FibroActive

Six Monthly Report

Author: Julie Barker (Chairperson) & Tracey Peel (Secretary)

March 2017

INTRODUCTION

My name is Julie Barker and I am the founder and Chairperson of Fibro Active.

My experience includes:

From the age of 21 I was a member of the Scout Association for 18 years in various posts, with the latter years being the Activities Manager at Drum Hill County Scout Campsite, the County Archery Advisor and an Offsite Activities Manager at the 100th World Scout Jamboree in 2007.

Oct 2007, I also graduated with Hons after studying Events and Facilities Management and Service Sector Management.

Nov 2007, I was employed as the Volunteer and Mentor Manager at Sporting Futures where I gained Investing in Volunteers status and Mentoring and Befriending Association Approved Provider Standard and alongside recruiting and training volunteer coaches and mentors around Derby I also recruited 160 volunteers for the Derby 10K each year and planned the logistics within Pride Park Stadium. During this time, I became one of the first female boxing coaches in Derbyshire and I was a community coach in the evenings. I trained to train with Derby City Safeguarding team and bartered services with other organizations such as the Princes Trust.

May 2011, I was a Project Worker with Endeavour, supporting adult and young offenders. We used outdoor activities including hillwalking and kayaking as well as planning accredited courses as positive and empowering experiences for the attendees.

Oct 2013, I was employed part time by a local Volunteer Centre as the Community Transport Coordinator.

I was diagnosed with Fibromyalgia in 2013 and this led to 2 capability reviews and a medical in my last 2 jobs. After researching the illness, I identified that I first showed symptoms at 14 years old after a big virus infection, mumps, sinusitis and flu. My Dad had also got Fibromyalgia and after he passed away, the trauma put me into a 2 year flare.

IDEA TO LAUNCH

Julie found herself alone and isolated, her condition had severely flared up after Julie's dad who also had Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS), passed away in his sleep of a heart attack in December 2014 after years of taking ineffective prescription drugs, his organs packed up before he did.

Kevin Hatton from Active Erewash and a former colleague of Julie's asked if there was any support. Unfortunately, the illness has no cause or cure and sufferers are left isolated or referred to pain clinics in the hospitals which are too far away for many sufferers to attend. Kevin offered to help start a local support group.

We knew that there were many people in the local community that had FM and CFS about 1 in 20. We had the help of Well-being teams to put out the word through the health practitioner circles and ask for referrals to the group.

It was also identified that every sufferer had different symptoms and at different levels of severity. It would be difficult to put on a programme ensuring everyone could be included. Another thing to consider was that weekly attendance will fluctuate and due to the nature of the illness there could be only one or two so relying on weekly fees would not be an option at that time.

In December 2015 Julie ran a workshop to allow council staff and well-being teams to understand the basics of the illness and how it effects sufferers every day.

Kevin used his connections and Erewash CVS agreed to give us six weeks' free room hire to give the group time to initially establish and find funding. The Active Erewash team could offer further sessions and referrals to Wellbeing classes and gym membership.

The free room hire enabled us to book quality activities with Strictly No Falling and Village Games.

Launch Day

The launch brought 8 potential members on March 3rd 2016. Posters and information were displayed about the illness and our vision for the group. Potential members sat round and introduced themselves and gave ideas what they would like to do. Dates were set for group meetings at Erewash CVS to start from April 26th.

Facebook

A Facebook page was created at the start of the group to allow members to see updates and to advertise the group. A group page was created for members to be able to talk freely and securely while the open page was used for marketing. They were kept identical but members kept getting mixed up so the open page was deleted.

The group page is the central hub of the group. It keeps members updated about the programme and about all aspects of the illness. Positive affirmations are also posted. The members who are not able to make the meetings, feel connected and supported. Photos of the group doing activities at meetings encouraged FB group members to attend and feel familiar with the member's photos and activities we do. Rules are posted on the group page to keep everyone as positive as they can be. There are a few members that are not on Facebook and they are on an email list to receive the updated programmes.

For the first few months of the group opening we met weekly. We made up our own circuits and talked about designing logo's and leaflets and a folder to keep handouts in as members couldn't remember if they had received them.

With the professional and knowledgeable guidance of the staff at Erewash CVS we decided to make the big step and started planning an inaugural meeting. Our Chair identified that some members had their own specialism and skills such as school teachers, secretaries, accountants who due to the illness had been forced to give up work but who were keen to use their skills and feel useful again. She approached the members who she felt would be suitable to be on the committee.

Members also expressed a wish to try was Tai Chi. We approached Impact Physio in Long Eaton who run Tai Chi for Arthritis classes. Five members signed up and attended the taster session in late August of which 3 went on to attend the 12-week course.

Through our advertising, organisations have started to hear about us and are offering their services to support the group meetings. A programme was written for September hoping that the funding would arrive in time. Finally, we heard about the funding and with great thanks this is what it has allowed us to do…

SEPTEMBER 2016 ONWARDS…

In September with the help of the CVS we formalised the group. We managed to get the services of a graphic designer and friend of the chair offered to put our ideas on paper and designed our first leaflet.

Room Hire

Erewash CVS was booked for 12 months and back paid. Disappointingly the funding confirmation came just too late and the room has been booked by another group on the first Tuesday of the month so we have adapted the programme. Although we pay a little bit more, this venue has given the group a secure base with a professional and supportive team to guide us through all the processes. It is accessible and has a large hall to do activities, sit in workshops and a kitchen area where we can make refreshments. After the inaugural meeting, we became a member of the Erewash CVS which has entitled us to a discounted room hire.

Marketing

Leaflets were printed and circulated in the local surgeries, hospital pain clinics and on community notice boards. The electronic version of the leaflet and the group programme was circulated via email to key contacts who could bulk email direct to health services around Erewash.

The Chair purchased a display stand to share information on fibromyalgia and ME/CFS at community events. This was successfully used at the inaugural meeting and at the Erewash CVS information network meeting with plans to use it at local events including the Carnivals.

A monthly newsletter about our group appears in the Long Eaton Extra in the community pages.

We have registered with Fibromyalgia UK so our group is on a national list of support groups and we have received new members through this. The membership entitles the group to discounts including the monthly magazine.

We attend information events at Erewash CVS to help recruit new members and network with other organisations

Membership

When members attend the group sessions we ask them to fill in registration and consent forms (provided by Erewash County Council) and personal profile forms (created by our chair). This enabled them to be full members for life, as the illness is for life and this also provides us with individual information that we can use for monitoring purposes and apply for future funding. We currently have 60 members on our database and this continues to grow. This process of collating information for this 6 monthly report has allowed us to identify areas where we can improve and we are now in the process of refining these forms to make it easier to collect future data.

Growth was initially slow, after the launch which attracted only 8 people the subsequent meetings had on average 5 members a week and 20 members on our Facebook page. The council took on the job of informing GP surgeries that the group was up and running but uptake was slow. In June, we decided to use social media to spread the word. Placing small adds on Facebook in the ‘Spotted in’ pages for Long Eaton, Sandiacre, Breaston, and Sawley, and in the ‘Good Old Days’ pages for Sandiacre and

Long Eaton. Below in table A is the results of our campaigns to date and their impact on member numbers.

Ad Campaign	Month	Weekly average attending group sessions	Facebook membership	
			Before campaign	After campaign
Facebook	April – June 2016	6	20	65
Facebook & email campaign to publicise the inaugural meeting	July – Sept 2016 - coincided with our inaugural meeting.	4 (August hols)	65	94
Leaflets	Oct - Dec 2016 -	11	94	150
Facebook	Jan – Feb 2017 – coincided with the launch of our Ilkeston group	19	150	160

Fundraising

We have contacted the community grant schemes for Boots, Tesco and M&S asking to be considered for donations towards our fundraising efforts. Tesco donated items to our Christmas tombola.

The Long Eaton Rotary donated £150 to our group in November. This was used initially to open our bank account and will be used to buy a Boccia set for FibroActive.

We are now looking to target the local carnivals and fairs to jointly raise funding and spread awareness. We have applied to Mental Health First Aid England for £250 for marketing equipment (2 vinyl banners and 2 pop ups) to promote our brand at local events.

One of our members who is unable to make the weekly meetings is donating £5 a month out of her pension as she is so impressed with the group. We are looking at offering this option of payment to members as an alternative to bringing weekly subs.

From September on the advice of Erewash CVS we started charging £1 for meetings to help cover room hire and refreshments. This was increased to £2 in January 2017 to aid our journey to self-sustainability.

The Inaugural Meeting was on September 27th. The committee was voted in and we had record numbers of 23 members attend. Full members were given their folders (handbook) with basic group rules and information. A raffle was held to start the fundraising.

At the end of November, we ran a tombola stall at the Long Eaton Christmas Lights Switch on which was a success. We raised £123 on the night, increased awareness of our group and recruited some new members. We timetabled hourly slots to make manning the stall manageable for members struggling with these conditions. It was lovely to see the achievements within the group. One member who is normally very quiet found his inner market trader which was the most recognisable achievement of the event. A few others with high levels of anxiety found the confidence not only to attend but enjoy the event and that was all down to the trust and comradery of the group. We also had the opportunity to attend a similar event the following week unfortunately due to the impact of these illnesses we did not have enough members who had recovered sufficiently to run another stall.

Training

Committee

The committee members are fully briefed about their roles and have been issued with role descriptions so they are fully aware of their roles and responsibilities. We strive to deliver a quality programme and maintain consistency with in quality and standards we deliver. They were made aware that they are volunteers and can claim expenses as part of their role.

Mental Health Champions

We have 2 trained mental health champions at Long Eaton and a further two members from Ilkeston will be attending the course in March. We think it is good practice that we can support and sign post those members who also have mental health issues. However, we must be aware that there is a fine line between supporting individuals and the group turning into a mental health support group.

Adult Safeguarding

We are all at some point a vulnerable adult in the group. Some of us have worked with children and vulnerable adults so we know the importance of safeguarding. The Chairperson has already attended a Volunteer Managers meeting with the guest speaker being the head of adult safeguarding. Our aim is to put the committee members on the courses subject to availability.

First aid

We were approached early in the summer by a lady wanting to deliver first aid for Fibromyalgia as her daughter has it and she would like to help others but unfortunately, I couldn’t do anything until the September programme. To keep in line with our health and safety policy and subject to funding we will be ensuring selected members of the group will be up to date with their first aid subject to funding.

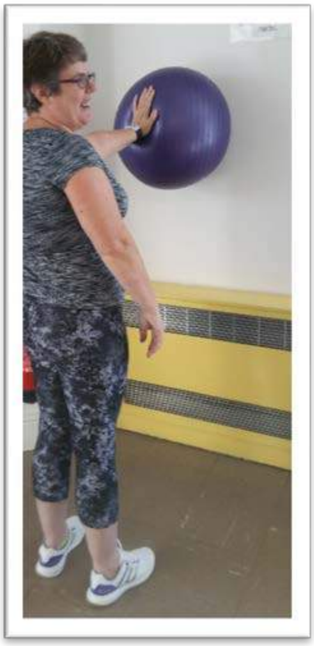
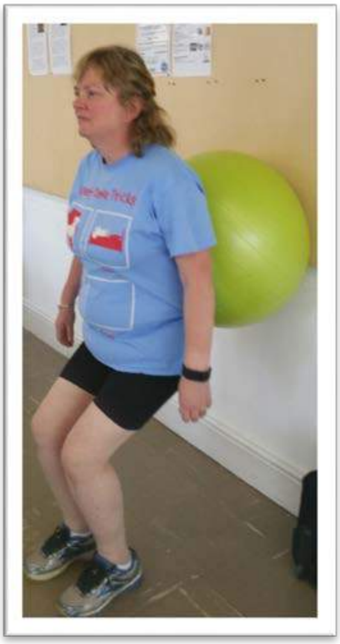
Food Safety

Our members like to bake. To enable us to branch out with cake sales and cooking sessions we are in the process of sourcing a Food Safety course.

Programme

The original idea was to run the programme as a 6-weekly block we have now changed this to planning two months at a time which gives us the time and flexibility to book outside agencies and guest speakers. This has been so successful that we are now booked until May with Relate and Arthritis Care.

Everything we do in the programme is carefully chosen to give direct and holistic support to all members. After spending time with members in the summer it was quickly identified that the symptoms of FM and CFS are for many exasperated by the trauma, stress and drama of their lives.


Most sufferers live with partners or family members that don’t understand the illness, a high percentage of our members report to have children who have been diagnosed with Asperger’s, Autism, ADHD and Dyslexia. The difficulties and stress of dealing with these family circumstances raise levels of anxiety which has a debilitating effect on their FM & ME/CFS. One or two have suffered brain injuries or accidents and have left them with CFS and or FM. Many members who walk through the doors report they are in denial and have little knowledge of either illness. To try and address the family issues that can arise form living with a long-term illness on the 22nd of September we held our first carer’s meeting at Friesland School. Disappointingly, only one carer turned out. We tried again in October after further advertising with a turn out four. Due to the health impact of organising and running additional sessions in the evening the committee decided to suspend these sessions until further notice.

We have been extremely lucky that the organisations who have supported us have been relevant and timely.

As our membership, has increased new members have expressed a wish to try Tai Chi. In November 2016, we negotiated with Impact Physio who have agreed to run a course at both Long Eaton and Ilkeston groups on alternate weeks. The cost will be £60 per person for 12-week course spread over the year with a maximum of 15 people at each session. We are hoping to find further funding for the costs which will amount to £1,800. Tai Chi for Arthritis is a gentle skill that members will learn the routine and we will be able to practice at the beginning of each session and at home as part of movement and meditation.

Mental Health Awareness and support

Alice from Relate attends once a month and has covered relevant issues such as acceptance and loss and family dynamics. More recent I have requested workshops to cover wellbeing and anxiety. She also attends on a drop-in basis if there is no workshop booked to offer 1-2-1 support.

As previously mentioned we have two mental health champions at Long Eaton and from this week (March 9th) we will also have two newly trained champions in Ilkeston. The Champions role is to inform the group of their role and support and sign post as and when required.

We have signposted all members to Talking Mental Health Derbyshire and Touchwood directly by giving out leaflets to the members and posting on the group Facebook page.

Supporting people living with long term conditions

We have been lucky to find Alyson from Arthritis Care. She has been able to run workshops from her own personal experience the difference between FM pain with RA pain. Her workshop in October enabled long term sufferers to learn something new. Alyson is delivering the ‘Living with Long Term Illness’ course once a month for 6 months starting March/April. This will benefit all members so they don’t have to travel the nearest city hospital to access it.

Alan Penn is the UK specialist for Irlen Syndrome, he has been to the group and delivered a presentation. The turnout for the presentation was over 20 members who all showed significant symptoms. Alan is also a member of the group. He suffers from ME/CFS and Irlen syndrome himself. Julie, our Chair, went through the assessment process with Alan and was diagnosed with severe Irlen. Since receiving her glasses she has the list of improvements she has reported have been life changing. Alan is creating a free bespoke self-assessment for FibroActive members to access. Because of Julie’s experience FibroActive are seeking funding to assess our group members and offer help towards purchasing bespoke tinted lenses. Alan is planning to use this partnership to undertake the largest case study into establishing if there is a link between ME/CFS, FM and Irlen’s syndrome.

Friendship and Socialising

Information below collected from the ‘Personal Profile’ forms from the first 30 full members on our database.

Do you go out?			
No	Yes	Occasionally	No data
3	10	7	8

Through our programme, we have aimed to increased independence and reduce social isolation. Once a month when the CVS is unavailable we encourage members to meet at alternative venues for social events, for example meals out, coffee mornings, crazy golf and short walks. Feedback from members is very positive (see ‘Quotes from member feedback) however data has been difficult to obtain and we are looking for way to improve our collection of these statistics.

Light Exercise

Information below collected from the 'Personal Profile' forms from the first 30 full members on our database.

Time sitting per day				
Varies	6-8 hours	8-10 hours	Most of the day	No data
5	5	3	3	12

Time for physical activity per day					
0-1 hour	1-2 hours	2-3 hours	3-4 hours	Varies	No data
7	6	1	2	1	7

During the better weather, we plan at least one walk a month. The walks are planned carefully ensuring there are adequate rest points, car parking, toilets and most importantly a good café. We don't go faster than the slowest member and we ensure all our walks are mobility scooters and wheelchair accessible. West Park is an ideal place as you can cut back at any point. The Nature reserve has less rest points and you are not able short cut back. However, those who want to stop at the Kingfisher hide can turn back and those who don't want to attend the walk can meet us in the café afterwards.

Fitness Circuits were popular when we were first setting up. The members enjoyed quiet noise free sessions where they could rest if needed and talk about issues while exercising.

Village Games were booked via Active Erewash to deliver Boccia. This has been a favourite in the group. Members have become quite competitive.

Gym Membership

Clifford’s Health Spa has become a group favourite. One or two of the group were already members of the gym and Clifford’s have recently built a swimming pool and spa. The water is warmer in the pool than at the local leisure centre, it is adult only and the steam rooms and sauna provide much relief. The fees are affordable and we have at least 7 full members now attending. Most members to go with a buddy from the group. It is not uncommon for us to have a Fibro session in the sauna or pool; Julie has been recognised by at least 3 Facebook members who have approached her asking if she is the ‘Fibro Lady!’ These chance encounters have led to one becoming a full group member and a second thinking about it.

To celebrate National Fibromyalgia Awareness Day on Friday May 12th we are teaming up with Impact Physio and block booking 4 x 45 minute Pilates taster sessions. This will allow 24 members to come and try it together under the safe guidance of a Pilates trained Physio Therapist for just £5 each. We are hoping to turn this into an advertising opportunity by inviting the local news to cover the event.

Healthy Lifestyle

We currently have 4/60 full members who are smokers, smoking up to 15 cigarettes a day. Through our links with Mandy Baker from ‘Live Life Better Derbyshire’ we have been able to offer these members a referral if they wish to stop smoking. Very few of our member’s drink alcohol. We have given members information sheets that show how certain foods and alcohol can trigger increased symptoms. We have had a positive response to this information. Also, regular articles about alcohol and fibromyalgia are posted on the Facebook page.

No of members	Alcohol consumption
43	Do not drink
8	Occasionally – (Christmas, birthdays etc.)
7	2 units to a bottle a week
2	10 -14 units a week

Many Fibro sufferers have some form of digestive issues whether it be IBS, gluten intolerance or yeast intolerance. Many of our member's report increase in weight due to the medications they are on, the lack of physical exercise they can achieve, poor sleep and heightened stress hormones. We are delivering the Live Life Better Derbyshire 12-week programme for weight loss inform members of recommended good practice. We have previously used the eat well plate to deliver nutrition advice along and members have had the opportunity to ride on the Active Erewash smoothie bike. Individual members inform us of the diets they are on and how well they are doing. From our 'Personal Profile' forms most members have recorded that they are eating a balanced diet. Out of those three members are on a LCHF diet and initial results are positive so we will be monitoring this diet closely to see how they do.

Crafts

Crafts can be very therapeutic to people suffering from a long term chronic illness. So far, we have had lots of fun creating the following:

Dream Catchers

Pumpkin Carving

Pumpkin carving was a challenge because of the impact on pain levels in hands, wrists, back and neck but we took it slowly and members worked to their ability. Suzi from LEAMAC who we met the Mental Health Training course agreed to come along and run the session, bringing special equipment and expertise. Everyone agreed it was a good session, they were proud of their achievements and when posted on Facebook they got a great response further boosting their self-esteem!

Christmas Wreath

Jane our Treasurer is a former florist. She agreed to run a craft workshop and supplied the materials for everyone to make a Christmas wreath. Everyone had a good time.

Future Craft projects include: We have secured some funding in collaboration with the Wash Arts project. Our Ilkeston group will create a piece to hang in the Erewash Museum in the first two weeks of March and Long Eaton will create a piece to hang in the Community Arts shop in Long Eaton on the last two weeks of the month.

Easter Crafts are popular and we are looking to deliver a craft session at each group.

Partnerships

Erewash CVS

Cats Paterson has fully supported the group from day one. She has helped the group with room hire prior to funding and steered us through the inaugural process. As members of Erewash CVS we have been involved with Volunteer Management meetings, information events and Mental Health Champions training that has allowed the group to identify opportunities and increase the quality and profile of the group.

Active Erewash

Kev Hatton has been a joint creator of the group and has used the team based in his office to initially create interest. They also enabled us to work with the ‘Well Being Team’ to access wellbeing classes and gym membership at West Park Leisure Centre. Kev also helped us write funding bids.

We are also in partnerships with the following organisations:

- Relate
- Impact Physio
- Weleda
- CAB
- Arthritis Care
- Wash Arts
- Alan Penn Irlen Specialist UK
- Healthwatch

Strictly No Falling Age UK Derby and Derbyshire

They run chair based exercises for people who sit for long periods or are chair bound.

Village Games

Provided equipment and ran fun sessions for the group.

Healthwatch

Healthwatch addressed the group and asked for feedback about the service members are receiving in the NHS. Both groups have given so much specific feedback that Healthwatch are going to submit the findings in the form of a report.

Ilkeston

In November 2016 through demand from our Facebook page we began a group meeting once a month in Ilkeston. There was a lot of anticipation for the Ilkeston group as the West Hallam Doctors Surgery were proactive and text the information to all their patients who suffers from FM and CFS. This intern lead to many calls being taken by interested people. However, due to the nature of the illnesses only 8 people turned out with 2 carers and 4 more of us were from Long Eaton to do a meet and greet. Heidi Wright came forward at Irlen's meeting to offer to run the Ilkeston group sessions after previously being approached by the Chair at the launch. From January 2017, the Ilkeston Group began weekly meetings following the same programme as the Long Eaton group but set out on different weeks to prevent a clash. The Chair writes the programme for both groups and the Secretary provides all the necessary paperwork and resources for Heidi to deliver the programme. This ensures we maintain the quality across both groups and ensures we maximise the use of our contacts. From the first week in February Ilkeston group move to a new home at the Weleda UK Ltd building in Ilkeston.

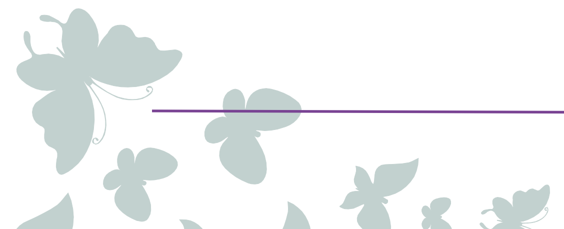
Future programme for 2017

2017 sees us working with the following organisations

- Relate
- Arthritis Care
- Art funding
- Live life better Derbyshire
- level 2 Thai Chi course
- CAB
- Chair based exercises
- Long Eaton Library Consultation
- Healthwatch Derbyshire
- Wash Arts project

The following opportunities are available to members to help support the group:

- Developing Volunteering Opportunities
- Becoming committee members
- To become a Mental Health Champion
- Fibro Welcoming Buddy encouraging established members to befriend Facebook members who require support to attend group.
- Fundraisers



Difficulties

As the summer holidays approached I was informed by Kevin that the Council could no longer support the group with manpower. The only sessions this would affect was the walking. Julie asked if the group could have at least a qualified walking leader as none of us were well enough to take responsibility while out on a walk.

The first week in December we held the second Ilkeston meeting. Twenty- four hours prior to the meeting Julie had 4 committee members attending with her but due to ill health and symptom flares everyone had to drop out at the last minute. Julie managed to persuade two Long Eaton members to attend with her but this situation is typical for these illnesses, sufferers want to attend but the illnesses take away their choices. The consequence of this is due to lack of support and the stress of having to reorganise everything on her own Julie's own health then suffered.

The group has grown quickly and the impact of the day to day running of the group impacts on the health of all those involved in running the group. Most don't have the experience in running a group. If they are too ill to attend meetings they don't come. If we are too ill we still must be there.

Solution: We have applied for funding to employ an assistant to support the background work and event work for the group. Sadly we were not successful.

Fundraising is a difficult one for the group. There are so many issues to consider. What can we do that the members can get involved in and can do without making themselves ill? Very little!

There are a lot of Facebook members who are not confident to attend group because of their anxieties. How do we help these members? I am setting up a volunteer buddy scheme that hopefully members who are well enough can befriend and visit isolated FB members and encourage them access the group.

We have some members with mental health issues who need additional support. We can sign post, however the attention needed initially for the person can be a strain on the group. We are also in danger of the group supporting mental health more so than FM and CFS. How have we addressed this? We have 2 mental health champions at each branch. If they attend a meeting where they are needed, we will ask them to take the member in need to another room and support them. Through our connections with Alice from Relate we have also been able to offer those members in need of support one to one sessions during group time when Alice is with us.

We have difficulties getting people to attend the group because it will have an impact on their benefits. We have one member who was refused ESA because she is attending the support group. When we do get the members through the door they are frightened to take part in gentle walks in fear of the DWP taking their benefits off them because they can walk further than 20 paces. We understand that the effort it takes to do a short gentle walk will impact on everyone involved and that it is all they will do that week but the DWP feel that if you have achieved it once you can do it again. If the impact is this great, why do we do it? Because so many of our members are house bound and only leave the house to attend our group. Giving them a chance to be outside trying a supported walk, even if only for a short time boosts their self-esteem, mental health and wellbeing. On one hand, we have the NHS trying to encourage sufferers to eat healthy, take part in gentle exercise and identify their limitations. On the other because we can bend over and touch our toes or cook a meal in the microwave we are told we are fit for work. Regardless of the consequences.

GP surgeries ask for information. I email it to them but they don't have patients email addresses. If GP surgeries asked for patient's email addresses they could bulk send information about specific support free and direct.

QUOTES FROM MEMBER FEEDBACK

Question posted on Facebook to all members

Before you found FibroActive what support did you wish for?

I just hoped to be able to talk to somebody who really understands.

Because I look really well and still find that frustrating I wanted to meet up with someone, anyone in the same shoes as me so that I know it wasn't all in my head.

I needed a local group that I could get to … plus it gets me out of the house to meet new people.

We don't have to waste time explain ourselves we can just be ourselves.

Christmas Party Feedback

It was great fun!

Fab fun!

What a great morning it went far too quickly thank you everyone for the lovely food and for the secret Santa.

Thank you for a lovely time everyone. Thanks also to Julie and Marian for organising the fun and games.

Thanks, everyone it was lovely to meet you all at last I had a wonderful time.

Thank you so much everyone today at fibro group. It was so helpful. I look forward to next week.

After a session with Alyson from 'Arthritis Care'

It was a really interesting meeting. I have had arthritis since the early 80's…. I have gone to meetings before but was only told what I already knew. So thank you Julie for organising it.

I'm looking forward to seeing my lovely fibro friends this morning and having a good catch up.

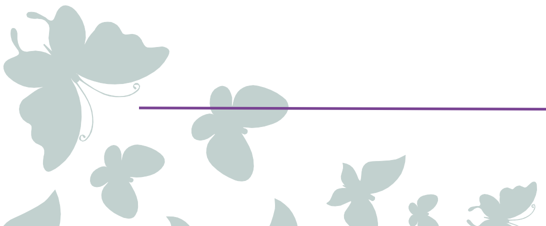
Its true, I'm so glad I finally was brave enough to go to the Long Eaton group and meet other people who are coping with chronic illness too. Thank you for making me so welcome.

After a session with Alice from 'Relate' discussing 'Acceptance and Loss'

Really enjoyed this morning…left on a high

Good. I love our group, its important that we feel that way when we come out of a meeting

A great meeting Julie
I really enjoyed this session. It was really helpful. It was a great meeting today. Its so nice we are all becoming friends and supporting each other.



Facebook discussion amongst members

Like some members, I am supporting via the Facebook pages. I can't always be where I want to be due to health and getting back to work but you're always important to me. I mean it Julie and I believe you know me well that I don't talk crap. This is a great group. You and the committee are all fantastic. Xx

I'd be lost without the group, I love it. Mx

What overall impact has the group had on your life?

Gets me out and meeting new people, helps with talking and sharing our stories, I enjoy going to the group finding out what everyone's been doing.

Offers more info on the fb page and links to new treatment options etc

It is good to keep in touch via Facebook and the one occasion when I did manage to join the group for a walk I enjoyed meeting other people with the same condition.

Not a lot apart from make me feel more isolated and as I can't afford. Luxury's Like gym bowling. Or dinner out for birthdays. Tia chi yoga wats the point in coming (Unfortunately this member feels aggrieved because we have raised our fees from £1 to £2 but we felt it important to include all feedback not just the positives)

How have you benefitted from attending FibroActive?

Changed my medication

I have learned much much more about this syndrome and I am convinced that I have had this for many years. Meeting each week has made me much more sociable and more confident in meeting people.

I feel more motivated and more confident

It gave me a purpose.

Uplifting meeting others who understand without explanation. Good to get advice from Relate and Arthritis Care. Meet new people, have a giggle, do crafts and light exercise.

Ilkeston feedback – this is a relatively new group who only began weekly meeting on 10th January

How did you feel before finding the group?

I felt alone and no one to talk and understand my condition.

Alone.

Confused didn't know much information about fibro because I was only newly diagnosed November 2016

Ok. Had found a lot of info for fibro on the internet but listening to others supported my findings.

How has the group helped you so far?

It's been lovely talking to likeminded people go out feeling elated.

Meet people with same condition.

I have gained more information and learned more about fibro and also about accessing occupational therapy to help with day to day living plus added info from Citizens advice.

Confirmed ailments i.e. others have experiences same symptoms.

Have you learnt anything about your condition since coming to the group? Is so what?

I have learnt to PACE myself a lot more and that we all have different strategies to cope.

Yes, that I'm not going mad and that my pains and feelings are understood, believed.

Confirmation that all my symptoms are normal for fibromyalgia and my memory or lack of it is not me going mad.

Only [that] others in the group have symptoms [that I've] not found on the internet.

Have you been signposted to other services from the group? If so what has been helpful?

Not at the moment but time will tell. Heidi has been a great and good leader.

OT, self-referral, other benefits yes very helpful.

Yes living with long term chronic illness programme plus learning I could access occupational therapy by self-referral.

Not yet have already researched other services before coming to group.