

Gentle Exercise for Fibromyalgia Pilot Scheme

Funded by LED



Purpose of Pilot

Since the inception of the Social Prescribing service in 2021, we have noticed a steady rise in the number of people with a fibromyalgia diagnosis referred into our service. This has proved to be something of a conundrum for us due to the lack of groups and support available to signpost them toward. Any general 'exercise on prescription schemes' may not be specific to the varied manifestations of the condition and result in people giving up before they have had a chance to reap any benefits.

Additionally, there are currently no peer support type groups where people living with the condition are able to meet over a coffee and perhaps share coping tips and advice with others who understand.

Due to this, our service has been keen to acknowledge this cohort and offer a combined gentle exercise and peer support class. It is hoped that this may result in reduced physical symptoms and improved overall mental health and wellbeing. This type of pilot was chosen due to the proven benefits of exercise including increase in dopamine and endorphins, with peer support offering individuals a sense of belonging thereby reducing isolation and increasing self-esteem.

Collaborative Need

LED is an ideal collaborative partner due to its positive reputation in the local community and its ability to facilitate and offer specific fitness programmes to meet the needs of our chosen cohort. Our service's collaborative dialogue with LED has been established due to this initial collaboration and is something we are really keen to develop further in the future to help address health inequalities across our patient population.

Class Information

The pilot scheme will last for 6 weeks starting on 14th September 2023 and its last session on 19th October 2023. These classes will be held at The Hangar fitness centre Leisure Centre from 14.00 – 15.15 with fitness instructor Carole Clark facilitating. The sessions will consist of 45 mins exercise / stretching with an opportunity to chat over a cup of tea for a further 30 mins. Each session will be a bit different to see what mode of activity works best for different people.

We are looking at a class of 10 – 12 participants with perhaps a further three on a standby list. It is hoped that following the pilot, LED will be able to offer the class as an ongoing referral class at £4.50. To ensure capture of appropriate data to inform any future Fibromyalgia related support an initial and end survey will be distributed to the participants to complete and a mid-point contact will be facilitated to gain feedback. However, ongoing feedback will be encouraged throughout the pilot.

The only participant criteria will include a diagnosis of Fibromyalgia and ability to attend all six sessions (health permitting). To ensure any future Fibromyalgia support is inclusive, the cohort will include a range of ages.

Each participant will be issued a pack to ensure all necessary information is provided. The pack includes...

Course information

Photo/Social Media Consent Form/ Third Party

Pre & Post Pilot Survey

SP Leaflet

LED Leaflets

Pilot Cohort

Participant	DOB/ Age	Sex	Ethnicity	Consent for Photos	Participant Pack Sent
1	35	F	White British	Yes	Yes
2	38	F	White British	Yes	Yes
3	58	F	White British	Yes	Yes
4	60	F	White British	Yes	Yes
5	63	F	White British	Yes	Yes
6	78	F	White British	Yes	Yes
7	48	F	White British	Yes	Yes
8	49	F	White British	Yes	Yes
9	52	F	White British	Yes	Yes
10	54	F	White British	Yes	Yes
11	64	F	White British	Yes	Yes
12	76	F	White British	Yes	No
13	69	F	White British	Yes	Yes

Consent Form

September 2023

The Jurassic Coast Primary Care Network's vision for the future is to create a patient care system that includes everyone. A system where member practices work closely together and in collaboration with health and social care, voluntary sectors, community groups and local people to deliver efficient and timely personalised care. To make the best use of available resources to ensure that everyone gets the right support, in the right place, at the right time.

As part of the Jurassic Coast Primary Care Network's Social Prescribing Service, we are able to distinguish gaps within our community. As a service we have identified one in supporting those with Fibromyalgia and we hope this gentle exercise pilot scheme may be a step in the right direction in developing community support. This class is being funded by LED to take place at their new state of the art facility, The Hangar, Cloakham Drive, Axminster. Your data, including information on health and medication, may be shared with LED to ensure that the classes are safe for you and to demonstrate the impact of the funding.

We would like to publicise the pilot scheme on our Social Media channels which include Facebook and Instagram, to increase awareness of Fibromyalgia and the need for support in our community and hopefully encourage long term support. LED have also requested use of any photographs taken so they can similarly publicise them, further demonstrating the need for support. We would like to take photographs of the class and publish these on our social media and website.

Please can you sign the below form and bring it with you to your first session along with your initial survey, if you consent to your photograph being taken for purposes detailed above.

I consent / do not consent to The Jurassic Coast Primary Care Network's Social Prescribing Team taking my photograph or videos as part of the Gentle Exercise for Fibromyalgia Pilot Scheme to publish on their Social Media platforms and website and sharing them with LED so they can publicise also.

Name:

Signature:

Date:

Initial Survey

1) Have you ever participated in exercise when trying to ease your fibromyalgia symptoms?

2) How much do you feel your Fibromyalgia symptoms impact your daily life currently?

No Impact

Affects all elements.

1 2 3 4 5 6 7 8 9 10

3) Do you feel your symptoms stop you from doing things you would like to do?

Not at all

Stops me a lot.

1 2 3 4 5 6 7 8 9 10

4) How does your symptoms affect your mental wellbeing?

Not at all

Impacts a lot.

1 2 3 4 5 6 7 8 9 10

5) Do you think there is enough support available for those with Fibromyalgia? What support would you like to see in your area for individuals experiencing Fibromyalgia?

6) Are there any activities you have found which help in easing/managing symptoms or any that you would be interested at exploring?

End Survey

1) Have you enjoyed being a part of the Gentle Exercise for Fibromyalgia Pilot?

2) From participating in this pilot do you think your Fibromyalgia symptoms have eased?

No change

Eased Greatly

1 2 3 4 5 6 7 8 9 10

3) Do you feel being in a group with people also experiencing Fibromyalgia helped?

Not at all

Helped Greatly

1 2 3 4 5 6 7 8 9 10

4) From participating in this pilot do you think your mental wellbeing has improved?

Not at all

Improved greatly

1 2 3 4 5 6 7 8 9 10

5) Was there anything specific from participating in the Gentle Exercise for Fibromyalgia Scheme that you enjoyed or found beneficial?

6) Is there anything specific from participating in the Gentle Exercise for Fibromyalgia Scheme that could be improved for future classes?

7) Would you continue these classes if able to?

Data Capture

Please see collated data from questionnaires pre and post pilot. A cohort of twelve started the course.

Pre-Pilot – Responses 10/12

Do you think there is enough support available for those with Fibromyalgia? What support would you like to see in your area for individuals experiencing Fibromyalgia?

- more understanding
- No. Mental and financial support would be good.
- I don't think there is enough emotional support, it is all drug based which don't really work for me.
- this is the first time I have been offered support.
- gentle exercising, advice on healthy / easy meals, relaxation techniques.
- unsure as newly diagnosed, not sure of any support groups although I have found one on Facebook. Would like more knowledge regarding alternative / more holistic treatments / complimentary treatments.
- In 20 years there has been nothing offered. An understanding of the condition, its impact & fluctuation / not being immediately dismissed because of it. Support groups that are f2f and not online.
- No there isn't much support or understanding around fibro, doctors included. It affects your daily life & everything you do. For Lyme Regis it would be great to have access to car parks close by, often they are super busy, and I can't walk for too long.
- I feel supported by my friends and feel have a good relationship with my GP. In general, though, I think FM is a very misunderstood condition, and this leads to difficulties.
- I have never known or expected any support in my area. Probably it helps to know others are 'in the same boat' locally, but I am used to managing on my own.

Are there any activities you have found which help in easing/managing symptoms or any that you would be interested at exploring?

- walking
- anything that helps, use hot tub daily, walking.
- stretching which I do at home. I think relaxation techniques as stress 100% exacerbates my symptoms.
- Yes, I had Graded exercise Therapy some years ago for fibro & ME/CFS. Unfortunately, it did not help. Meditating helps me, it calms the brain / thoughts and can help manage pain in a mindful way. Yoga is also very good, as long as it is gentle.
- tried walking. Gentle stretching, relaxation / meditation.
- Yes, yoga & water exercise. Have had to give up yoga as cannot get on the floor anymore. Neither could I cope with heat in the swimming pool. I do seated / lying stretches. Warmth, hot tube, jacuzzi, walking.
- hydrotherapy
- I attend aquafit 3-4 times a week, I find it being low impact takes pressure off my joints and muscles. Would try mediation, mindfulness. Have found stretching / tai chi can help.
- Not with a group but do try to walk as much as possible. Arts & crafts help me with symptoms of FM / chronic fatigue, and also makes PTSD symptoms more manageable. Walking too can be beneficial as long as it is carefully paced.
- keeping active, especially mobile, by regular exercise - swimming three early mornings, and walking 2 other mornings per week. Gardening etc. Have considered Pilates but not sure it would help.

Additional comments

- I think this illness leaves people feeling very isolated and you're very much left to cope alone, and with it brings a lot of mental issues alongside the very long list of physical symptoms.
- wish family would understand more, it would help.
- day to day life is challenging. Now having osteoarthritis in spine / hips, and effects of menopause on top of FM. Days can be almost impossible to get through without high level of pain & fatigue. Unable to access any benefits, e.g., PIP & blue badge as no ongoing medical evidence or consultant. GP is not enough to support. FM still viewed by some as psychosomatic. You can look ok. Level of anxiety high and sleeplessness.
- I find the fatigue is really difficult to deal with
- I suffer with mixed connective tissue disease, fibro is only one of six conditions that I have, so I may feel a bit out of place in a fibro specific group. It is hard to distinguish one disease from the rest.
- Very excited and grateful to be starting this 6-week course! Thank you!

We asked a series of scaling questions with one being least and ten being most.

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Have you ever tried exercise to ease your fibro symptoms	Y		N	Y	Y	Y	Y	N	N		Y	N
How much do you feel fibro symptoms impact your daily life currently?	9		8	4	9	8	8	9	10		8	9
Do you feel your symptoms stop you doing things you would like to do	10		8	2	8	5	8	10	10		8	9
How do you feel your symptoms affect your mental wellbeing	8		6	1	9	9	9	10	10		8	9
Total Score	27	0	22	7	26	22	25	29	30	0	24	27

During the pilot, we received generally positive feedback with regards to the range of exercises they were exposed to, with some liking some more than others. There was overwhelming feedback regarding the high quality of the class and level of understanding of the condition demonstrated by instructor Carole Clark.

Post Pilot we set the participants another questionnaire. There had been some dropouts as the course progressed, with one feeling that the classes were not for her, two did not return after the first session and we were unable to contact for feedback. Please see feedback from questions below

Post Pilot - responses 7 / 12

Have you enjoyed being part of the pilot scheme?

- Absolutely, it has been so nice to meet people in the same position as you and you don't have to explain why you need to sit down, or why you have limited ability or energy.
- Yes, I am only sorry that I was too unwell to attend some of the sessions.
- Yes, it's been a good mix of exercises and nice to meet and chat with others.
- Yes 100%
- Yes. Has been really good to be part of a group where people understand.

- Yes, really enjoyed it and being with other people that understand.

Was there anything specific from the scheme that you enjoyed or found beneficial?

- Company, talking with people, being with others who understand.
- Guide exercise, graded and paced alongside others experiencing same issues.
- chatting to women/making friends has been hugely important as I tend to be a bit isolated. Also, I have conquered my fear of gyms / gym equipment!
- I loved the first session, the circuit, I have bought a wellness ball for home, and I repeat these exercises. I also had so much with the dance class, it me feel 'normal' again, having a boogie about and laughing at ourselves.
- Yes, the neck and arm exercises were really good. Being part of a group with similar symptoms, preferred exercise to gym session.
- I found it fun and motivating. Enjoyed trying new workouts / exercises, meeting new people too. Being part of a group - greater accountability to attend.
- Sometimes she turned up even though she had vertigo, really enjoyed the dance-based class. Enjoyed the gym more than I expected. I would now feel comfortable to attend a gym and discuss my FM and an exercise plan with staff.

Anything that could be improved for future classes?

- It is a real shame that attendance dropped towards the end. I do feel the mental health aspects of FM are never addressed. Physicality is only part of it. I would like to be part of a talking sharing group, to support mentally as it is a massive part of the illness.
- Maybe longer sessions with an assistant to help trainer to ensure proper form for the exercises to avoid injuries. For fibro maybe target exercise to: Pilates, stretches, tai chi and talk on nutrition.
- Not that comes to mind, each class was a great variety and gradually got more difficult as the weeks went on. This was perfect as you were encouraged to always go at your own pace - which us fibro people don't always do, and then have a flair up.
- Would have been nice to have 5 minutes so they could all talk through their symptoms beforehand.

Would you continue these classes if able to?

- Yes, if transport allowed
- Yes! Very good to have this scheme in our area of Lyme Regis, good to also meet people experiencing same health condition.
- Absolutely! I would them after work, 17:30 onwards so I can attend without booking an afternoon off work.
- Yes, but Thursdays are difficult.
- Would do it again 100%
- Would do it again, struggled at times but felt very grateful that something was being done to help people with fibro.

Additional comments?

- Diagnosed 20 years ago with FM. First time I have been offered anything! I have found out about pain clinic and hydro pool. FM is dismissed usually, a hidden disability, but none the less real, with a massive physical and mental impact. There should be more support readily available.
- I never look forward to exercising because of fibro and seeing people can be draining, but these ladies and Carole were amazing!
- Thank you so much for this opportunity! Although my symptoms are pretty much the same, I do feel less isolated and have met a couple of very lovely women.
- Would be really interested in future initiatives and / or coffee mornings.

- Pleased I was asked to participate. Variety of exercises given, and trainer made them all enjoyable.
- Previously I wouldn't have considered exercise a priority, given that I can only do so much each day, but now I would. Thank you for doing this. ck.

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12
Have you enjoyed being part of the pilot?	Y		y	y	y			y			y	y
From participating in this pilot do you think your fibro symptoms have eased?	7		1	7	2			2			2	5
Do you feel being in a group with people also experiencing fibro helped?	10		8	7	8			10			10	7
Following the pilot has your mental wellbeing improved?	9		6	5	1			7			5	7
Would you continue these classes if able to?	y		y	y	y			y			y	y
Total Score	26	0	15	19	19	0	0	19	0	0	17	19

Conclusion

This project has been an absolute joy to collaborate on. Thank you LED for your enthusiasm and expertise. We hope this will be the beginning of ongoing collaborative projects and initiatives.

Drawing on the data above, it is clear that people with a fibro diagnosis do not feel well supported in either a healthcare or community setting. There is a general feeling that post diagnosis they are offered medication and 'left to get on with it.' Participants mentioned anecdotally that they would rather self-manage with a minimum of medication where possible.

About half of the participants had tried exercise or some form of movement previously to relieve symptoms. Interestingly, the majority of these activities were solitary, rather than class or group based. Participants reported a lack of confidence to take part in a normal group exercise class with concerns about what others would think and general lack of understanding of the condition. Referring to feedback post-course, there was an overwhelming feeling that it had been a positive experience to be in a group of people with similar symptoms, which removed the feeling of having to 'explain' why they have to sit down or can't always attend. This gave them the chance to feel 'normal' and reap the benefits of group work.

About 40% of respondents reported at least an incremental improvement in physical symptoms, but it should be noted that the pilot scheme was relatively short, and most participants missed at least one session. However, 100% reported a marked improvement in mental wellbeing and a feeling of support and camaraderie gained from the group environment.

The Peer support part of the group allowed participants to have a cup of tea, catch their breath and chat with other participants. 100% felt that this part of the session was really valuable with more than one feeling it was at least as important as the physical exercise. Moving forward it would be vital that any offering incorporates this element.

The pilot scheme provided just a small sample of the many people in the locality who suffer with Fibromyalgia and chronic pain conditions. We received an overwhelming response to our invite to the pilot scheme and there were many people who did not make it onto the short list. Even within this small group it became apparent that these conditions are highly individual. The wider array of activity types that can be offered the more people within this cohort will be able to take part. This will lead to enhanced wellbeing as people supported and connected within their community reducing the need for meds and health interventions.

All the participants who completed the pilot said that they would take part again as long as the days and times suited, and they were able to get there. They would also be interested to hear about any other initiatives run by either LED or Jurassic Coast PCN.


In September and October 2023 we ran a pilot scheme, in collaboration with LED Leisure. The sessions consisted of 5x 45 mins exercise / stretching with an opportunity to chat over a cup of tea afterwards.

Each session was a bit different to see what mode of activity works best for different people.

Participants: 12
 Responses before: 10
 Responses after: 7



Target Audience:
 Patients with
 Fibromyalgia



Location:
 LED: The Hangar,
 Axminster



Before



After



“

“Chatting to women/making friends has been hugely important as I tend to be a bit isolated. Also I have conquered my fear of gyms / gym equipment!”

“Previously I wouldn't have considered exercise a priority, given that I can only do so much each day, but now I would. Thank you for doing this.”

“each class was a great variety and gradually got more difficult as the weeks went on. This was perfect as you were encouraged to always go at your own pace - which us fibro people don't always do”

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“I loved the first session, the circuit, I have bought a wellness ball for home and I repeat these exercises. I also had so much with the dance class, it made me feel 'normal' again, having a boogie about and laughing at ourselves.”

“It has been so nice to meet people in the same position as you and you don't have to explain why you need to sit down, or why you have limited ability or energy.”

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