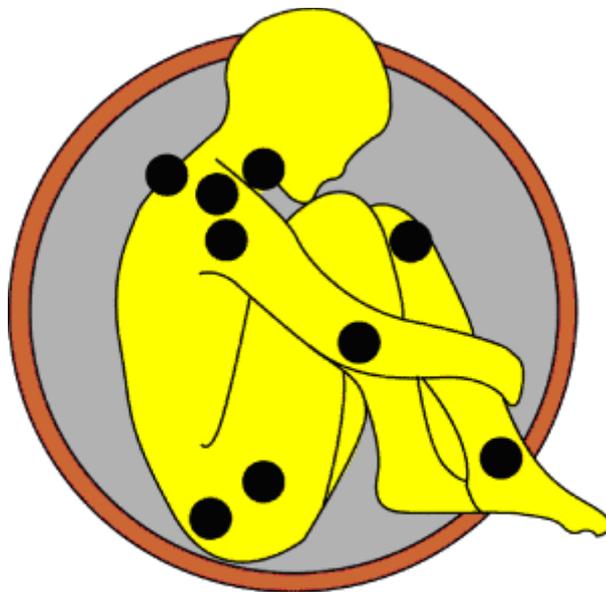


Swindon Foggy's
The Swindon Fibromyalgia Support Group

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Working with FMA UK
Registered Charity No. 1042582
www.fmauk.org

Newsletter 2

20th September 2010

We had good turnouts again at meetings 2 and 3. Our afternoon meeting had around 14 people, which is good. I don't mind numbers being lower for the afternoon meetings, they were made for people unable to attend evenings.

Membership packs are available at £5, although attending our meetings is free. I didn't want to have to charge, but photocopying costs are horrendous, although I have sourced it a lot cheaper now.

Merchandise is available ribbons, bands, badges and mugs. Buy them, wear them, tell people about us and FM, get them to buy and use and wear too. Our groups' motto/aim is "dedicated to raising awareness and providing support".

I have posted some listings onto eBay and Amazon, 50% of the proceeds going to the Group (they do say 100% on the site that's because I'll get listing cost refunded). If you have any items you want to sell, I can list them on Amazon for you, or if you use eBay, search for Swindon Foggy's and donate a percentage to the group.

I personally like the meetings not structured, I like the social chatting over cup of tea/coffee and sharing stories, hassles, grumps and laughs, but I'm worried we'll lose the interest of some of us. Thoughts, ideas welcome 😊

We have Dawn MacGregor, a newly qualified physiotherapist joining us at our afternoon meeting, Tuesday 5th October 1 – 3pm and I shall ask if she will attend an evening meeting too.

John Freeman from Swindon Primary Care Psychology Service will be joining us Tuesday 2nd November for about an hour at 1pm and Monday 15th November he will be joining us 7.30pm onwards to discuss what work they do at Swindon Primary Care and what help he can give us.

John is a NHS Clinical Psychologist and works for Swindon Primary Care which now works from Eldene Surgery, (separately not connected to them) he also works at the Pain Clinic at GWH.

You can contact them direct to be put on courses related to long term pain and Chronic Fatigue, you don't need to be GP referred, although it is better if you are. Must stress, they don't diagnose any condition !!

Their telephone number is 01793 836836.

I am visiting the Swindon Therapy Centre on Monday 4th October to see what services they have available to us.

A number of simple, drug-free therapies are available at the Centre, including Oxygen Therapy (HDOT), Physiotherapy, Dietary Advice, Reiki, Reflexology, Indian Head Therapy, Full Body Massage and Bowen Technique and some beauty treatments (manicures, pedicures, facials, etc).

I'm not sure that all of the treatments would benefit any of us, but certainly some of them shouldn't do us any harm. Not sure about the Oxygen Therapy, perhaps if anyone has tried it, they could let us know how that goes?

There is a £10 membership fee and they ask for donations towards the treatments. They can be contacted on 01793 481700.

I need to issue a disclaimer at this point. Swindon Foggy's is here to assist and support, I or Swindon Foggy's do not claim that any treatment you try will cure FM. Sadly, there is no cure, but there are services available and techniques to be learned, out there to alleviate pain. Any suggestions to services are just that, suggestions !!

If anyone wants to assist with fundraising please let me know. I could do with someone booking events, and drumming up people to help. Of course, a lot of our members aren't mobile, and I don't expect anyone to help if they don't want to or can't, nobody should be press-ganged or made to feel bad.

I won't provide a link to a newly setup national group who said "*We evicted a woman from our Support Group because she hadn't contributed in anyway, but expected all the benefits the group provided*", I think that is appalling.

If I could supply everything free, with no support from anyone, I would.

So if you don't or can't want to help, no problem!! However if you do say yes, you must be committed, it won't help anyone if you agree to rattle a tin for example but on the day change your mind.

Question:

How do I get referred to Bath Pain clinic ? or any clinic/department that you wish to be referred to ? What to do with an unsympathetic doctor ?

Answer:

First of all, the doctors are there to serve us !! If you can't get any help with your doctor, you can INSIST on being referred. If referred to GWH Swindon and you feel they aren't helping, again you can INSIST on being referred to Bath Pain Clinic.

http://www.ruh.nhs.uk/patients/services/clinics/pain_clinic/index.asp?menu_id=new

Take someone with you to the doctor, especially if they're a braver person than yourself. I'm lucky that my current doctor is brilliant, but I have had some awful ones in the past, taking my dad for example with me, has got me referred on, when denied before.

Also see above regarding Swindon Primary Care.

Question:

Has anyone tried spraying water onto the area of pain ? and does it work? According to our member who has tried this, (and it seems plausible to me), that when he sprays the area and lets it dry, it eases or stops the pain. The downside complaint is that he has wet carpets ☺

Answer:

I think this may work as I wonder if it interrupts the brain signal that tells us we hurt ?

I personally can't try this, as today, my pain is in the base of my neck or shoulder joint ... I'm sure someone in the house, would love spraying water at me, but not giving them the chance. Is anyone willing to give this a go?

Question:

Is Fibromyalgia connected to MS (Multiple Sclerosis) ? Does it run parallel ?

Answer:

Having searched the web, I could not find a site (well reputable one anyway) that could confirm a connection. There are similarities, but there is no suggestion to say that FM will develop into MS, see ...

<http://www.nhs.uk/conditions/Fibromyalgia/pages/diagnosis.aspx>

If your GP thinks you may have Fibromyalgia, they will first have to rule out any other conditions that could be causing your symptoms. These conditions include:

- [chronic fatigue syndrome](#) (also known as Myalgic Encephalomyelitis, or ME) - a condition that causes long-term tiredness
- [rheumatoid arthritis](#) - a condition that causes pain and inflammation (swelling) in the joints
- [multiple sclerosis](#) (MS) - a condition of the central nervous system (the brain and spinal cord) that affects movement and balance

You may have blood tests, X-rays and other scans to rule out these and any other condition with symptoms similar to Fibromyalgia. If you are found to have another condition, you could still have Fibromyalgia as well.

Hope this puts minds to rest, as I'm sure we've all been blood tested and x-rayed/scanned and had this ruled out.

Don't forget meetings are always;

first Tuesday afternoon of the month 1 – 3pm and
third Monday of the month 7.30pm onwards

at Liden Community Centre

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