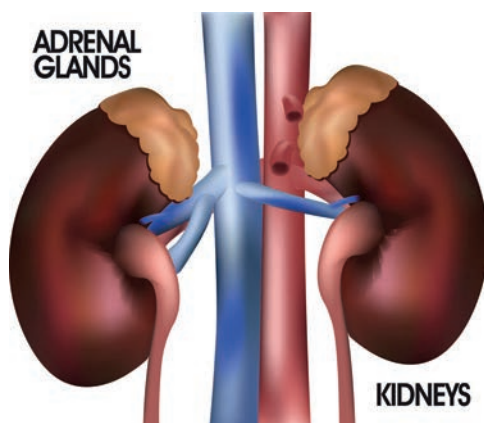
Deep-seated Health Problems Occurring with Fibromyalgia

by Christine Craggs-Hinton

People with fibromyalgia often suffer from muscle pain, fatigue, morning stiffness, headaches, poor sleep, anxiety, Irritable Bowel Syndrome, depression and cold intolerance, among other things. These symptoms show themselves clearly. However, it's a sad fact that sufferers often have hidden health problems that may be very deep-seated. These problems are often at the root of the symptoms of which we ARE aware.

Adrenal Exhaustion

Adrenal exhaustion is common in chronic illness, and fibromyalgia is no exception. The adrenal glands, which sit on top of the kidneys and may be thought of as the 'batteries', produce the adrenalin that fires the heart. However, excessive stress causes these glands to pump more adrenalin than necessary, which is obviously very draining for them.



Apart from adrenalin, the adrenal glands manufacture approximately fifty hormones and other substances, which play key roles in virtually every bodily function. It makes sense then to say that adrenal exhaustion leads to problems in many areas. The stress, which damages the adrenal glands comes from mental, physical and emotional sources. Examples are shocks, worry, emotional upsets, lack of sleep, illness, caffeine, alcohol, smoking, drugs (both illegal and medicinal), overwork, shift work, skipped meals and rapid weight loss.

In order to treat adrenal exhaustion and low blood sugar (see below), the vicious circle of over stimulation must be broken while simultaneously repairing adrenal damage. An additive-free wholefood diet is of great benefit to these glands, as are the supplements recommended in my book (see below for information). However, pantothenic acid (vitamin B5) is the most useful, 500mg daily being the therapeutic dosage. Vitamin C is also useful, at a daily dosage of 1000 - 3000 mgs.

As well as elimination of the above-mentioned stressors, meditation and relaxation will make a huge difference. Siberian ginseng - which protects the body from stress - can be greatly beneficial, as can the famous Rescue Remedy - a Bach flower remedy - which helps to ease shock and panic attacks. However, if you are experiencing a situation that is particularly stressful or have unresolved emotional issues, I strongly advise that you see a skilled counsellor.

When, finally, the adrenal glands are functioning more efficiently, virtually every bodily system will improve. Qualified nutritional consultants now offer a test which can determine adrenal exhaustion.

Low blood sugar

Because the adrenal glands help to control blood sugar levels, poor sugar metabolism (hypoglycaemia) is often a knock-on effect of adrenal exhaustion. When hypoglycaemia occurs, any sugar consumed will travel straight into the bloodstream, pushing up blood sugar levels - only to later make levels fall dramatically in a yo-yo effect. Continued bombardment of white refined sugar and caffeine will ultimately overstimulate the pancreas to produce greater amounts of insulin than required.

It is most important that a low blood sugar situation is attended to, as the system may break down further - diabetes may even develop. The diet guidelines outlined in my book will aid the situation, as will pantothenic acid, the B complex vitamins and vitamin C.

Hypothyroidism

Poor thyroid function (hypothyroidism) is another offshoot of adrenal exhaustion - and believed to be fairly common in fibromyalgia. When left untreated, it can have profound consequences for health and wellbeing, for the thyroid gland acts as a thermostat and controls the body's metabolic rate. Typical symptoms include weight gain, below-normal body temperature, depression, anxiety, memory impairment, dry hair and skin, cold hands and feet and loss of libido.

Unfortunately, the standard medical laboratory test for thyroid function often indicates normal function when there is actually low output. The basal temperature test - where the individual takes their temperature with a glass thermometer daily upon waking - is a more accurate measure of thyroid activity. It should read between 36.6c (97.8f) and 36.8c (98.2f). A temperature of 36.4c (97.4) or less suggests impaired function.

The prescribed medication - thyroxine - does not always improve symptoms, however. In fact, thyroxine - a synthetic substance - appears to be poorly utilized by the body, and it may not be prescribed anyway without an abnormal laboratory test result.



Thyroid function can be greatly improved by the use of specific vitamins, minerals and amino acids. These include iodine, selenium, calcium, magnesium, Vitamin A and L-Tyrosine. 'Thyro Complex' is a special formulation containing all the above in the correct balance. Adaptogenic herbs such as Siberian Ginseng, Ashwaganda and Rhodiola Rosea can be considered as useful extras, too, as they help to balance the whole endocrine system, of which both the thyroid and adrenal glands are part. The above supplements are available from health food shops or specialist supplement manufacturers.

Candida

Adrenal exhaustion is common in chronic illness, and Yeasts live all around us. It is even normal to have a certain amount of yeast - candida albicans - inside the body, and particularly within the digestive tract. Unfortunately, people with compromised immune systems, such as those with fibromyalgia, are particularly susceptible to candida overgrowth, as are people who have taken repeated courses of antibiotics, steroids or use the birth control pill. The outward signs of a candida infection (candidiasis) include recurring athlete's foot, oral and/or vaginal thrush, digestive symptoms and a craving for sugar. As often there are no outward signs of candidiasis, however, it may be helpful to take the test offered by a qualified nutritionist.

When the immune system is too weak to combat the growing infection, as may be the case with fibromyalgia, candida can spread throughout the body, in many cases

even damaging the gut wall. This situation is commonly known as leaky gut. A high amount of escaped food molecules may eventually weaken the immune system, giving rise to fatigue, depression, headaches, impaired memory, digestive problems, recurrent vaginitis and cystitis, PMS, loss of libido, irritability, hypothyroidism (underactive thyroid function) and hypoglycaemia (low blood sugar.) It also commonly causes food, drug and chemical sensitivities.

Because many of the symptoms of candida overgrowth are the same as those of fibromyalgia, it can be difficult to distinguish the two. In some sufferers, candidiasis may be the chief cause of symptoms, in which case a diet that is very low in sugar (sugar feeds candida) and yeast will help to clear the infection and alleviate symptoms.

In most cases, however, specific antibiotics and/or anti-fungal indications are required from your doctor to tackle the condition, and should be used in conjunction with a low sugar and yeast-free diet.

My book 'The Fibromyalgia Healing Diet' describes the diet and supplements recommended for repairing damage to all the bodily systems.

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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
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John Allen	Swindon & area Wiltshire Fibromyalgia information & support 01793 751920 (answer-phone phone buddy etc support) highlyfly29@hotmail.com (emails preferred) 21 Heberden House, Cricklade, Wilts SN6 6AS
Maddie Seacombe	Bristol - Tel 07790130403 - best time is 3pm - 8.30pm.
Claire Hilton 4	3 Alexandra Road, Thornton Cleveleys (nr Blackpool) Lancs FY5 5DB Tel 07912 792250 Any day 11am-6pm shelbyeatenton@hotmail.com
Linda Holder	Luton, Bedfordshire - 01582 570240. Phone chats or meetings phone in the afternoon.
Mrs Teresa White	Bracklesham/Witterings/Selsey Support Groups West Sussex telephone support/group meetings/social lunches 01243 670 783 any pm or evenings
Denise Shotter	Guildford and Bordon monthly meetings 08448872358 5-7pm email denise.guildfordfibro@yahoo.co.uk
Diane Jaques	Burnley, Lancashire - 01282 701390 after 7.30pm Mon-Fri if you would like to chat
Diane Leak	Darlington Friendship Group - 1st Wednesday of the month 12pm-2pm. Upstairs Café of the Darlington Dolphin Centre.
Mrs Jane Wallace	Bursledon Hampshire Contact number: 08448872409 Email: bursledonfibrofriends@gmail.com
Mrs Natalie Hicks	Chorley Fibromyalgia Support, Lancashire - Contact number: 01257 275145 Please leave a message if no answer. Email: nataliehix@gmail.com
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