

Thursday, 1 December 2016

Dumfries & Galloway ME and Fibromyalgia Network

Monthly Meeting - FMA UK (Fibromyalgia Action UK) with Hazel Borland

About Hazel

Hazel Borland from FMA UK (Fibromyalgia Action UK) attended to talk about the work they do. Hazel is an administrator with FMA UK and came from Paisley to see us. Hazel has had Fibromyalgia for 23 years, 12 of these she was told it was in her head, she was being neurotic and got told to get back to work. Hazel explained there are areas where support is good but still a lot of areas where support is not. Hazel was medically retired at 28 years. Her nearest support group was some distance away. Hazel has since had dealings with volunteering and setting up local support groups.

How was FMA UK established?

FMA UK (Fibromyalgia Association UK) was started in 1994 by Bob Stewart in England after he was diagnosed with Fibromyalgia. At this time, there was limited information available and online. The 'butterfly' logo came about when Fibro Action UK merged with FMA UK in July 2015. The FMA UK office moved from England to Paisley four years ago. The charity is mainly supported by volunteers.

What can the FMA UK provide?

- FMA UK are currently supporting 200+ support groups and local helplines, of these 190 are registered as working with the FMA UK. 10-15 support groups, like our group is not registered with FMA UK.
- Literature is provided to groups free of charge, although postage is asked to be covered.
- Insurance is also provided to registered groups.
- 0844 numbers are provided to registered groups, which enable calls to be directed to home lines.

What are the FMA UK aims?

- Raise awareness about Fibromyalgia
- Give support and information to people with Fibromyalgia

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What support mechanisms are available?

- On average 200 information packs are sent out monthly by FMA UK. They have a patient booklet, a young persons booklet and a health professional booklet.
- They have two national telephone helpline numbers. Both numbers have recently changed to 0300 numbers which are free on most phone packages.
- They have an online forum on their webpage.

Questions / Answers

Q: What type of information are you asked for?

A: Information, which is why the information pack is provided. Patients are not always told what Fibromyalgia is. GPs may treat the symptoms rather than confirming where symptoms are covered by 'Fibromyalgia' e.g. stomach, pain, fatigue. A lot of their clients comment 'You were the first person I spoke to who understood'. It is recognised that it is an invisible illness.

Q: In relation to the research on serotonin, what is substance P?

A: It is a chemical that raises your pain signals. People with Fibromyalgia are believed to have too much of this. Traditionally people were sent to Rheumatology, where a diagnosis of Fibromyalgia may be given. Some people are referred to Neurology who will test for MS and may give a diagnosis of Fibromyalgia.

Q: What support can physiotherapists provide?

A: Generally physiotherapists do not have specialist training or an understanding of Fibromyalgia. By getting you to do repetitive exercise, they don't realise they are making you worse. 'Normal' physiotherapy is not ideal for people with Fibromyalgia. In Paisley they have a Rheumatology Physiotherapist who runs a Fibromyalgia self management programme, where conditioning exercises are taught. Tia Chi, in a sitting position designed for people with arthritis is included in the programme: a full video by Dr Paul Lamb is available on Youtube.

Q: What is available to health professionals?

A: The health professional booklet is available with medical terminology and links. Recommended aerobic activity is about increasing your heart rate and could be as simple as a 5 minute walk, where you are able to walk. The less you do, the more your body has to work when you are active. Hydrotherapy can be available. CBT and mindfulness will help to train your mind. It may not help to deal with your pain but it may help you deal with the 'baggage'.

Q: What medication can be useful?

A: Medication e.g. paracetamol, tramadol can be helpful, although anti-inflammatories are generally not recommended as there is not evidence of inflammation in people with

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Fibromyalgia. Low dose antidepressants like amitriptyline are found to be helpful and can assist with sleep. Duloxetine can be used. Gabapentin and pregabalin are helpful for neuropathic pain. Hazel gets a private prescription for a low dose naltrexone which she personally finds beneficial. (www.idnresearchtrust.org or www.dicksonchemist.co.uk has more information)

Q: Are there any long term concerns with using amitriptyline?

A: Hazel is not personally aware of any known long term issues. A lot of medications have side effects, it is about getting something that works for you and helps you to manage things along with using pacing. There are a lot of studies and research going on currently, which do take a long time to progress.

Q: Have you any thoughts on using CBD oil, which is based on the Cannabis plant with the THC (psycho active) elements removed?

A: Hazel has been using the oil and not the vape for 5-6 months and does feel it takes the edge off things and has been able to cut down on her pain medication. The government is currently trying to class it as a medicine.

Q: Is Fibromyalgia hereditary?

A: There is a predisposition for it to be in the family. It is a genetic factor, which can be triggered by a number of different things e.g. stress, virus etc. Unless you step back and stop doing what may have triggered it, you will see no change. A lot of people who have been diagnosed with Fibromyalgia have been very active or sporty.

Q: Is the need to go into hibernation, to avoid people and the wish to remain in a safe environment a symptom?

A: Your body will try to conserve as much energy as it can. People will generally not see you on bad days for this reason. It is about awareness for others; Fibromyalgia patients do not get better and are unable to sustain 'normal' activities. You need to learn to put strategies in place that help you manage e.g. using aids, considering parking etc. Sometimes it is about finding outlets to break the cycle.

Q: How can you plan for anything when your illness is so unpredictable?

A: You may need to plan ahead by having a rest day before an activity. Writing things down will help with 'fibro-fog'.

Q: In what way do you support carers?

A: FMA UK do not currently have anything specific for carers other than what is in the patient booklet, although they are looking to create a booklet for employers. They would redirect carers to the Carers Association. The children's handbook has sections for the child, the parent and the school. Hazel will take this back to FMA UK to consider.

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Q: What alternative therapies have been found to be useful?

A: Alternative therapies can help, although they can be expensive e.g. reiki. What works for one may not work for another. Exercise in water is meant to be very beneficial but the temperature has to be right. Acupuncture and TENS machines work for some but there is nothing to support that they work across the board for people.

Q: Is the hyperbaric chamber in Glasgow available for people with Fibromyalgia?

A: Hazel used it once a week but did not find it helpful. Other people using it did find benefit. There is a group in England doing a more intense treatment e.g. daily, but Hazel has not heard back on any results.

What should you do?

- The most important thing is pacing, get yourself out of pushing yourself too hard.
- Try to do some sort of activity or exercise, which could even be completed in bed.
- Be gentle on yourself, we beat ourselves up because we can't do things. Accept your limitations.

What should you not to do?

- Don't crash and burn.
- Try not to lose hope and go into despair.

Contact:

FMA UK (Fibromyalgia Action UK)

Studio 3007, Mile End Mill, 12 Seedhill Road, Paisley PA1 1JS

Phone: 0844 826 9022 (Head Office)

Helpline Phone: 0300 999 3333 (Mon-Fri 10am-4pm)

Benefits Helpline: 0300 999 0055 (Mon & Fri 10am-12pm)

Website: www.fmauk.org

Email: charity@fmauk.org