



6th Anniversary Report

Part 2: Outcomes Achieved

Compiled and written by: Julie Barker Chairperson

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Introduction

Part 1 of our 6th Anniversary Review identifies how we meet our objectives. In part 2 we asked our members, students and Facebook members how they have benefited from group activities and services.

The group is member led; therefore, this is a quite in depth look at each activity to ensure members have their voices heard, ideas put forward and we have the correct level of support in place.

Following the review, we will highlight the difficulties we have had and are facing, followed by our future developments.

The Review

A general rule to go by is that there will only be between 10-15% of members who are pro-active at group meetings or on Facebook. With this in mind, we have attempted to target the key groups of members.

Full surveys were sent out to 26 members and former members of which 13 replied.

Facebook survey was put on the Facebook page with only 13 replies.

ActiveAte survey was sent to 20 out of 24 people who signed up to the programme. This was because some ActiveAte members were from other Fibromyalgia support groups. We only had 4 replies and this could be some full members had replied in the full survey under workshops.

The Lockdown survey was opened up to the Small Steps to Health Students who accessed zoom throughout Lockdown.

The questions and answers are in order of the Part 1 layout.

Members Baseline Measurements.

To establish the baseline measurements, we asked the members similar questions to those we asked members when the group first started. These are the results:

What type of Fibro Active Member ship do you have?	
Full member Purple Emperor	10
Occasional member Holly Blue	
Facebook member only	
Group and Facebook member	
Former member still connecting on Facebook	1
Group and Facebook member	
Former member	2
I am not a member	
Before joining weekly meetings, what was your knowledge of Fibromyalgia/ CFS/ME?	
I knew	4
Very Little	5
Moderate to get by	2
Very Knowledgeable	2
Before you found Fibro Active, what support did you wish for?	
<ul style="list-style-type: none"> • <i>More than just a leaflet</i> • <i>To become more knowledgeable about the condition, to share information and experiences. To give something back to the group in return for their support. To form new friendships. To be supportive of newcomers and those who were struggling to come to terms with their illness.</i> • <i>A lot as I only knew what the specialist had diagnosed and his team then covid hit no support really not even the Doctor</i> • <i>To meet others with the same diagnosis and to find out what I could do to improve my mobility and reduce dependency on aids, wheelchair etc.</i> • <i>More from doctor, hospital about where to get help and advice,</i> • <i>A way of getting out of the house, a place where there is no pressure.</i> • <i>Knowledge and empathy.</i> • <i>Somewhere that can help me understand my condition</i> • <i>To have support from people who were also going through the same things as me, who would understand exactly how I felt.</i> • <i>Gentle exercise group led by someone who understood the condition. Up-to-date medical info on how to improve condition. Frustration.</i> • <i>Any practical support, was beneficial, I just needed someone to talk to who knew what I was going through any extra help I found was a bonus</i> • <i>I just accepted what information I received from my doctor</i> 	
How did you feel before finding Fibro Active?	
<ul style="list-style-type: none"> • <i>Anxious, lots of pain and fatigue, just went from day to day</i> • <i>Absolutely worn out, exhausted, struggling with everyday activities.</i> 	

- *I was given this number by Team as I felt nothing was really given about sign posts and felt totally alone in chronic pain not knowing why I had this plus osteoarthritis, depression also flared up*
- *Devastated, confused, angry, lost and despondent. I had never felt so alone and my identity was gone.*
- *Abandoned by health service and couldn't afford to pay for resources like books.*
- *Isolated and lacking in confidence*
- *Desperate, sad, frightened, shell shocked, confused, all alone, worthless, bereft.*
- *Alone, especially as a male with Fibromyalgia*
- *Very isolated, alone with pain no one could understand*
- *Frustrated at not being able to get help. All the doctors offered were more pain killers and Amitriptyline, not that interested. A feeling of resignation, just put up with it.*
- *I felt so lost, and not receiving the practical support, I was so isolated and had severe anxiety and depression. I was trying everything to find the right support I needed*
- *Fine, just got on with it.*

Before joining Fibro Active, how long do you sit for on a typical day?

Varies	10
6-8 hours	
8-10 hours	
Most of the day	3
Other:	

Comments:

- *Energy levels are unpredictable, some days can do no more than sit it out, other days making the most of feeling more energised.*
- *I was unable to walk and I had severe muscle weakness. I went from bed to sofa. Whether I was having a good day or bad day.*

Before joining Fibro Active, did you go back to bed during the daytime on a typical day?

No	7
Yes, but only for an hour	3
Yes, for a couple of hours	2
Yes, for half the day	1
Yes, for most of the day	

Before joining Fibro Active, did you do any physical activities such as house chores, gardening, walking, gym, swim, any exercise class?

0-1hr	3
1-2hrs	6
2-3hrs	3
3-4hrs	
Varies	1

Before joining Fibro Active how much Alcohol did you drink?

Do not drink	3
Only on special occasions	6

2 units to a bottle a week	3
10-14 units a week	1
I am a heavy drinker	
Before joining Fibro Active did you smoke?	
I'm a non-smoker	10
I used to smoke but not any more	
I am a social smoker	2
I smoke up to 10 a day	
I smoke up to 20 a day	1
I smoke up to 30 a day	
I smoke up to 40 a day	
Before joining Fibro Active, did you meet and socialise with friends? EG at cafe, theatre, pub.	
No	4
Occasionally	6
Once a month	
Once a week	2
Daily	
I'm a party animal	
Skipped	1



Connect

Facebook

Does the Fibro Active Support group Facebook page make you feel safe and comfortable?	Yes 12	No	Other	Skipped
Are the posts on the Fibro Active Support page relevant to your needs?	Yes 12	No	Other	Skipped
What do you find most useful on the Fibro Active Support Group Facebook page? <ul style="list-style-type: none"> • <i>The links to reliable information</i> • <i>Links to the latest info about fibromyalgia. Motivational pictures, slogans etc.</i> • <i>To know others, face the same trials and tribulations as me but we are not alone</i> • <i>Survival tips and encouraging messages</i> • <i>Interesting Information and updates. Also feeling connected to the group</i> • <i>Information posts. Interaction between other people in group. Mindfulness posts.</i> • <i>Advice</i> • <i>Concise, well-produced and relevant charts, posters, posts Re: FM specific info easily comprehended and useful to share with family and friends who don't have the experience of FM.</i> • <i>The information and support</i> • <i>The general positivity: it's more about getting as full a life as possible by doing things that improve fibro symptoms.</i> • <i>Up to date class schedule, good news stories, photos and videos</i> <p>Skipped x 1</p>				
Is there anything that you would like to see posted on the Fibro Active Support page?	Yes 3	No 9	Other	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>I think you are doing a fantastic job</i> • <i>Continue doing the fine work u do</i> • <i>Not sure what yet x2</i> • <i>It would be good to have some resources for online classes/alternative classes to those that are by the group. I'm sure I'm not the only one that works (including the volunteers who run the group) but struggle to find fibro-friendly classes to do around my working hours.</i> 				

- *Links to published information*
- *Signposts to useful supplementary online help or apps (reviews might be useful too) i.e. Sleep app to learn good sleep hygiene or CFS online email course at Stamford Uni – I found both of these extremely useful.*
- *An extension of articles you have written previously for the magazine, perhaps invite practical tips from others on those subjects that works for them i.e. coping tools for fibro fog – I always love reading about the Fibro bloopers, really made my day and made me laugh and not feel alone but practical tips to combat symptoms can also be funny to read and interesting!*

What sort of member are you?

I am active and attend group sessions too:	5
I like to observe in the background	5
I like to ask questions	
I want to chat but too scared to	
Other (please specify):	4

Comments:

- *Often comment and have taken part in initiatives.*
- *I'm in Canada, so a bystander, but very interested in your content.*
- *I am shy and also the physical group reminds me of a good friend who we lost early in the pandemic due to cancer. Also, I have to still shirks because of other health conditions so the FB page is very useful.*
- *I dip in and out when I have the capacity but don't like to use Facebook to post but prefer to use messenger*

If you are unable to attend group meetings, please let us know why?

I live too far away	3
I am not well enough to travel	
I work	2
I am a parent	
I am too anxious in groups	1
Other (please specify):	

Comments

- *Work due to most groups being in the day*
- *Transport and health issues*
- *I have other commitments on the day they are held.*
- *I manage my symptoms with qigong and tai chi exercise classes that I teach. Having had Fibro for over 12 years I have a pretty good idea how to manage it currently*
- *Also, as above. Shy, brings up memories of a good friend, now lost, who I let down not coming to the group. Since the Pandemic started, I still have to shield even now and before then I didn't have the energy to attend the wonderful and varied meetings.*
- *Sometimes other things crop up or I'm unwell*

Skipped x 2

Have you visited our Website?	Yes
If yes what have you found useful to you on the website?	Yes

Comments:

- *Really simple to use*

- *Links to information that I can share with friends and family to try and encourage understanding*
- *Symptoms section*
- *Having so many good quality and trusted resources in one place*
- *Haven't done that....yet....*
- *Interesting self-help information*
- *Yes, very informative and easy to navigate*
- *Need to visit.*
- *All the information*
- *I didn't realise there was a website! Off to explore now.*
- *Symptoms Wheel*

Skipped x1

Would you be interested in accessing our group sessions of classes on Zoom?	Yes 6	No 4	Skipped 2
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Comments:

- *Already do*
- *I can't due to work commitments, but do have limited time as involved in a number of social, educational and informative zooms and workshops.*
- *This would be brilliant! I work from home so being able to do a class over my lunch hour without the addition of commuting would be excellent. Happy to pay as well. I've also mentioned the group to my GP & he asked for more details as he struggles to recommend things to his fibro patients and wants to do better. I'm sure online access would be helpful to so many!*

How has the Facebook page helped you since you joined the page?

- *Given me more information*
- *Helps me to keep in touch with members and the activities that are taking place.*
- *It helps me keep connected with other Fibromites which feels comforting*
- *More knowledge gained... knowledge = power*
- *Feel connected to a community*
- *Feel less alone and learnt so much about my condition and how we are all so different but the same makes us all connect on the same level ...fibro family xx*
- *Advice and support*
- *Information growth, enabled me to share info, can put forward questions, if necessary, good to read other people's experiences and tips. Non-intimidating. Able to 'attend/learn/participate' whilst still shielding.*
- *Understanding more about fibromyalgia and other underlying symptoms*
- *I've learned about my condition & found an online qigong class.*
- *Feeling less lonely, Professional and friendly and specialised advice*

Skipped x 2

We schedule 2 posts a day and if there is any relevant information that is posted as it is found. Do you find this to be ok?	Yes 13	No	Other
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Website

Which areas of the website have you accessed and what did you find helpful?

Comments:

- *Symptom's area*
- *All very helpful*
- *Symptom's checker*
- *Fibro facts*
- *SOTM. Group schedule.*
- *I've looked at all of the areas, but the symptoms page is the most helpful, especially when trying to explain to non-sufferers*
- *Symptoms Wheel*

Newsletters

**Do you read our bi-monthly newsletters?
If so, what do you find the most informative?**

Comments:

- *Yes, Group information, activities*
- *Good to catch up with events and information on the group and members.*
- *Yes. It's very well laid-out and informative, covering a variety of subject matters.*
- *No*

Skipped x 2

Signposting and Guest Speakers

Have you been able to access benefits through group signposting and advice?	Yes 2	No	
We offer to connect by Zoom on Mondays and Tuesdays, is there any specific reason you don't want to use Zoom?		1	
Comments: <ul style="list-style-type: none"> • <i>Depression</i> • <i>Monthly cost.</i> • <i>I prefer face-2-face</i> <i>Skipped x 1</i>			
Have you attended a workshop with a guest speaker? EG Citizens Advice, NHS, Erewash Borough Council, Alan Penn, Healthwatch etc	7	2	
Comments: <ul style="list-style-type: none"> • <i>Alan Penn most interesting. Never heard of the Irlen condition.</i> 			
Were the guest speakers helpful to you? Did you access the service and was it successful?	5	1	
Comments:			

- Working progress
- Have ordered Irlen glasses which I hope will improve Fibro and balance.
- Very informative and good to get our experiences out there.
- Not sure

Skipped x 2

Cuppa and Chat

Have you attended a Fibro Active cuppa and chat session either at group or cafe?	Yes 10	No 2	
Did you enjoy the Fibro Active Cuppa and Chat session?	Yes 10	No	Skipped 2
Comments: <ul style="list-style-type: none"> • So relaxed with lovely people. Great way for me to escape everyday life. Learnt so much about myself by talking to others • Good, friendly group. Conversation flowed on numerous topics. • I'm presuming it's the one that happens on a Tuesday during group, otherwise I haven't • They give members a chance to chat and get to know each other, sometimes a bit of guidance with topics is helpful, but they should be fun. 			
Do you meet with other group members outside of group meetings?	Yes 6	No 5	Skipped 1
Comments: <ul style="list-style-type: none"> • Not often • Only Dawn, as we go to the same art group for Mental Health in Ilkeston (Creative Arts Project) 			
How has meeting other members outside of group benefited you?			
Comments: <ul style="list-style-type: none"> • Friendship • Helped to make new friends • A more informal chance to chat about things in general • Listening to other people's experiences, mutual support, friendship. • Enjoy going on group walks. Easier to communicate • Friendship, camaraderie 			
Skipped x4			



Be Active

Boccia

Feedback from Boccia sessions

Facebook Comments

- *It was great fun. I'm not a competitive person until today*
- *Gutted I missed this hopefully play it again soon when I'm back x*
- *Never even heard of it but thoroughly enjoyed it*
- *Really good fun cheered me up no end today xx*
- *So funny 😂ooohhhhhh ahhhhh 😂*
- *We do look like we are really concentrating and had a fun time*
- *We have boccia at school, I love it.*

Tai Chi for Arthritis, Qigong, Otago

Tai Chi for Arthritis, Qigong, Otago	Yes	No	Skipped
Do you enjoy the class?	9	1	2
Comments:			
<ul style="list-style-type: none"> • <i>I have previously participated in tai chi classes and really enjoyed them. I also like Qigong. Both are very therapeutic for body and mind.</i> • <i>I can't clear my mind, no matter how much i try, but i do enjoy watching the others.</i> 			
Do you benefit from the class?	9		3
Comments:			
<ul style="list-style-type: none"> • <i>Not sure, need to try again</i> • <i>Relaxes me while watching others, even though the mind is still very active.</i> 			
Please tell us your experience of the classes, how do you benefit?			
Comments:			
<ul style="list-style-type: none"> • <i>Learning something new and helping with the aches and pains</i> • <i>Helps with stiffness of the body</i> • <i>Find difficult and tiring but enjoy them</i> • <i>Gives confidence and tips on how to make things easier e.g. getting up from chairs.</i> • <i>Knowing the need for exercise, these lessons helped to motivate and take an interest in health and mental well-being.</i> • <i>I really enjoyed coming to the classes, and am hoping to achieve a lot more thanks for all the support I have received</i> 			

- *It reduces my anxiety*

Skipped x 3

If you do not attend weekly classes either, please tell us why?

I'm not interested	
It's too expensive	2
I get too fatigued	2
I work	2
I'm a parent and have no child care	
I'd love to but classes are at the wrong time for me	
Skipped	5



Take Notice

Have you been on our weekly gentle walks?	Yes 10	No 2	Skipped
Did you enjoy the walk? What do you enjoy about the walk?	Yes 10	No 1	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>General chit chat with friends</i> • <i>Fresh air Friendly people Suited my pace</i> • <i>Fresh air and exercise always do me good and it's a good opportunity to connect with friends.</i> • <i>Able to walk at own pace without thinking you are holding the group up. Chatting to different people.</i> 			
Do you benefit from the walks? How do you benefit?	Yes 9	No 1	Skipped 2
Comments: <ul style="list-style-type: none"> • <i>Its exercise</i> • <i>Great way to get some exercise meet up with people for chat gets me out of house</i> • <i>Helps me to switch off and sort through my thoughts. Love to walk and take in the scenery.</i> • <i>Meeting others</i> • <i>Gradually able to walk further more easily.</i> • <i>Improved mental health, fitness and wellbeing</i> • <i>Walks causes problems in other areas, making it very uncomfortable. I feel it is better to be preventative than reactive</i> • <i>It's nice to talk to others</i> 			
Is there anything you don't like about the walks?	Yes	No 3	Skipped 5
Comments: <ul style="list-style-type: none"> • <i>Cold weather</i> • <i>The unreliability of the weather.</i> 			
If you don't attend the walks, please let us know why?	Yes	No	Skipped 7
I can't walk			
It's too much effort and it makes me worse			2
I work			
I live too far away			1
Other (please specify):			1
<i>It clashes with other support</i>			



Keep Learning

Symptom of the Month

Have you attended any of the Symptom of the Month workshops?	Yes 8	No 1	Skipped
Did you enjoy the SOTM workshops?	8		1
Comments: <ul style="list-style-type: none"> • <i>Find it easier than reading about it</i> • <i>Informative, bite-size pieces.</i> • <i>Empowering, knowing it's not just you, as well as comforting.</i> 			
Are the SOTM subjects beneficial to you?	8		1
Comments: <ul style="list-style-type: none"> • <i>Always something new to learn and to get a better understanding of the body and how it works.</i> • <i>Refresh's knowledge and discussion is beneficial</i> • <i>I'm learning a lot</i> • <i>They are interesting and the broader knowledge of overlapping symptoms has helped me understand health issues that have gone back for years. I realise it was linked to fibro and I was not the hypochondriac that some of my family told me I was.</i> 			
Have the SOTM workshops helped you to manage your symptoms?	Yes 7	No 1	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>In small beneficial ways x</i> • <i>I was already managing them, but they have confirmed that I was on the right track</i> 			
Is there any symptom or part of the illness that you would like to see on the programme that we have not already covered?	Yes 2	No 5	Skipped 2
Comments: <ul style="list-style-type: none"> • <i>Difficult to answer still a lot to learn</i> • <i>Fibro and age-related conditions as we age.</i> 			

Emotional Support: Open Minds

Have you attended any emotional workshops run by Sue from Open Minds?	Yes 10	No 1	
Did you enjoy the emotional support sessions run by Sue from Open Minds?	Yes 10	No	Don't Remember 1
Are the emotional support sessions helpful to you?	Yes 10	No 1	
Are the emotional support sessions relevant to you?	Yes 10	No 1	
Is there anything you would like Sue to cover that we haven't done so already?			
Comments: <ul style="list-style-type: none"> • <i>Coping skills to maintain good relationships with family and friends when struggling with your condition.</i> • <i>No current thoughts at the moment x 3, Sue has comprehensively covered everything.</i> • <i>I would say grief and loss of identity but I believe that's on the schedule soon.</i> 			
Skipped x 4			

Emotional Support: Think Hypno

Have you attended any of Sharrie from Think Hypno sessions?	Yes 7	No 3	Don't know 1
Did you enjoy Sharrie's sessions?	Yes 6	No 1	Don't remember 4
Are Sharrie's sessions helpful?	Yes 6	No 1	Can't remember 4
Are Sharrie's sessions relevant to you?	Yes 6	No 1	Don't know 4
Is there anything you would like Sharrie to cover that she has not already done?			
Comments: <ul style="list-style-type: none"> • <i>More on meditation and its benefits.</i> • <i>I don't think I've attended any yet</i> • <i>No, but difficult to answer the questions on Sharrie, having stated I haven't attended a session</i> • <i>I can't remember if I have attended any of her sessions</i> • <i>I think most of the topics have been covered</i> 			
Skipped x 3			

Emotional Support: Inspiritive Arts

Have you attended Marie from Inspiritive Art workshops?	Yes 11	No	
Did you enjoy the Inspiritive Arts workshops?	Yes 7	No 3	
Comments: <i>Sometimes</i>			
Are the Inspiritive Arts workshops helpful to you?	Yes 6	No 5	
Comments: <ul style="list-style-type: none"> <i>I haven't found the sessions helpful. Enjoyable, yes. No real purpose or direction provided.</i> <i>Disappointed, with little enjoyment. Poorly planned for Adults, Marie has little input once start instructions given. Limited materials available and those that are poor quality and worn out</i> <i>It's lovely to chat and try new things. A way to redirect thoughts and feelings</i> <i>I find these sessions very helpful as they help distract my mind and help me focus on something more positive the other sessions can be difficult for me but help me understand myself better and help with self-healing</i> <i>Sometimes it takes some working out what we need to be doing and a bit short on creative tools.</i> <i>I find the sessions with Marie really helpful, as it takes my mind off my anxiety and depressive disorder and keeps my brain working. I find keeping busy and doing practical activities really helps</i> <i>I find some of the activities a bit childish and the materials provided are a bit limited.</i> 			
Are the Inspiritive Arts workshops relevant?	Yes 8	No 3	
Comments: <ul style="list-style-type: none"> <i>Not to me</i> 			

Creative Arts

Have you attended any of the arts and crafts sessions? Pottery, painting, Christmas crafts, diamond painting etc	Yes 7	No 2	skipped
Do you enjoy the arts and crafts sessions?	Yes 6	No 1	skipped 1
Comments: <ul style="list-style-type: none"> <i>Love these</i> <i>Not very interested. Also, sitting for two hours tiring and painful.</i> 			
Are there any arts or crafts you would like to try?	Yes 2	No 3	Skipped 3
Comments: <ul style="list-style-type: none"> <i>Crochet</i> <i>Anything, don't mind</i> <i>Watercolours.</i> <i>I go with the flow, as learning a new craft can be just as beneficial as doing skills I already know.</i> 			



Give

Volunteering

Do you volunteer or have previously volunteered for Fibro Active?	Yes 5	No 3	
Are you enjoying or did you enjoy your experience volunteering for Fibro Active?	Yes 5	No 1	Skipped 2
Comments: <ul style="list-style-type: none"> • <i>Not done it but would be interested</i> • <i>Fun and fulfilling. Helped to raise awareness outside of the group and also did fundraising for the group.</i> 			
What does volunteering or did volunteering for Fibro Active mean to you?			
Comments: <ul style="list-style-type: none"> • <i>Being able what I can to help</i> • <i>Getting awareness about fibro out to people, more people understanding will make suffers feel heard and not alone</i> • <i>The group has so much to give to all members and it's vital to me that I can give something back, in return. Good feeling to know that I am helping and being of some use to members, fulfilling.</i> • <i>Giving support where I can to the committee and Fibro Active members. Volunteering has taken me out of my comfort zone and pushed me to do things I would normally shy away from. Having some free time, it is nice to offer help to other Fibromite's.</i> Skipped 2			
Do you/ did you get enough support in your role?	Yes 5	No 1	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>Support and guidance are available from other committee members.</i> 			
What support would you like to see as a Fibro Active volunteer? Training/supervision etc			
Comments: <ul style="list-style-type: none"> • <i>More training in anything that is relevant</i> • <i>Any training available. Also, I'd be interested in emotional support on the phone</i> • <i>I haven't volunteered for anything recently</i> • <i>Experienced volunteer could be paired with a trainee to help build skills and capabilities.</i> • <i>Training is offered when courses become available if one wants to attend.</i> Skipped x1			

If you don't already volunteer, what would attract you to become a volunteer for Fibro Active?

Comments:

- *Being a member, I was just asked*
- *Emotional support on the phone*
- *A role in support others*
- *Nothing. My experience at the Enables Centre has made me realise that volunteering wasn't for me, mainly because I can't commit to it and my mental health suffers when there is any pressure on me.*

Skipped x 3

Overall, please comment how volunteering at Fibro Active has impacted on your life?

Comments:

- *Fills in time as part of the group*
- *Very good, positive effect. Stimulating to thought processes. Increases desire to make more and more improvements and developments.*
- *It has given a purpose at a time when life is turned upside down with the diagnosis of a chronic condition. Meeting and making friends.*

Skipped x 3

Lockdown

During Lockdown, did you think Fibro Active were quick to adapt to the restrictions?	Yes 17	No	Not Sure 4
During Lockdown, were you able to access the support you needed from Fibro Active?	Yes 16	No 3	Skipped 1
<p>Comments:</p> <ul style="list-style-type: none"> • <i>Great team of people always a message away. Thank you for that support it was priceless</i> • <i>I wasn't part of the group at this time x3</i> • <i>Setting up Zoom was brilliant we could support one another and found it amusing at times especially in the beginning whilst we got used to zoom it was a life saver for me as I live alone.</i> • <i>The classes were a good support during lockdown. I think that would have been particularly helpful for people living alone. It was good to be able to check in with people, and also focus on the moves.</i> • <i>none</i> 			
Was the support Fibro Active offered during Lockdown relevant to your needs?	Yes 14	No	Not sure 5
Did you access any of the support sessions on Zoom during Lockdown?	Yes 13	No 6	
How did the Fibro Active zoom meetings help you during Lockdown?			
<p>Comments:</p> <ul style="list-style-type: none"> • <i>Broke the day up and something to focus on</i> • <i>Helped me feel part of something outside my 4 walls. Being able to see and talk to each other and support each other was amazing</i> • <i>Helped with the isolation, the anxiety</i> • <i>Considering we all have not experienced Zoom, it was a learning curve. It made me feel happy to see everybody on the screen and able to join in variety of topics, and how we felt or a general chit chat. It was lovely to be in contact with the group as we could not meet up at hall. To me as I live on my own, we could discuss how we felt which was a big thing for me as you can see the group made me laugh as well which we needed it was brilliant.</i> • <i>Kept the connection between members. Group could still offer as much support as constraints allowed.</i> • <i>I was shielding so it benefitted my mental health and enabled me to access support and exercise</i> • <i>Able to connect with people outside of my house in a way which made you feel less isolated</i> • <i>One of fun high spots of strange weeks.</i> • <i>Contact with friends which helped mental health. Exercise to keep mobile.</i> • <i>Stopped me feeling so isolated and lonely</i> • <i>The classes were a good support during lockdown. I think that would have been particularly helpful for people living alone. It was good to be able to check in with people, and also focus on the moves.</i> 			

- *The weekly sessions helped us to remember the moves which could have been easily forgotten. Also was good to keep in touch with the other class members and gave myself a good form of exercise during lockdown*
- *I wasn't a member 3*

Skipped x 3

If you didn't access the zoom sessions, can you tell us why?

I don't have the internet	1
I was anxious to use Zoom	1
I was a frontline worker	
I had a family at home	
I didn't feel the need to connect	2
Other (please specify):	1

Comments:

- *Wasn't a member x 2*

Did you have any other support networks that you were able to connect with during Lockdown?	Yes 10	No 8	Skipped 1
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If yes please comment below:

Comments:

- *Doctors not much help as it took too long to get through and it's hard to do an assessment on phone really against it prefer face to face*
- *Open minds*
- *Family*
- *Art Group, Creative Arts Group. However, I wasn't a member of Fibro Active when lockdown occurred.*
- *Yes, I received practical support through Mencap x 2*
- *Only support, we did not look for any other. Hard to comprehend what our mental health and physical health would have been without FibroActive.*
- *Frontline worker*
- *Husband and family/friends online*

Did you access the Tai Chi and gentle exercise sessions on Zoom during Lockdown?	Yes 13	No 7	
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Were the exercise sessions on Zoom easy to follow? Tell us about any difficulties you had.	Yes 11	No 4	Skipped 4
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Comments:

- *Only on the phone, screen too small*
- *Sometime zoom froze Also sometimes hard to follow as had to stand a long way from screen so could not hear very well or see otherwise still good to join in knowing you have completed the moves and also learning new ones, I thought it was great*
- *Obviously not as easy as face to face but most moves, I was familiar with that I could follow verbal prompts*
- *Didn't use them*
- *Wasn't a member when lockdown occurred*
- *Fairly easy, limitations due to screen size and seeing moves. The home was not the easiest place but was manageable.*

- *Was a bit different but could still get involved*

Could Fibro Active have done anything differently during Lockdown?	Yes	No	Skipped
	1	14	2

Comments:

- *I wasn't part of the group*
- *Because of Covid could not fault how we were supported by the Fibro Active well done to Julie and Jane*
- *Don't know.*
- *I think under the circumstances the program was quickly put in place. Messages frequent, with regular updates and patience in logging onto zoom.*
- *I think Fibro Active provided a lot of support during lockdown, even though I didn't need to access all of it. I think it would have been very helpful for people living alone.*
- *Nothing more that I could think of. They were there on Zoom and phone should we have needed to contact them to discuss any problems. Helped both physically and mentally*

Skipped x1

Projects



Which classes do you attend? If you attend more than one, please pop in the comments:			
Mon Yang			3
Mon BHQA			1
Tue TCA			5
Thu SSTH			4
Thu TCA			3
Comments: <ul style="list-style-type: none"> • I absolutely love it! Has greatly helped me both physically & mentally. • Enjoy & found helpful • Enjoyable class, good atmosphere, encouraging. 			
How did you find out about the classes?			
Notice board outside Petersham Hall			2
Facebook Spotted Sandiacre			1
Facebook			2
From a friend			6
Local Magazine			3
Talking to the course leader			1
Fibro Active			1
Neighbour			1
Do you enjoy the classes?	Yes 17	No	
Comments: <ul style="list-style-type: none"> • Yes, very much so • Very challenging but beneficial for me • It's the only form of exercise I do. • Love it! • I try very, very hard and I think I can do more now than when I started • Some exercises are challenging but are good for me. • I joined in November 2021 • Yes, very much • Would like to be less of a break between warm up and main session as I tend to seize up otherwise. 			
How do you benefit from attending the class/s?			
Comments: <ul style="list-style-type: none"> • Maintaining mobility • The exercise and concentration. Good for balance • Hope to improve balance & posture • Yes, has helped with back problem 			

- *Improved mental health. Feel it has helped my balance issue.*
- *Good exercise*
- *Strength and confidence, less anxious*
- *I get up from the chair better, feel fitter.*
- *Feel more relaxed*
- *It has made a difference in the neck exercises and has helped my backache*
- *Company, physical benefits, learning new skill*
- *Balance and exercise*
- *Flexibility, meeting people*
- *Increased fitness and well being*
- *For an older person it helps with mental and physical fitness without being too aggressive. Also helps with balance and stopping falling and concentration.*
- *Obvious benefits such as gentle exercise, building muscles, improving balance, calming effects, but also because I have committed to the classes it encourages me to leave the house at least once in the week as I would be letting people down if I didn't attend. It gives a certain amount of structure to the week too and because it is gentle exercise, I feel it is attainable even with my chronic fatigue syndrome (CFS) which gives a sense of achievement which is often lacking for me due to CFS.*
- *Enjoyment, satisfaction at learning to do the routine well! Learning grace!*

What motivates you to go to class each week?

Comments:

- *Look forward to learning*
- *Commitment*
- *Spending an hour in likeminded company. Aim to perform better each week.*
- *Improvement*
- *I have a balance problem and it helps me. The camaraderie and being with others. Jane has been fantastic, helping me 1-2-1.*
- *To keep my body fit, good company*
- *It is good to meet different people.*
- *To exercise and to keep fit*
- *Enjoyable, Flexibility, meeting people*
- *Learning something new, be in a class and meet new people*
- *The physical exercise and the friendliness of participants & instructors*
- *I attend with a friend so I wouldn't want to let her down or the instructors who take the time to put the classes on. I know it is good for my health, both physical and mental, to attend. Also, I can do some of the class seated if I need to and there is no judgement, so even if I know I won't be able to manage a full class I can still attend do as much as I feel able and not feel ashamed at not being able to manage. Very inclusive.*
- *Hoping I'm going to learn new techniques, an opportunity to ask questions.*

Skipped x2

Tell us about the class content, is it challenging enough?

It's too easy

Yes, it's just right

17

I'm finding it difficult (please tell us why)			
<p>Comments:</p> <ul style="list-style-type: none"> • <i>Sometimes challenging</i> • <i>For me yes.</i> • <i>Difficult to practice outside of class due to not being able to remember moves</i> • <i>Just right for me. Some weeks are more challenging than others but a lot of that is due to my CFS, either the fatigue or poor concentration levels. Always encouraged just to do the best you can, whatever level that puts you at that day and the main thing is to enjoy it.</i> 			
<p>Is there anything you would like to see in the classes that we don't currently offer?</p>			
<p>Comments:</p> <ul style="list-style-type: none"> • <i>No x16</i> • <i>I'm still practicing on current objectives</i> • <i>A variation in the warm up exercises, to maintain interest.</i> 			
<p>What do you enjoy the most about the classes?</p>			
<p>Comments:</p> <ul style="list-style-type: none"> • <i>Very nice friendly group</i> • <i>The exercise & social side</i> • <i>Social aspect and feeling relaxed and accomplished.</i> • <i>Learning the moves.</i> • <i>Both Jane & Julie are lovely and I love their gentle encouragements.</i> • <i>Camaraderie</i> • <i>Friendship</i> • <i>The different exercises.</i> • <i>Company, learning a new skill</i> • <i>Keeping fit</i> • <i>Doing the moves, learning new things</i> • <i>Increase in fitness and challenging myself to do it</i> • <i>The exercises, the achievement when a routine is remembered & carried out and the companionship</i> • <i>The exercise, a feeling of belonging, self-improvement, the classes are fun, non-judgemental. I feel I am doing something to challenge my CFS, gives me a little victory over it.</i> • <i>Actually, going through the routine and noticing my progress.</i> <p>Skipped x2</p>			
<p>Do you think that the classes are delivered to a professional standard?</p>	<table border="1"> <tr> <td data-bbox="1190 1644 1297 1715">Yes 17</td> <td data-bbox="1297 1644 1399 1715">No</td> </tr> </table>	Yes 17	No
Yes 17	No		
<p>Comments:</p> <ul style="list-style-type: none"> • <i>Absolutely!</i> • <i>Professional and taught with a laugh</i> • <i>Sometimes we stray off the track a little talking about other forms, but the instructors are both very dedicated, encouraging and patient.</i> 			
<p>Are the instructors friendly and approachable?</p>	<table border="1"> <tr> <td data-bbox="1190 1906 1297 1977">Yes 16</td> <td data-bbox="1297 1906 1399 1977">No</td> </tr> </table>	Yes 16	No
Yes 16	No		
<p>Comments:</p>			

- *Yes, putting the courses over very well with a lot of patience*
- *Non-judgemental. Always supportive when I have difficulties with some of finer aspects.*
- *Very Approachable*
- *Very much so*
- *Most definitely*
- *Very, they make the classes very enjoyable and never make you feel silly for asking questions or asking to go over something again cos you don't get it.*
- *Perhaps less theoretical explanation and more practice.*

Do you think your confidence has increased since starting classes?

Yes
13

No

Comments:

- *It's a working progress x 3*
- *A little bit*
- *Yes, and continues.*
- *Yes, my confidence has definitely increased and it's nice to feel a part of something. Living with a long-term illness can easily strip you of your confidence as you are not the person you were. The classes are a place to boost it again through both the physical improvements and the interactions with others.*
- *The principles reinforce other disciplines I have done – yoga, meditation, Pilates*

Is there anything that you would like to say about you, your experience and the classes?

Comments:

- *Jane and Julie are very sympathetic about my 'dodderyness'. They don't make it an issue. Jane is very good giving discrete support.*
- *Julie and Jane make you feel relaxed, their voices make you so relaxed.*
- *I have been doing the Tai Chi classes for over 3 years now and have enjoyed the experience of learning a form that helps both mentally and physically. I find it good for my age group & abilities and feel my coordination is slowly improving. Also helps calm the mind.*
- *Thank you. The classes are very welcoming, enjoyable and have benefits both for physical and mental health. I feel lucky to have them so close and accessible.*
- *I haven't found them particularly helpful with my arthritis – in fact, I often have a flare up after a class. Particularly in my neck and back. I didn't join the class for this reason anyway, so am prepared to tolerate it. I appreciate the trouble taken to put the handouts together!*



Have you accessed either 1-2-1 sessions or group sessions with Sue on the Space to Think project since January 2020?	Yes 5	No 6	Skipped 1
Were the sessions helpful to you?	Yes 5	No 6	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>A fantastic service. Sue helped a lot</i> • <i>These sessions have been immensely beneficial to me during times of isolation and when feeling overwhelmed</i> • <i>At the moment mental health is not my problem, but would seek help if required.</i> 			
If you haven't accessed a 1-2-1 on the Space to Think project, would you, if you felt you needed it?	Yes 6	No 2	Skipped 4
Is there anything more we can add to our Emotional Support services?	Yes 1	No 9	Skipped 1
Comments: <ul style="list-style-type: none"> • <i>Can't think of anything</i> • <i>We're living in a world as we've never known it before. I think we would all benefit on ways to stay calm in the face of what can be a very scary world.</i> • <i>There's contact and services on the group page, and everyone who attends are all supportive and understands what others are going through.</i> 			
Have you been referred to other Mental Health Services?	Yes 5	No 6	
Have you attended your appointments?	Yes 4	No 1	Skipped 4
Did the sessions help you?	Yes 3	No 1	Skipped 6



Have you attended any of the ActiveAte workshops?	Yes 4	No	
Did you enjoy the workshops?	Yes 3	No 1	
Comments: <ul style="list-style-type: none"> • <i>Lots of variety, nice to chat with other people</i> • <i>I thought I knew lots about healthy eating but I learnt a lot more!</i> • <i>Very formal and reminded me of being back in a class room or lecture theatre! Too long as well</i> • <i>Workshops are probably best kept in group programme time, using Zoom would help others from further afield to join in.</i> 			
Did the workshops support your diet choices?	Yes 4	No	
Comments: <ul style="list-style-type: none"> • <i>It was great to be able to ask about nutritional questions- quite detailed, or individual things. Really helpful.</i> • <i>I don't eat gluten or dairy but there were always alternative suggestions.</i> • <i>The information provided made it easier to make a choice suited to me.</i> 			
Please tell us how you were able to make changes to your diet and why you made them?			
<ul style="list-style-type: none"> • <i>Having support from Sophie and (?? Mind's gone blank!) was really helpful. I was also following slimming world.</i> • <i>The main thing was that I included more good fats like avocado and olive oil plus more oily fish.</i> • <i>I made small changes to eat healthier and cut out more sugar from my diet</i> • <i>I tried the fast 800, because of the covid pandemic.</i> 			
Was there anything we could have done differently?			
<ul style="list-style-type: none"> • <i>No, I thought it was all great.</i> • <i>The communication was not always great and a bit short notice.</i> • <i>Just to generally keep in touch more.</i> • <i>Class lengths shorter. I lost concentration</i> 			



FIBRO5 CHALLENGE

Have you joined in with this challenge in previous years?	Yes 5	No 5	Skipped 2
Did the challenge encourage you to do more steps?	Yes 5	No 4	Skipped 3
If you don't take part in the challenge, is there a specific reason why?	Yes	No 1	Skipped 5
Comments: <ul style="list-style-type: none"> • <i>Remembering to report steps</i> • <i>Have not got a counting device.</i> • <i>Have not got service to count steps</i> 			

Carers

As a carer, how did you feel when the person you care for was first diagnosed?			
Comments:			
<ul style="list-style-type: none"> <i>It was unsettling at an early age when Peter was diagnosed. I can remember we was stunned and booked a break away to clear our thoughts. As a wife or husband, you always care for that person and I know Peters family thought well you should do that anyway but it took his independence away from him and now my role was his carer. We have been strong with our support from our son and since joining group we have had the support of friends.</i> 			
As a carer, how did you feel before you found Fibro Active?			
Comments:			
<ul style="list-style-type: none"> <i>As a carer I felt alone with no support from Peters family and doctors. But now we are more aware of what help we have and can have from the group and its members.</i> 			
As a carer, do you feel you have a better understanding of the illness after attending Fibro Active?	Yes 1	No	Other
As a carer, how are you able to help the person you care for after attending Fibro Active?			
Comments:			
<ul style="list-style-type: none"> <i>A better understanding of the illness and how it effects the person suffering and the implications of the carer as well.</i> 			
As a carer, do you feel less isolated?			Yes
As a carer, do you feel less helpless?			Yes
As a carer, do you feel included at group session?			Yes
As a carer, what overall impact has Fibro Active had on your life and on the person, you care for life?			
Comments:			
<ul style="list-style-type: none"> <i>Fibro active has been a beacon for people like myself and Peter who like many in our group whose lives as well as careers have been affected by this awful illness.</i> 			
As a carer, do you enjoy the group sessions?	Yes 1	No	Other
As a carer, are the group sessions relevant to your needs?	Yes 1	No	Other
As a carer, is there anything in the programme that you would like to see that has not already been covered?	Yes	No 1	

Difficulties

The main difficulty that affects everything that we do is that we are volunteer, sufferer led and our members are sufferers who have accessed the group for support.

Due to the nature of our illnesses, some members barely have the capacity to function at group. They have difficulty concentrating to do tasks such as filling in forms and this will be the reason for low feedback from this review.

The free online survey creators are very limited and this had an effect on the limited replies. Julie sent out word document surveys by email. However, many members only have mobile phones and found it difficult to fill in.

Members who have taken the roll of membership secretary have found the roll demanding and it has triggered their symptoms and ultimately resigned. To reduce the workload, membership area was put onto the website and looked after by Julie. Moving the membership area online has divided members and students with few IT skills or no internet. We have offered to sit with individuals and take them through the process.

Prior to Lockdown we had built up a good number of volunteers that would help out at events. Post Lockdown we are starting again. Not necessarily with new members but with lower numbers and capabilities that restricts what we are able to do as a group, such as community events. It's not the manning of the stall, it's the organising, transport, setting up and most importantly - take down.

We have been forced to make the decision to reduce our projects and meetings outside of normal group activities because the Chairperson and Treasurer are unable to do everything. Although Facebook members are asking for alternate meetings, there is no one to run them and when we have previously put them on, no one has attended because they are tired from work or forget.

The same fear is still amongst some members that if they are able to walk or take part in events, that they will lose their benefits.

Members also fear trying to help as it puts pressure on them and increases fatigue and fibro fog. Due to low self-esteem, they fear, they will not be good enough to do simple tasks.

Members are asking to train as telephone support. However, Julie has not been able to put together a training package, due to other group priorities taking up so much time.

Training members can be difficult as their attendance at courses can be unpredictable, this means that Fibro Active could lose money, but more importantly training opportunities may not be offered in the future. Members may not have the confidence or capability to manage some of the courses, for example, First Aid.

Social Media

Members either have not got the knowledge, don't want the responsibility, haven't got the time or are not functioning well enough to help with social media. This again is time consuming and the chairperson has started to schedule weekly posts at the weekend to save time during the week.

Adapting to Lockdown

Learning to use Zoom and then supporting members to log on took patience. It was challenging and although we sent links to a step-by-step guide to getting on and also hard copies. This was too much for many members, especially those who struggled with their mental health.

Membership had to change as we couldn't run a drop-in service anymore due to a cap on numbers at the venue. Finding an affordable solution took planning and accepting by the members.

Some members who have not returned have found it difficult to cope with restrictions.

Projects

The Space to Think project had to be adapted due to the small size of the room it was run in. Also, Inspiritive Arts were working with arts materials. This was difficult for some members to follow on Zoom and many of them didn't have the materials.

The ActiveAte project was to be run by two external volunteers. However, leading up to the start of the project the organising created more work for Julie and Janet who was at the time the membership secretary. All the extra work, under pressure made both Julie and Janet ill and Janet ultimately resigned.

Julie and Jane split their time and Jane hosted the Wednesday night Zoom session and Julie the Saturday morning. However, when Julie and Jane's tai chi and qigong training started, they were not available to host and remind members when the workshops were on.

The volunteers used their own private zoom accounts so the workshops had two links and a break in between as the free zoom accounts could only do 40 minutes. It was suggested we put in a waiting room, so there was no wasted time waiting for people to join. However, members were being overlooked when they arrived late and got despondent.

One of the volunteers was struggling with her own mental health after a series of deaths of friends and family. This ultimately caused her to resign from the project. Which left one volunteer to run the project. The last 4 sessions were postponed until 2022.

Location

We are based in a location with a long-ingrained history of non-engagement. All of our members live in other locations and only 2 current students are from the estate. We are working with the Petersham Partnership Forum, working together to try to engage local residents.

Training

We are offering training; however, members forget to attend, they are not well enough or they are not available. It is difficult for members to commit.

Future Developments

Due to Lockdown, we have had to take a few steps back. Before we can move forward again, we have to go back to basics.

We are looking for more volunteers that are non-members who can help with the core running of the group. So that the members who are seeking support feel less pressured to help. Even though we make it very clear they do not have to.

We want to offer more training opportunities for volunteers and we have already started to do this. We have to be mindful of how many external training opportunities are not attended, because if people drop out at the last minute, we are not offered further training opportunities. We would like to Trademark our brand as we are being asked by other groups if they can use the Fibro 5 concept. This we need help with.

We would like to develop our newsletter into more of an online magazine but it would still include our group updates.

We would like to introduce podcasts.

We would like to create an interactive training course for health professionals, sufferers and carers / family members that can be accessed online, in their own time, informing them about how to manage the symptoms and understanding more about FM and CFS/ME.

We asked: *What impact has the group had on your life?*

Overall, what impact has the group had on your life which-ever way you access us?

- *It's been so helpful getting information and joining the group, making friends*
- *They make me feel welcome. Great group as it's a warm and friendly place*
- *I no longer feel alone and have learnt so much more about my condition*
- *I have more of an understanding of fibro, when I'm able going to group making new friends*
- *A good, positive impact.*
- *It's given me a support group, that I feel comfortable with.*
- *I was newly diagnosed and completely lost with nobody who understood. It was a lifeline when I found this group. It gave me hope and the incentive to fight for a better me* 💜
- *It's such a help to know that there is always someone there to ask for information, support, suggestions etc. etc!*
- *Hope, support, information, encouragement and community* 😊

Member Testimony

- I was diagnosed with Fibromyalgia in May 2018 by a hospital consultant after 6 months of scans and tests. I was told that as a result of an anaphylactic reaction I had had to intravenous antibiotics, 6 months previous, I now had this condition. Unfortunately, he then told me there was no cure and that they could only treat my pain. Initially I felt relieved that I knew what was wrong as I'd been told I was depressed up until that point, which I fervently denied.
- I was sent to a physiotherapist and to occupational health for support splints. The physiotherapist told me she couldn't help me but directed me to a tai chi class to try and strengthen my weakened muscles. I was in a wheelchair by then.
- That was when I found the Fibro Active group. It is no exaggeration that it changed my life. Instead of being dependant on tablets for pain, and sleep, there was an abundance of information for alternative ways to help myself. This group provides information about all aspects of this debilitating condition, including pain. I am able to access one-to-one sessions, for therapy as well as group meetings on zoom with fellow sufferers. Also, Qigong, Tai Chi and Otago for falls prevention. I am so much more active, less reliant on my wheelchair and have reduced my pain medication significantly. I would recommend anyone with a Fibromyalgia diagnosis seek this group out for advice and support in order to enable them to live a more proactive lifestyle.

Susan Irwin Monk

