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Stories of change

MOVING FORWARD WITH FIBROMYALGIA IN GREATER GLASGOW AND CLYDE

This pilot service developed a Tai Chi group and education as a treatment for fibromyalgia.



What we did

Our initial programme started 15 years ago and was hospital-based. We offered hydrotherapy classes and education sessions. We couldn't meet the demand for hydrotherapy as so many patients were being referred, so we changed to low-level group-based exercise classes. We've evolved it onto Tai Chi sessions, where people can sit or stand. In addition, there is group pain management and education. We teach stretches and talk about pacing. This combination seems to be the most successful. We try and offer a stepping-stone into community activities. We did not accept direct GP referrals because demand is so high. We got funding from a single health and social care partnership to run a pilot scheme in local leisure centres. This covered a part-time assistant practitioner, some admin and leadership support to change the outpatient services.

Our motivation

Treating fibromyalgia is challenging, and in some areas, there is no patient pathway. People seeking help sometimes report they are not believed by professionals. Some areas are remote, and people struggle to access healthcare. We used a hydrotherapy pool for chronic pain, but the need was so great, I knew we had to investigate different models for pain management.

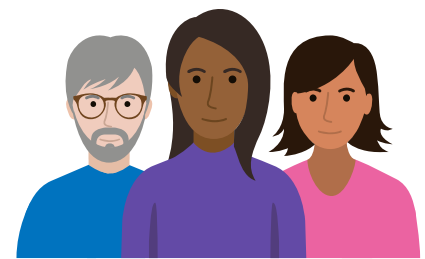


The difference we are making

Evaluation showed patients like the groups. Every so often I will get a letter or a card from a patient that says this has completely changed their life. Completion rates are always going to be variable. Those living with more severe symptoms did not do as well as those with moderate symptoms.

What's next?

A year from now, I would like to have organised a pilot project where we can support expert patients who are interested in becoming role models for others to take the programme forwards.





Making change happen

I feel so sorry that these people don't get the help they need. I've heard so many times from various professionals through my career 'Oh, we don't do fibromyalgia' and you wonder what is going to happen for them then? Pain is pain. These people have really difficult symptoms to cope with. We've come to the conclusion that we shouldn't call it fibromyalgia in our area. Maybe just pain or chronic fatigue. The stigma is still there.

Early intervention is crucial, so we must find more ways to support people as early on their journey as possible. Timing is also key. If people get help when they are at their most ready, they can make great progress and have a life changing experience from the help they receive. 'Living Life to the Full' is a helpful Cognitive Behavioural Therapy resource, and we also give out the Versus Arthritis leaflets to people.

More needs to be set up outside of the NHS, so patients are helped in places they can keep on attending. This helps them feel that their best coping strategies lie in their community.

Getting better from fibromyalgia is like a game of Snakes and Ladders. If we can get you off the bottom line, then that's progress. But life will continue to be full of ups and downs. We can't undo ten years of pain in a few sessions in a clinic. Accepting little bits of progress is what we should focus on. Being able to say 'What do we want to be able to achieve here?' would be a good way to look at it, rather than setting goals that will fail both patients and professionals. Staff want to get job satisfaction and you don't always get that with fibromyalgia. That needs to be acknowledged too.

Most people with fibromyalgia are unfortunately still not able to access this service. So much more needs to be done to help people living with this condition.

**VERSUS
ARTHRITIS**

"If life was just one big hydrotherapy pool that would be great, but it isn't."

Top tips

- Support services are best set up in the community rather than in healthcare settings.
- Find ways to work on the negativity from some professions and help reduce the stigma by re-framing what is possible for people living with fibromyalgia.
- Sharing peer-to-peer experiences does help.

"I found speaking to others on the course helped, as I didn't feel it was just me complaining. I was not alone in how it affected people." Participant



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