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INTRODUCTION

This first year has been quite a journey. We have formed a committee from scratch, we have created a holistic and relevant programme which is full to brimming until the New Year. We have raised awareness around Erewash advertising and fundraising. Our membership has grown beyond expectation and we have opened a 2nd group in Ilkeston and shortly an evening group will start in Long Eaton to support members unable to attend our day time meetings.

We are privileged to have on board a team of knowledgeable and supportive experts to support our members from educating long term illness strategies and emotional wellbeing to gentle exercise and nutrition. Not forgetting the behind the scenes support from partners such as Erewash CVS, Active Erewash, Public Health, Wellbeing and Erewash Borough Council.

I would like to present to you our First Anniversary Report. For this report, we opened up the following questions to the Facebook group compared to the six monthly report which was based on the full members only. This will not affect our results as there are different people attending group and the group continues to grow.

We have gathered information used on our Personal Profile from on line polls to open to all members. This includes Alcohol consumption, smoking, time sitting, physical exercise and socialising/ isolation.

We then opened a second questionnaire to the whole of the group about our services. I have averaged each score and pasted the comments.

There is a short description of each activity with photographs where possible.

Finally, a list of difficulties that we have found along the way and need to address.

MEMBERSHIP

We currently have **263** Facebook members and **77** full members of which **20** have attended one or more group meetings between March and the end of August.

Monthly attendance figures for the period of March to end of August 2017					
March April May June July Aug					Aug
49	51	72	60	72	57

Tracey and Kayleigh are supporting Heidi at the Ilkeston group as the group was slow to increase membership. However, over the summer the group has grown and has a regular 8



to 12 members attend each week. Unfortunately, from the beginning of May onwards the Long Eaton attendance has dropped. This has coincided with the Tai Chi starting and the increased activity of fundraising. I was hoping that the questionnaires would give feedback to the drop-in attendance, however, those who have dropped off have not filled in the questionnaire.

FACEBOOK

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. There are a number of Ilkeston members who do not use Facebook and they have been using another social media site to communicate. However, this could potentially isolate them from the rest of the group.

Questionnaire feedback

Are you a member of our Facebook group?	Yes: 12	No: 5	
Do you think the group page is positive and informative?	Average: 8.1		
Facebook page content:			
Do you take part in discussions?	Yes: 7	No: 3	
Do you join in the Wide Awake Club page?	Yes: 2	No: 10	
Does the Wide Awake page help you feel supported when you are unable to sleep?	Yes:	No: 1	
What improvements would you like to see on the Facebook group page? 1 reply: Less posts a day and more discussion.			

Internet Development

We have received funding to create a website that will enable members to log in and access information. We will also be changing the Facebook page to a business Facebook page, the current page will be deleted off Julie's personal page. The funding also includes 4 social media/ internet training sessions for members and we have been able to purchase two Lenovo tablets to enable each group to access our page and other online services during meetings.

GROUPS AND ROOM HIRE

Long Eaton

Erewash CVS have been a significant support to the group. We have benefited from being a member of the CVS and have attended the Volunteer Manager forums, training courses and Quality for Health Mark. We also attend Information Events which have been key for networking and awareness. We continue to top up the room hire from the funding pot due to the fluctuation in weekly attendance.

Ilkeston

Weleda UK Ltd hire the community hall to our Ilkeston group. The group has recently increased in size and Tracey our secretary and Kayleigh a committee member both attend the group on a long-term basis to support Heidi the Facilitator until support can be identified from within the group. We continue cover the room hire with attendance contributions.

Accessibility Average: 8.82

Comments:

The CVS building in LE is good, a little noisy sometimes but only because of inconsiderate people taking a shortcut through the main room.

Location Average: 8.70

Comments:

Good location and plenty of parking, tea and coffee facilities.

Bad parking at the Ilkeston Venue

Parking a nightmare at Ilkeston.

Group Developments

From Thursday October 5^{th,} there will be an evening group meeting at Broad Street Spiritualist Centre every 1st and 3rd Thursdays in the month from 7pm to 9pm. We have been approached by the centre as they have many members who have Fibromyalgia and many of which are already Facebook members of Fibro Active. We currently have about 14 members interested in initially attending. The programme will be slightly different from the day time sessions due to the availability of the partners. Room Hire will be paid direct from the weekly contributions at the centre and will not have an impact on the group's current bank balance.



PROGRAMME

From April 2017, the programme is full until the New Year. This has left little room for cancellations and changes. There is a lot to fit in and has had mixed reviews from the members. Some members are stating that a formal programme is best, others would like more time for a cuppa and a chat. It is challenging trying to find the right balance. We have emailed questionnaires out, we have uploaded them onto our Facebook page and we printed hard copies for members at the meetings to fill in. Just 17 members replied.

MENTAL HEALTH AWARENESS AND SUPPORT



Alice from Relate continues to be an asset to the programme. She has been able to secure 12 more months attending our sessions once a month starting in April and delivering a work shop or one to one. Alice has covered important topics including: Acceptance and Loss, Family Dynamics, Anxiety, Communication and Conflict management. Sadly, Alice's work is taking her elsewhere and we wait patiently for her replacement.



	Yes	No
Have you attended a workshop by Alice?	12	6
Did you enjoy the workshops?	8.61	
Are the workshops helpful to you?	8	
Are the workshops relevant?	8.09	

Comments:

Yes, I did enjoy Alice's workshops; she is very easy to listen to, very caring and approachable.

Yes, at the time, but I have a real problem remembering, I did get hand-outs but I also struggle to put paperwork in logical places. It's in a big pile in the corner of the kitchen. I have stuff that needs attending to but struggle to find the motivation to do it.

At the time the sessions are delivered, they seem very relevant and interesting but retention of information is a weakness of mine since developing fm, it is embarrassing and getting worse all the time.



Our mental Health Champions started off well and presented their new role to the group. Due to unforeseen circumstances one Mental Health Champion resigned her posts and left the group and the second has been unable to attend group sessions.

Two Ilkeston members attended a Mental Health Awareness course at Erewash CVS.

We have also signposted members to Talking Mental Health Derbyshire and Live Life Better Derbyshire. Sadly, Touchwood in Long Eaton has closed.

Have you been signposted to any Mental Health service?				
Yes No Did you take the What stopped Did the service opportunity? you? help?				
2	15	2		2

Did you know that our Mental Health Champion is available to chat privately and can signpost you to the relevant help?				
Yes 8 No 9				



Development

We need to update our Mental Health Policy. Due to their illness, champions are not able to attend every session. We need to look at how we can support this area.



We have a new member who has trained as a Mental Health Champion and we have got a committee member earmarked for the next MHFA course in November to support this role subject to health.

We also gained funding to purchase pop ups and banners from the mhfa to help with our fundraising and awareness strategy.



SUPPORTING PEOPLE LIVING WITH LONG TERM CONDITIONS



Alyson from Arthritis Care has been delivering the long-term conditions course. However, due to unforeseen circumstances, movements in our calendar and structural changes at Arthritis Care, the sessions have been cancelled and moved to the end of the course. This has lacked a consistent delivery for the members. On the other hand, we have identified that our programme is the practical living with long term conditions course and we plan to develop our programme further along the lines of the course.

	Yes	No
Have you attended workshops by Alyson?	13	4
Did you enjoy the workshops?	7.69	
Are the workshops helpful?	7.53	
Are the workshops relevant?	7	.69

Comments:

Yes, Alyson has real empathy and knows from experience the difficulties that are encountered with having both arthritis and fm. It is good to be with others who share an understanding of the conditions.

Very helpful as I have a degree in Osteoarthritis in my knees and lower back: knowledge gained about the condition doesn't take the discomfort away but understanding why I hurt validates my discomfort and helps me accept it.

Yes, I actively seek information about any condition that I have, understanding what I am dealing with is for me, one step towards mastering it knowing what I can do to improve things and knowing what I shouldn't do that might be detrimental.

0 scores: I have already attended this course elsewhere so it was a bit repetitive (not Alyson's fault and no reflection on her). It would have been relevant if I had not already been on it.



LIGHT EXERCISE

Time sitting per day				
Varies	4-6 hours	6-8 hours	8-10 hours	Most of the day
21	1	1	1	6

Time for physical activity per day					
0-1 hour 1-2 hours 2-3 hours 3-4 hours Varies					
2 9 1 0 16					

Tai Chi for Arthritis

reduction in attendance and at Ilkeston where members were very reserved about it being in the programme, we have seen increased attendance. However, some group members just watch and don't join in. We have been awarded the funding to run the Tai Chi course. Six sessions of Tai Chi have been delivered to Long Eaton and Ilkeston. There has been a vast improvement from day one. There have been mixed reactions to the classes. At Long Eaton where members asked for Tai Chi in the programme, we have seen a



Have you attended a Tai Chi for Arthritis class?	Yes: 12	No: 5
Did you enjoy the class?	8.6	9
Are the classes helpful to you?	8.38	
Are the classes relevant?	8.5	3

Comments:

Enjoyable but needs more training to help using it at home between sessions

Remembering the moves for the next session

Yes, I did enjoy the classes that I took part in, I would like to do more when able to.

Yes, the classes have been helpful, they have shown me that gentle exercise is of great benefit both physically and mentally. Just because I can't jog or run does not mean that I am unable to maintain my health. It's all about empowerment, mind over matter. I think I may not be able to do x, y or z but I can do Tai Chi.

Very enjoyable, it doesn't matter if you are not brilliant at it, Chris is very patient, easy to listen to and knows how to encourage you and put you at ease.

Illness and injury have prevented me from taking part in some sessions, I would welcome doing more in September and afterwards.

Wonderful class, I really enjoyed it. More please!

Yes, very good for balance +a brain/memory work out.

Future Developments

Jane Gordon (treasurer) and I are looking at training as instructors as soon as possible. We both meet course entry requirements. This will allow us to run classes at the evening meetings and continue beginner sessions allowing Chris to progress the improvers.



Due to lower than anticipated attendance over the past 6 classes we will be offering free classes leading up to Christmas to encourage as many members as possible to have a go without them having to choose between their health and buying Christmas presents.





Our gentle walks have been complimented by Helen Mitchem from Erewash Borough Council. She is a walking leader and has brought with her knowledge of nature to keep the walks interesting and lessening the impact of pain. We still need to work on the negative impressions surrounding the walks and encourage members to attend.

Have you attended a gentle walk?	Yes: 8	No: 9
Did you enjoy the walk?	9.5	
Are the walks helpful to you?	9.25	
Are the walks relevant?	9.37	

Comments:

I think it's good to get out and about and some people find this difficult on their own so I would say it is important to go in a group.

Like the walks not keen on the walk leader activities, would rather just walk and chat to members.

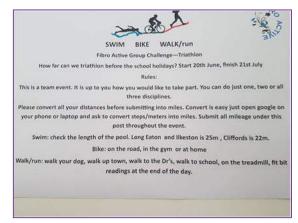
Facebook group challenges



New group challenges have been run on the group page to encourage all members to take part in the group light exercise programme and feel included. To start we challenged members to collectively take part in a walk/run Marathon. We calculated that 200 members only had to walk/run 289 steps to meet the target of 26 miles. A small number of members joined in and we beat the target in 2 days so we extended it to see how far we could get by May 12th, FM Awareness Day the total was 677.67 miles.



A second challenge was set to launch the Fibro Lites project and for the month leading up to the school holidays. Swim, Cycle and/or walk/run as far as we can. Four members got involved in the swimming with a total of 7.9 miles, one member cycled a total of 6.97 miles and a minimum of 11 members walked a total of 610.81. The totals showed that walking challenges are the preferred option. However, there is still a strong belief that members are unable to walk as it



causes more pain and that they will lose their benefits if they are found to be walking.

Have you joined in our group challenges?	Yes: 3	No: 14
Did you enjoy the class?	9	
Are the classes helpful to you?	8.66	
the classes relevant? 9		9

Comments:

Time and work commitments

Lack of interest

Would like to attend meetings to find out more first

Yes, a good idea however, I got a little left behind as I had more pressing matters to deal with when it was established. I always meant to join in once I got a pedometer or other device to measure steps but I failed miserably to join in. Sorry.

I haven't participated in any group challenges but I think they are nice idea.

Future Developments

Although only a small percentage of group members take part in the challenges, those that do really enjoy submitting their weekly totals and challenging themselves to do better. Most of these members are already active and work they have measuring devices such as Fitbits and phone apps to add up their mileage. We will be continuing with our challenges and hopefully encourage small groups to form to support each other as currently everyone is taking part individually.



Chair Based Exercise



Jo and Katie from Strictly No Falls attended the groups in the spring. Members have been sign posted to the existing groups in Erewash if they wish to take up chair based exercises.

Have you joined in a chair based exercise session?	Yes: 7	No: 10		
Did you enjoy the class?	9.42			
Are the classes helpful to you?	9.28			
Are the classes relevant?	9.20			
Comments:				



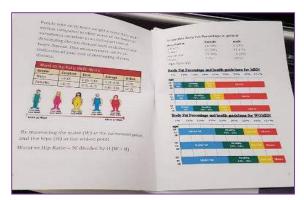
HEALTHY LIFESTYLE

No of members	Alcohol consumption
13	Do not drink
13	Occasionally – (Christmas, birthday etc)
3	2 units to a bottle a week
1	4 – 6 units a week
2	10 – 14 units a week
2	Other

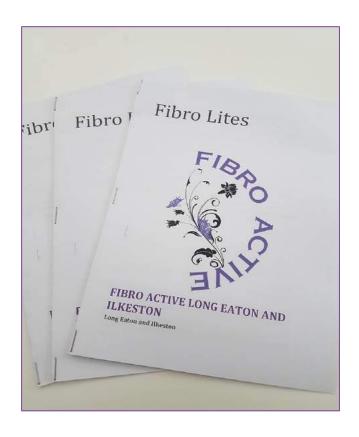
No of members	Do you smoke?
29	I do not smoke
0	Social Smoker
1	Up to 10 a day
1	11-20 a day
1	Other: vape

Mandy Baker from Live Life Better Derbyshire has visited the Ilkeston group to see if they are wanting any support with improving their lifestyle. She is keen to visit them again in the near future.

Fibro Lites









In June, we launched a project called Fibro Lites. We have been fortunate to have been approached by Amanda Letts who is in her final year studying a Masters in Nutrition Science and specialising in chronic illness. She has offered to volunteer and educate our members in a series of workshops looking at how some food causes inflammation and pain along with how the gut works, food and sleep and food and exercise. The aim of the project is to learn which foods help reduce pain levels, aid sleep and increase activity with the bonus of weight management. This is a self-help project where it is the individual's responsibility to find the right diet for them. In return Amanda is gaining valuable experience. Tracey our Secretary has designed a booklet and Amanda comes armed with informative handouts.

Have you attended a Fibro Lites workshop?	Yes: 13	No: 4
d you enjoy the class? 6.92		2
Are the classes helpful to you? 6.61		1
Are the classes relevant? 5.71		1

Comments:

Confusing information on handouts

Relevant – to some yes others no

Yes, I did enjoy the session that I attended. I missed the first one due to illness but was given the information that I missed afterwards. I am over weight but I am trying to address this issue so anything that will help keep me focussed on this aspect of my health, and positively reinforce my efforts has got to be beneficial to me.

Yes, the classes are helpful. I already attend Slimming World and have managed to lose almost a stone in the last 5 months. I still have a long way to go to reach my optimum BMI so anything that helps me keep on task is worthwhile.

I would like to say that the Fibro Lites input is very relevant as the added stress of carrying too much weight will exacerbate the painful symptoms of FM and other related conditions. I am not saying that losing weight will cure me but I recognise that a healthier weight will put less strain on my physical body, improve my self-esteem and thereby promote a healthier psychological well-being too.

Very interesting

Yes, I need to lose weight

Yes, group support helps with weight loss.



Findings so far

Ilkeston and Long Eaton group members need differ greatly in this project. We are trying to find a balance that is beneficial for everyone. As new members attend each group their needs and dynamics will change but we need to ensure everyone is offered this service.

As group Chairperson, I thought it best to lead by example and have lost nearly a stone in weight by cutting out foods that are causing inflammation and pain.

ART SESSIONS

Wash Arts gained funding to deliver a series of 4 sessions to the group. Two to Ilkeston and two to Long Eaton. Members created a number of hanging spring prints that were hung in the ReVive shop in Long Eaton. Wash Arts have gained further funding to deliver 10 sessions to the group. Sessions include charcoal, watercolours and mixed media.













Have you joined in a Wash Arts class?	Yes: 10	No: 7
Did you enjoy the class?	ou enjoy the class?	
Are the classes helpful to you?		5
Are the classes relevant?	8.7	

Comments:

Very relaxing and enjoyable, a distraction from aches and pains and satisfying to see the end results displayed.

Yes, I loved art at school but sadly have not found much time to participate in any as an adult. The two sessions awakened my sleeping creativity and I have done a few small paintings since.

Very, enjoyable, thank you/ It wasn't about creating a masterpiece but about having fun and appreciating the end results.

Cuppa and a Chat

Do you meet and socialise with friends? Café, theatre, pub etc?					
No	Occasionally	Once a month	Once a week	Daily	I'm a party animal
6	15	2	9	0	1



We try to fit a cuppa and a chat into the programme as often as we can. The programme has been so busy over the past 6 months that speakers have been squeezed into these slots.



Have you attended a Cuppa and a Chat session?	Yes: 14	No: 3
Did you enjoy the session?	u enjoy the session? 9.78	
Are the sessions helpful to you? 9.42		-2
Are the sessions relevant?	nt? 9.35	

Comments:

I love the cuppa and chat sessions. There are no expectations, just time to make friends, appreciate that you are not alone on this journey that at times seems very lonely and isolating.

An opportunity to gain further insight into the conditions and a forum to exchange hints and tips about coping mechanisms. Above all a valuable time to laugh among friends. It's all about making friends and building a support network around you, an opportunity to give and take as much or as little as you want from the group meetings.

Want more and only one event a day.

Having a good moan makes everyone feel better.

Sharing support, ideas is just lovely social session. Lifts spirits.

Developments

The Ilkeston group have requested that when Tai Chi is on the programme that they don't have a second speaker that day and that they would prefer a cuppa and a chat. This is something to look at when planning the 2018 programme but also being mindful of offering a holistic programme and reaching set targets.

Guest Speaker

Relexology

We get asked now and then if people can come and be a guest speaker. Lyndsay approached us at the Long Eaton Carnival and came along in August to talk about the great benefits of reflexology. She educated the group with an informative presentation and tempted a few with some taster sessions.







FUNDRAISING

Awareness Day



Fibromyalgia Awareness Day on May 12th was a success. Prior to the event we were featured in the Ilkeston Advertiser and Local Magazines. Long Eaton had a stall on the Old Market Place with a tombola and raised £80. This was better than expected as the weather was very wet. We gained new members and it was quite emotional for sufferers to come up to the stall and finally find support.

The Ilkeston group held an Awareness Stall at the Pavilion on Victoria Park. The bowls club laid on a few games and refreshments were available. Two of the Long Eaton group members attended to assist with the awareness stall. A new member joined on the day.





As part of the awareness on May 12th we booked 2 x 45 minute Pilates taster sessions at Impact Physio. The sessions catered for all abilities including raised beds for those who couldn't get on the floor. We all come out completely relaxed and with reduced pain levels. The instructor has offered us a similar format at group as the Tai Chi,

however the cost is £12 per person per session. Impact Physio gave participants personalised handouts and we featured on their Facebook page.



Long Eaton Carnival



On Saturday June 17^{th,} we stood an awareness/ fundraising stand. We raised £178.00. However, this was a lot of hard work for the return and with only 5 members turning up to help, it made us all ill and it took a long time to recover.



Ockbrook School



Our 3rd Fundraiser in 2017 on July 8th was at Ockbrook School. We raised £37.



Wilne 10K

We have been chosen as the community cause at this year's Wilne 10K on Sunday September 3rd. Following the success of last year's charity, I saw this as an opportunity to raise enough money to not worry about fundraising for a while and focus on getting the vital support we all need. We have had good exposure from the Wilne 10K campaign which has led to us increasing our membership by 40 members along with the Asda campaign. We held a tombola which we already had half the prizes and Boots donated 50 prizes to fill out the stall. Julie wrote out to local companies and gained 16 quality raffle prizes and group members and a Facebook campaign got everyone baking cakes for the cake stall. 13 runners have signed up to the race to raise money for us and we have a Just Giving page to aid the fundraising. Our target is £2000. We made £527.80 on the day and we still have 3 weeks on the Just Giving page which currently has £154 in. Runners will hopefully pay in.



Asda

From July 1st we have been on the community board at Asda and we have been doing a Facebook campaign to get everyone behind us and put the green tokens in our box. The winner after 3 months will receive £500 and the runners up will receive £200.





Have you helped with the fundraising events?	Yes: 7	No:10
Did you enjoy the event?	7.71	
Did helping make your condition worse?	Yes: 4	
Any ideas that would make it more manageable?	Coffee and Cake day	

Comments:

I helped out at the awareness day at Ilkeston outdoor bowling green on Victoria Park. It was nice to have a go even though it rained. The hot drinks and snacks were welcome and I think a new recruit for the Ilkeston group as welcomed from the event.



TRAINING

Adult Safeguarding

Three committee members attended an adult safeguarding course on July 13th and two attended on the 1st September. Unfortunately, one member was too ill to attend and we are expecting a £40 charge for non-attendance.

First aid

We were awarded funding from Erewash Borough Council to train originally 10 members. However, dates could not be synced between members and the training agency so we will have to do 2 separate sessions, this has led to only being able to train 7 members as the cost changes. Two members attended the course on August 4th and 5 members are booked for September 21st.

Food Safety

This has not been a priority. We have identified free courses at the adult education centre for the future.

QUALITY FOR HEALTH MARK

We are working towards the Quality for Health Mark foundation level. This is a quality assurance system that has been developed in partnership with Calderdale CCG. The deadline is December to submit our application. We are currently collating information to submit.

PARTNERSHIPS

Erewash CVS - guest speaker

Tracey and I were approached by Matt Allbones from the Derbyshire Mental Health Forum and asked to be a guest speaker at the Mental Health Peer Groups meeting at Erewash CVS. We put together a presentation of best practice in setting up a support group to give members a guide to how we did things.

UK Fibromyalgia

From the success of our 6 months report I was asked to write a series of 12 articles for the UK Fibromyalgia magazine on best practice in setting up a support group. Tracey Peel has

joint written some of the articles with article 6 being currently written. We aim to condense the articles into an e book at the end of the process.

Healthwatch

Healthwatch have submitted their findings from the new year in the form of a report to the health departments that they consider appropriate.

DIFFICULTIES

The group has grown beyond anyone's expectations and with the best will in the world and the best concept and strategies we are unable to support sufferers solely with sufferers when additional requirements are needed of us. As the group grows, the group needs increase. This is great news but we do not have the capacity to deliver it. I cannot ask anymore from the committee members and they are not in the position to give more. I am too close to burn out. We/ I need regular support, such as regular attendance at meetings, fundraising, meeting deadlines, having capacity to complete tasks, growth and developing projects and volunteer opportunities.

We desperately need a part time staff member with good health and experience, that can support the group and put the energy into the awareness, fundraising, feedback, report writing, developing policies, marketing and promotion, communication and ensuring all the groups have the write handouts and information, preparation support.

The Fibro Buddies volunteer scheme and the groups volunteer pathway is on hold because I/ we do not have the capacity to develop it.

Policies need updating prior to The Quality for Health Mark is submitted again there is no capacity to complete this.

The Website development is looking like it will be delayed because I/ we do not have the time to put the information together.

This is all on hold because we are having to prioritise fundraising to ensure we have enough in the pot to carry the group forward.

We still have the conflict of interest between the requirements of the DWP and the support of the NHS and Job Centre Plus. This is still having an effect on our walks but ironically the group challenges are supported and the questionnaire scored high.

Many GP's are still unaware of the group.

To leave you with positive thoughts I asked the group:



What impact has the group had on your life since you joined either the Facebook page and/or weekly meetings?

Not been able to attend meetings due to work commitments, hoping to join evening group in September. Following Facebook as has a lot of useful information and a very friendly group. Feel more supported knowing that there are other people in the same situation as me and understand the impact of fibro.

Helping to cope with the negatives, to try and focus on the positives and above all, the realisation that a fibro active friend is always not far away.

My heartfelt thanks for making me feel so welcome and for giving me a way out of the black hole I found myself in.

It has given us a place to meet likeminded people. A place to go and socialise, normally we would not mix and meet.

I know there are friendly, kind and knowledgeable people, who I can turn to for help, advice or just understanding.

It has given me the chance to meet people with similar problem Just nice mixing with Likeminded people More informed about fibro and the help that's available to anyone who needs it. The group sessions are very friendly and we always manage a good laugh at some point and they say laughter is the best medicine.

Very positive. I've gained so much more awareness of CF and how to get diagnosed, plus how to cope with everyday life.

The chance to meet others.

I get out a lot more and I'm not on my own.

Just nice mixing with Likeminded people.

It's good to know people who understand.

POSITIVE FIBRO ATTITUDE!

Weekly

get more

meetings, I

benefit from.

