

MAY 2020 NEWSLETTER



Celebrating Florence Nightingales 200th Birthday

The month of May is International Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS) / ME Awareness Month. May 12th celebrates International Nurses day and more recently has been adopted universally as International FM and CFS Day. I was privileged to have written an article for the UK Fibromyalgia Magazine, it was in the April edition, and I thought that there is no better time like the present to celebrate Florence Nightingale's achievements, but also to pay homage to all the NHS staff, frontline services and care; to remind ourselves how things could have been very different. Below are just a few highlights but if anyone would like a copy of the full article please



Florence Nightingale came from an affluent background and was a pioneering statistician. In that time, it was quite rare for a woman to be in such a field. She became one of the most prominent statisticians in history.

Florence found her calling in her early 20's. In 1854, she took a group of 38 nurses over to the Crimean war, the death toll being high from infection and poor nutrition. Florence conducted pioneering and brave work and used her passion for statistics to save lives of soldiers during the Crimean War, doing ground-breaking work in data visualisation that continues to be influential to this day.

While working at the British base hospital in Constantinople, Florence contracted a bacterial infection called 'Crimean Fever'. Florence never fully recovered, however, she continued to care for the soldiers, making her rounds during the night and she gained the name 'the Lady with the Lamp'. One of the main symptoms of the 'disorder' is sleeplessness. Could it be that Florence earned her name inadvertently due to this chronic illness?

Florence was a meticulous note taker, keeping a detailed diary that described the perpetual pain, fatigue and general brain fog that related to an illness of no name. The medically trained of the era would disparagingly refer to it as 'female hysteria.' From the age of 38 she was almost entirely bedridden until she died reaching the age of 90.

Florence went on to achieve so much more. Nursing was championed through her, the first professional nursing school was established, Florence founded London's Nightingale School of Nursing; the reputation of nursing was raised to profession status through this. Her direct influence led to the setting up of the Red Cross in 1870, Queen Victoria awarded her the first Royal Red Cross in 1883. A woman of great distinction appreciated by many, understood by Fibro and CFS/ME sufferers for what she endured.



Coronavirus Contingency Plan

I hope that all the organisations that read this newsletter, and the people associated with you are safe and have been able to navigate through these unprecedented times.

What a contrast this newsletter is compared to our March edition. Our much anticipated Pamper Day was hanging by a thread during the week prior to lockdown. Public Health was happy for us to continue, showing we were taking every precaution required at the time. However, unforeseen circumstances made the decision for us, which was a bit of a blow after all the work Janet and I had put in. I had just picked up stock from Boots to make up 55 goody bags too. Then to put the final nail in the coffin, Boris Johnson announced lockdown the night before it was due to be held. It's OK though, because we have everything in place to come back bigger and better as soon as we are able. In the meantime, my house smells nice with all the Boots items.

We spent the following week cancelling events, meetings, classes, guest speakers etc. It's surprising how much work is involved after building the group up.

Staying Connected

We consulted with our insurance company and found we were covered to run live group and Tai Chi classes on Zoom, which has allowed us to continue a limited programme and Tai Chi classes. It was a very slow start, as we had to navigate zoom and then assist members with joining us too. However, the average Zoom attendance of meetings over the past 5 weeks is only 9.6.

Our priority was to ensure our members were ok and to keep them connected. Finding that you are in isolation again is having a detrimental affect on individuals. We are getting feedback from members saying that their conditions have regressed back to how they were prior to accessing group. Some have no access to the Internet, or little knowledge or experience with technology.



We asked for members to volunteer to ring other members as an adaption to the buddy system, again the take up for members to talk to others was low.

We keep plugging away and slowly as each week passes, one or two more full members are asking to join the zoom sessions and one or two Facebook members are engaging and asking about the Tai Chi classes.



Group Programme

We have had cuppa and chat sessions, Sue from Open Minds, Qigong classes, Symptom of the Month covered pain and we could run the PowerPoint on the Zoom meeting. Sophie Lester joined us for a very enlightening nutrition class too.



We also thought this would be an ideal opportunity for Facebook members who were finding it difficult to physically attend group meetings to join us on Zoom, however, this has had the opposite effect. Facebook also went quiet and at any mention of Zoom and we got tumbleweed.

Group Zoom Meetings

Date	11am	12 0'clock
5 th May	Qigong	Symptom of the Month: Stress
12 th May	Fibromyalgia and CFS/ME Awareness Day: Sue Open Minds	
19 th May	Qigong	Guest Speaker: Rachel Bates
26 th May	Pacing	Show and tell

Our Facebook membership has risen to 458 members. We have posted positive affirmations, a couple of live activities, Corona Advice and Julie posted lots of spring photos from her mindfulness walks during her daily exercise.

Initially our page went very quiet, it is slowly building up again and we have found over the past week or so, one or two existing members who are normally in the background, have posted comments.

We have mainly been posting articles to keep up moral and mental wellbeing. This month we are concentrating on Fibromyalgia and CFS/ME.

Projects

Hobby Chat

Our members have been keeping themselves busy and posting their masterpieces on our sister page Hobby Chat, encouraging members to be creative and try new things. Here are just a few examples of their craft projects, baking recipes, gardening achievements and pastimes.















Space to Think

The 'Space to Think' project is on hold. With everything changing, we currently are not seeing the individuals that we were supporting. Awards for All have contacted us and assured us that we can remain flexible with the project and adapt to our needs when lockdown ends.

With this in mind, the committee have already met to discuss a strategy to integrate the members back to group, when we get given the go ahead. We are under no illusion that it will be the same, more likely it's going to be like starting the group all over again.

Cuppa at Cogs

Our once a month social meet has been temporarily renamed in homage to Janet's colourful and uplifting throw on her sofa. We have nick named it the Flamingo Club and we meet on Zoom on the First Wednesday of the month.

Walking to Awareness

With just one week to go, we knew that the distance would be shorter than last time; some of us have given it a good go. So far, we have walked: 358.01 miles.



Open Tai Chi Classes

We have been fortunate to receive a small pot of funding from Strictly No Falling: Age UK to help the classes keep running. Conditions are to contact all students that don't attend the zoom classes to make sure they are ok. The income from this will pay for Zoom. We are running all our Zoom classes for free during lockdown as we appreciate income may be tight for some and we want them to keep moving and stay connected.

The Monday 1.30pm advanced class is running as normal. We have a regular half dozen students attend. We have decided not to progress with learning new Yang steps for safety reasons, but we are working in more depth on Qigong, TCA part 1 & 2 and 2/3 of Yang 24.

The Monday 2.30pm class has moved to 3pm and we are working on TCA part 2. We have also been joined by some of our group members who don't want to lose what they have learned over the past couple of years.

Thursday evening classes had been cancelled up until 3 or 4 weeks prior to lockdown. We decided to run them at an earlier time during lockdown. However, we seem to have lost most of those students due to them being keyworkers or having to provide childcare. We decided to encourage our neighbours to join with us, to help relieve isolation and boredom, after the initial surge of interest we are now running two TCA 1 classes; at 11am and 1.30pm.

Tai Chi Open Classes

Date	Time	Class	
Zoom			
Jan 6 – Mar 23	13.30 – 14.30	Advanced	
Jan 6 – Mar 23	15.00 – 16.00	Sun Style TCA Part 2	
Zoom			
Alternate weeks	11.00 – 12.00	Fibro Active Members Only – Mixed Ability	
Zoom			
Feb 20 – May 1	11.00 – 12.00	Sun Style Beginner's	
Feb 20 - May 1	13.30 – 14.30	Sun Style Beginner's	

World Tai Chi Day

This is celebrated on the last Saturday of the April. The group gatherings have been moved to May 30th. We were still encouragement to get everyone practicing, so at 10am on Saturday 25th, we arranged a last-minute zoom class, which had a modest attendance.

Tai Chi in the Park

These free practice sessions will resume when it is safe to do so.

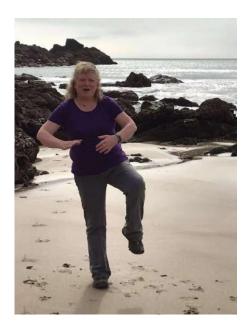
We thought we would add a featured Blog in our newsletter during lockdown. Please carry on reading. We hope you enjoy it!



Jane's Tai Chi Blog

How it all began

I joined this group called 'Fibro Active' in March 2016, just after I'd been diagnosed with fibromyalgia. If you are a believer in fate, it certainly looked planned! The first thing is that I have known Julie and her family for 'donkeys' years', but we'd lost touch a bit. I met Julie on the park a couple of weeks after being diagnosed and found out that not only did Julie have fibro and CFS, but she was launching a support group. I had to go along.



Within a few weeks some of our new members asked if we could learn Tai Chi, we'd all heard how it was beneficial to everyone's health, but especially so for certain groups, like us for instance, and others with mobility, balance, memory and anxiety issues. I was fairly non-committal at this stage; I'd tried tai chi many years previously and hated it. Julie couldn't find an instructor, so I put tai chi completely out of my thoughts.

Some months later, after seeing her physio, Chris Davenport, Julie announced that she had found an instructor, she'd told Chris that the group was wanting to try tai chi, but she couldn't find anyone anywhere to teach us – and guess what? Chris was a tai chi instructor! Not only that, but he was starting a beginner's class imminently.

My Challenge

When I joined Fibro Active, I made a pact with myself, it was to try anything that was offered, even if it was out of my comfort zone, so when Julie announced she'd found a class, much against my "better" judgement I agreed to give it a go. I'm so glad that I did, without being melodramatic; tai chi has changed my life!

Learning Tai Chi

My first experience of tai chi was with a very strict 'Master', there was no humour and no fun, it was all very serious and to a shy nervous person like me (yes, me) the experience was very daunting. I'd joined a class where everyone had been practicing for some-while and I was



completely out of my depth and left to 'just get on with it'. Chris' class was completely different, he was welcoming, friendly and he had a sense of humour. I can't say that I was completely relaxed at that first class, but I realised that in that hour I had thought of nothing other, than the move I was trying to learn; so, that was it, I was hooked!

Even though I knew I was going to keep learning tai chi, it didn't stop me feeling that I was the stupidest person in the group, I wasn't able to instantly recognise whether Chris was using his left or right arm or leg, so I got a bit panicky about this and of course people laughed, but it was all good natured and I wasn't the only one! My breakthrough came when I realised, I could recognise Chris' left hand and my left hand if we were both wearing watches! Chris was in serious trouble with me if he forgot to wear his watch!!

I still have trouble with this, I do know my left from right, but not when I'm copying someone who has their left hand or foot twisted over their right. I think something in my brain is not correctly wired!

As I learned more of the tai chi and had more of the form to practice, I could see the improvements in myself, I could relax into 'the zone' and forget all of my whittles, I recognised this feeling of being at peace with myself and



my body as the sort of meditative state that I had experienced for years when I was swimming, unfortunately I had been forced to give up my swimming as it was causing me quite serious sinus problems.

Swimming had been a big part of my life since I was about 4 years old and when I had to give it up I was lost, I tried other forms of exercise like cycling and running but I didn't find anything that could produce this feeling of just 'being' until I discovered tai chi.

There is a big heartfelt thanks here to Julie who persuaded me to give tai chi another go and to Chris who is such a kind, encouraging and patient instructor.



The Benefits of Tai Chi

- Pain relief and less stiffness
- Improved balance and less falls
- Uplifting of the spirit and greater relaxation
- Improved ability to do daily tasks
- Improved muscle strength and joints flexibility

Some things, like improved balance I haven't been aware of. As far as I was concerned my balance was ok before I started, but I do know that my posture has improved. I have seen these improvements in others and been told by some that tai chi has helped relieve pain and low mood. In some people I saw amazing changes with balance, mobility and stamina. I have seen enough in the four short years that I have been learning tai chi to convince me of its immense value.



The sad thing or is it? with tai chi is that it is not easy to learn, nor is not a quick fix. It seems in society today that we want everything now and science has persuaded us that modern medicine can cure everything with a pill. Those of us with fibromyalgia / CFS know particularly that this is not so. If we can be prepared to put in time and patience tai chi will reward us with improved physical and mental health.

Here comes the hard sell from the reformed tai chi practitioner!

It will take around 12 weeks to notice a difference in muscle strength, balance and stamina, although some notice changes along the way. It takes a lot longer, probably the rest of our lives to really start to understand tai chi and its principles. Tai Chi is a way of life; the many forms of 'Tai Chi Chuan' are a small part of this. Just 'playing' tai chi and devoting the time for this form of exercise will provide a workout for body and mind, it doesn't matter how good or bad you are at it, it still works. It can be done pretty much anywhere, doesn't need any specialist equipment, can be done by young and old, it can be practiced standing, sitting and some forms can be done lying in bed and for rehabilitation. It is especially good for keeping the mind active for those of us who are getting a bit older, remembering a longer form of tai chi



like the Yang 24 or Sun 73 takes dedication, patience and practice, practice, but it is worth every minute!

Every morning, I try to work through all the forms I know and spend a little time working on whatever I am presently learning, if I don't get the chance to do this I don't beat myself up about it, but I do miss it! My days flow better when I practice and somehow, life is more manageable. I know that if I had experienced this Covid-19 lockdown situation and all the stress and business worries that I'm now experiencing, before my tai chi, I would have been in a constant state of worry and panic. Ok, I'm not going to say that I don't ever get stressed and irritated, but I really am amazed at how calm and accepting I have become.

With this in mind, it saddens me that so many give up tai chi because it is too slow, or too difficult or they cannot remember the moves, but I accept that it is not for everybody.

With this blog, so far, I have tried to explain a bit about Tai Chi Chuan and how much it has added to my life, but it is getting a bit long, so I will finish now. I will write part 2 soon and explain how Julie, Chris and I brought tai chi to our Fibro Active group meetings, so watch out for our next newsletter and in the meantime have a look at our website.

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Positive Fibro Attitude