

Welcome, I hope everyone has started to pick up after the Christmas and New Year break.

Yoga is the first Wednesday of the Month. If anyone would like to try it please come along. You can try it seated or standing and using mats. I do it seated and usually have a 5 minute breather in the middle! you can do as much as you want to try. Dawn adapts it to your capability. Its £2 per session just turn up 5pm at Caledon club (same place as the meetings)



### Sandy's Journey

One of our members, Sandy, has agreed to write a piece for each of our newsletters under the heading "**The Road To Recovery**". Sandy has had ME for fifty years, initially trying to live as normal a life as possible (since there was no diagnosis) until eventually it all caught up with her and she ended up bedridden in a darkened room for nearly five years. She is going to tell us about some of her experiences, things that helped her get her life back and things that didn't, and give general information, advice and encouragement. Part 1 will start on page 4 in the newsletter.

### Welcome New Volunteers

We have some new, much appreciated volunteers who are also members.

**Sandy, Martin, Daphne and Ayshe** are going to be our phone line team. We will have the phone line once a week on a Monday 10am to 1pm. This is for enquiries from potential members and enquiries but also for current members if you want to check something or have a chat.

**Fiona** is taking on publicity and Marketing so we can get the message to GP's, organisations and other sources that we are here.

**John** is our mindfulness trainer also relaxation meditation, tai chi and many other things. He now spends some time on mindfulness and debating and discussing at meetings. We aim to set up a second mindfulness session for 1 hr possibly the last wed of the month. Details to follow.

### Therapy Taster Morning

Wed 15<sup>th</sup> March 10am to 12.30pm at the Caledon Club, London Colney..... I already have my socks off and am waiting!! Don't forget to email me if you are aiming to come. For those who have already Thank you.

MEDITATION.....because not all questions can be answered by Google!

# January Meeting

We had a guest speaker Emma Paisley who had CFS herself, from Herts Wellbeing Team. The wellbeing team is part of Hertfordshire Partnership and University NHS foundation trust. All the services they offer are free and aim to support mental health, including for people with chronic health issues. You need to be registered with a GP in Hertfordshire to access this service.

The link to the website is <http://talkwellbeing.co.uk/>

What may be helpful to a lot of our members is they offer telephone support for people who can't attend the sessions due to mobility or ability to get out. For those who can they have group sessions, one to one sessions and online courses.

You can refer yourself via the website or call 0300 777 070 but Emma said the phone line is very busy. Your GP will not be informed unless you consent to them being informed. Once they have received the referral they will send you a letter or call you to clarify any details then a local team member will contact you to arrange times and assess needs. Emma said that the aim is to start sessions within 28 days, which is fantastic.



# February Meeting

It was great to see everyone and we welcomed some new members. Our guest speaker was Hilary who is a Mindfulness trainer and counsellor. She told us the history of mindfulness, explained what it was and did some exercises with us. We had to take an object out of our bag/pocket and we had to focus on it, feel it, smell it, it was quite difficult keeping the mind focused on it and not wander off but if we did then we acknowledged those thoughts and tried to focus again. It was about being in that moment with the object. She spoke about making time to start a new page, so at any point in the day you can:

**Pause:** Take a few moments break in your day

**Awareness:** Becoming aware of your thought, your feelings/emotions and the sensations in your body

**Gathering:** Gently bringing the focus of attention to your breathing

**Expanding:** Becoming aware of a sense of the whole body breathing, bringing attention to the feet in contact with the ground, to your posture, to your facial expression

We all discussed how having M.E/Fibro can actually make you notice the smaller things and details because of being forced to stop and be an observer.

Some of the group already use mindfulness and meditation which can help. They have recommended some websites with free meditations and Apps:

<http://www.breathworks-mindfulness.org.uk/>

<https://www.tarabrach.com/guided-meditations/>

<http://www.stopbreathethink.org/> (website, android and ios)

<https://www.headspace.com/>



After some refreshments John used mindfulness to bring up issues and discussion followed by a short meditation to gather ourselves.

## Dates for the calendar

All meetings and events are at Caledon club, Caledon rd, London Colney, St Albans, AL2 1PU

**Wed 1<sup>st</sup> March:** Yoga 5pm £2

**Wed 8<sup>th</sup> March:** Monthly meeting, 11am-1pm AGM with Guest speaker: Annie Brewster. Former Mayor of St Albans who has M.E. Then refreshments followed by discussion and mindfulness, meditation to end with. £2

**Wed 15<sup>th</sup> March:** Taster Therapy morning 10am to 12.30pm Try a Therapy including Reiki, Reflexology, Massage, Indian Head Massage. Please email to let me know if you aim to attend. No charge

**Wed 5<sup>th</sup> April:** Yoga , time to be confirmed we may try daytime. £2

**Wed 12<sup>th</sup> April:** Monthly meeting: Its our First Birthday! Refreshments, discussion and Mindfulness, Meditation at the end. £2

**Wed 3<sup>rd</sup> May:** Yoga 5pm £2

**Wed 10<sup>th</sup> May:** Monthly meeting £2 will be doing arts & crafts with Maureen as well as refreshments and chat.

We are hoping to introduce an hour a month mindfulness session 2 weeks after the main meeting. We will need 8 to 10 people to cover the cost of the room hire. Please email interest.

### Guest Speakers

Got an Idea for a Guest Speaker or any other ideas for a themed meeting ?

Email me! it would be great to hear your ideas

### Herts CFS Clinic

Would you like Herts Chronic Fatigue Service to attend a meeting and tell us what services are available?

Some people may have attended the courses already and there have been different experiences. It may also be a good opportunity for them to hear feedback and see what happens to us afterwards. It could be an opening for us to try and have some input on our local services. We will bring this up at the next meeting or email me any thoughts. Thanks

### Mindfulness Tips from John...

Let go, move on and forget about the past. The past cannot be changed.

Be with who you want. Don't live life how others want you to.

Think Positively. Something good will come from everything.

Remember .Everything happens for a reason.

Change for the better.

Be Passionate, devoted and caring.

Build relationships.

Find a purpose in life.

Take responsibility. Don't blame other people for your mistakes/

Smile it will make someone's day.

Email [stalbans.m.e.group@gmail.com](mailto:stalbans.m.e.group@gmail.com)

## THE ROAD TO RECOVERY

### WISE AFTER THE EVENT

My ME experience started fifty years ago living in Madrid, though of course it had no name in those days. A strange recurring illness, dismissed by all medics, and when later I was given a range of hospital tests in the UK as an in-patient, it was a case of “Send that girl home, there's nothing at all the matter with her !”

I have heard of many people who can trace their ME back to foreign travel especially in poor countries where you are never sure what you are eating or drinking or the purity of medicines and drugs. These days you can get checked for parasites and foreign diseases quite easily and even if they are not the cause of your ME they will be putting a strain on your immune system and general health so I would say that's well worth doing.

Today, my year out in Madrid would be called a postgraduate gap year, but back in the sixties it was unusual and difficult to do – the foreign travel industry for 'ordinary' people had not yet taken off and £50 was the maximum amount you could take out of the UK in one year. Most people thought I was a bit crazy; it was in fact a wonderful year in every aspect except my health.

Spain in the 1960s was a third world country still recovering from its bloody civil war. It was a police state under Franco's fascist rule. Living conditions were poor and unhygienic. I drank the water ( full of bacteria and microscopic parasites I later discovered.) I learnt to live with cockroaches and mosquitos and intense heat in the summer. Even though I taught English to pay my way I often couldn't afford food and existed on the tapas my boyfriend would buy me in the university bars. I had many long bouts of what is now affectionately called 'spanish tummy'. Not surprising really that while there I caught a variety of blood and bacterial infections which were treated with antibiotics. I would take the little phials to the local 'practicante'. There would be a long queue of us at certain times of the day reaching down into the street from his flat, each with our little phial which he would put into his syringe while we proffered our backsides. I noticed there was always a residue of various colours in his syringe; I also noticed he never changed the needle !

Of course nowadays there is much more awareness of the risks but I was young and naïve and those things were never talked about then.

ME is often caused by abnormal gut bacteria from past infections and viruses and I felt this was so in my case. I was a prize target, having been on long courses of antibiotics for several years before even going to Madrid. My guts were an open goal and towards the end of the year I was completely knocked out by what seemed to be a terrible virus from which I couldn't seem to recover. It sapped my energy in a way I had never before experienced. I know that was the start of my ME experience. After that I never felt the same again; I could never take my health for granted. Continued in the next newsletter.

