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Stories of change

A POWER SHIFT AT PAIN CLINICS IN BRISTOL

We figured out a protocol for changing the ending of group clinics, so there would be long-lasting peer support without clinical input.

What we did

We realised that that the 'professionals know best' model wasn't working too well for many people. About ten years ago, we began training volunteers who had been participants at previous clinics, to co-deliver the training. This helped, but people needed longer term support and social groups to help them maintain their progress. One group helped us change our protocol, so a social network is now built by every group. This means group support carries on beyond the clinical input in a way that suits people's needs.



Our motivation

When people come to our pain service, they have been living with pain for an average of 8 or 9 years. They have struggled in their relationships with healthcare professionals who are unable to cure the core problem. Living with pain can be incredibly isolating. In healthcare, we don't address the social dimension of recovery. Not well enough anyway. People attending pain clinics often don't get good long-term outcomes.

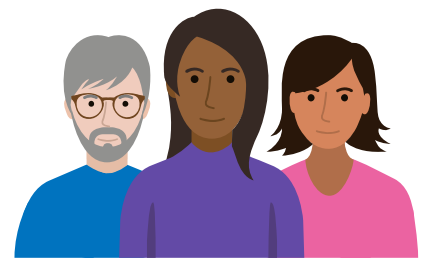


The difference we are making

Introducing patient tutors portrayed empowerment. Over 30 have since trained and worked alongside the professional staff. The idea of whole groups maintaining their own meetings flowed from this. Qualitative findings suggest patients have fewer setbacks. We have seen how groups gather around to support individuals when they need it. When additional professional support is required, individuals are much clearer about what specific help they need because they already have that social support around them. That reduces demand on our services.

What's next?

We have already partnered with a team in Southampton and another in Glasgow to help spread this approach. We'd also like to be able to gather more evidence about its impact both for individuals with chronic pain and for the healthcare system that supports them.





Making change happen

Ten years ago, we were running therapy courses for the effects of chronic pain in which the health professionals led everything. Two types of courses matched different levels of need and we ran in varying locations. We believed it was an accessible, flexible, effective set-up. We appreciated that course participants learned as much from each other as they did from the professionals and we nurtured this. We began a new model where people who had completed the programme trained as co-tutors, to act as a role model for how much can be achieved in the treatment programme. But we still underestimated their eventual impact.

When a course ended, many felt that they could get a great deal more from further support. There was a particular event at the end of one course when the participants directly challenged me. ***"This is not fair. You're gonna drop us, but we still need help. We've all found this useful. What are you going to do about this?"*** I put it back to them, that they figured out how best to move this forward and I agreed to support them. They found a venue and started meeting regularly, and there wasn't much more to it than that. I met with them 6 months later and they were really well organised. They had continued to follow the treatment method for tackling their areas of difficulty. They drew confidence from being able to solve problems and make progress without professional input. They learned from each other. They made it sociable, more pleasurable than attending a treatment course and they supported each other when anyone had a difficult spell.

I asked for help to figure out how we could encourage others to do what they had done. Eventually, I mean several years later, we had a protocol that changes the end of our groups. A volunteer visits to describe how to set up. There's a video and information. The therapists withdraw without closing the group. Since then, numerous groups have kept going. We give guidance but most groups organise themselves in a way that suits them. This is jaw-dropping because we are not used to seeing these kinds of long-term successes. I've noticed that our NHS follow-up meetings were not being led by me anymore. I'm a guest whose role is to try to catch up with what they've been doing. If this catches on it could make a huge difference for people living with pain.

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"People living with pain can build their own unique social dimension for recovery and recuperation from something that's incapacitating. If you look at it on paper it looks small and subtle, but it's radically different."

Top tips

- You'll be amazed by the impact of involving patients in your service delivery. It's the single biggest potential revolution in the care of long-term conditions.
- You have to figure out the local way which you can do it and be realistic, so what you start doesn't just fizzle out.
- Don't be frightened to give it a go, you're not going to lose anything from trying.



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