

Airing Pain Programme 55: More power to you

Prescriptions for yoga and harnessing the power of social interaction.

In episode 55 we hear about two very different ways of giving people in pain the knowledge and power to help themselves.

Will we soon be able to get a prescription of yoga on the NHS? Christine Johnson speaks to yoga teacher Anna Semlyen about a study that shows yoga can be an effective and cost-effective treatment for chronic low back pain. Semlyen, who helped design the programme used by the research trial, recalls how she has seen people get back into gardening or extreme sports after taking up yoga. The research study found a similar effect among the group of patients using yoga: reduced levels of disability and fewer days off work compared to the control group. Not only is this a low-tech and cheap treatment, but it's also empowering, argues Semlyen, as it lets people 'be their own healers'.

'How are you?' are three little words often dreaded by people in pain. Gareth Parsons explains to Paul Evans why these simple social rituals can be so difficult for people in pain and how social interactions can instead be made empowering. Parsons' work on participatory action research gets people in pain together to recognise the negative attitudes or oppression experienced in daily life and find ways to help themselves. The real experts on pain are not the clinicians or researchers, but the people who live with it every day, he argues.

Paul Evans: Hello and welcome to **Airing Pain**, a programme brought to you by Pain Concern, a UK-based charity working to help, support and inform people living with pain and healthcare professionals. This edition's been funded by a grant from the Scottish Government. Today, I'll be looking at two research studies on the management of chronic pain, the outcomes of which, if accepted and adopted by the NHS [National Health Service], would not only improve the quality of our lives, but save money.

Anna Semlyen has been involved in teaching backcare yoga for around 18 years. She was involved in a randomised control trial by the University of York with funding by Arthritis Research UK into the effectiveness of yoga as a treatment for chronic and recurring low-back pain. Over 300 adults were recruited from 39 GP practices across England. They were randomly divided into two groups: one assigned to the Yoga for Healthy Lower Backs 12-week course developed for this trial; the other, to a non-yoga group.

Pain Concern's Christine Johnson went to meet her.

Anna Semlyen: We were trying to encourage people to do, in some ways, the minimum amount of exercise that would be needed to maintain back health. So we used 22 other research trials and synthesised them into what the minimum amount of exercise is, and variations on those exercises, that would give you all-round flexibility, strength, comfort and ability to function well within your body. It was designed for people who had no awareness – absolutely beginner therapeutic on-the-floor-type yoga. So you need a reasonably warm venue. You need people to feel quite safe. The yoga programme was designed for all kinds of lower back problems – whether you had a slipped disc, whether you had sacral pain caused by an imbalance in the sacroiliac joints or one side of the pelvis further forward and twisted compared to the other, the programme can deal with it and [help people] find comfort and ease of movement.

We found that originally, people in our trial referred from their GP had about eight different problems on a scale called the 'Roland Morris Disability Questionnaire': problems like not being able to put on their socks without pain from their back or sleeping less well because of their back. Three months into the trial, the yoga group had two and a bit less problems than the group who had gone just to GP care. What we've proven is that... statistically valid results for yoga within 3 months carry on for a whole year of benefits after starting classes.

We also found that people were very safe practising yoga – there were not any serious adverse events in the yoga group. We found that it was cost-effective. Its main effect was to reduce the number of days off work by eight over the year between the two groups, with the yoga group doing significantly better.

We also had yoga teachers from two different traditions teaching: we had British Wheel of Yoga teachers – I'm the British Wheel of Yoga's specialist advisor on backcare and therapeutic research – and we also had Iyengar Yoga teachers, so we helped bring two yoga organisations together and proved that teachers from different traditions could both teach a standardised programme. This was not in any way a sort of yoga-teacher-do-what-you-like programme; there were written, class plans that each teacher was made to follow, and somebody came in to quality-check that they were doing the exercises in the right order, to the right amount of time and with the right props.

So, it works, it's safe, it's cost-effective and it's [been] proven with a proper, randomised controlled trial on a large study. So it was like having a prescription of yoga.

Christine Johnson: From your own experiences, could you tell me about some of the benefits you've seen in people you've taught or how their daily lives have changed because of doing yoga?

Semlyen: Do you know – this work is just fantastic for job satisfaction because people tell me that their lives are transformed? A lady who, for instance, had a large garden and wanted to retire to her gardening, found that she couldn't garden anymore and this had completely blown her vision of what her later years would be like. She needed help with this large garden and was thinking of having to move because she couldn't cope with it. She did my course [and] she's a happy gardener. It's made her feel independent again.

There are people who are in their 20s [with] back pain, and they are seriously worried that they won't be able to keep their jobs or find a partner because of their back pain. So it's transforming the other end of the spectrum in terms of ages. And it very much helps people to feel *well*. Of all the issues in our lives, yoga teachers recognise that health is very, very important, and when you have good health, everything else is easier – whether it's working or playing with your children or doing the sports that you love to do. I've had people go back to canoeing, for instance, that they enjoy but weren't able to safely do because if they had a back spasm, what could they do? I've had people go back to rock-climbing and quite adventurous activities because they've done the course and feel better.

I'm sure it's saving marriages; I'm sure it's saving people's jobs. If back pain is actually keeping you away from jobs that you would otherwise be doing, then learning a simple set of exercises is a massive transformation in people's quality of life.

Johnson: Now that this research has been published and people can really see the results, what knock-on effect do you think it could have or do you hope it could have?

Semlyen: First of all, we hope that a lot of yoga teachers will train, maybe 500 in the next year or two. Secondly, that the NHS will buy yoga, now that yoga has an evidence-base. It's medically proven to work for people suffering [from] chronic and recurrent lower back pain, which is a huge burden on society, so the NHS should buy yoga – that's what the research says. Thirdly, that yoga will become something that is more normal as an activity for anybody who has restricted mobility because of their back. They will feel confident [about] doing yoga, particularly with a trained yoga teacher – because this is specialist yoga. There are types of yoga that are too vigorous for people with backache. In searching out a yoga teacher, you want somebody who does specialise in back pain, to be sure that you're safe with them. So, yoga is something that GPs ought to be buying their patients and I hope that yoga will become free on the NHS.

Certainly as the NHS changes away from the primary care trust towards clinical commissioning groups at GP-level, I can imagine yoga being a very important part of the future of the NHS. For instance, you want people to come to local clinics, rather than main

hospitals and a yoga class could be taught at a GP practice, I think, or a local hall. We used non-NHS premises in our trial – we used community centres and schools and the like, and found that it's very low-tech. A minimum amount of props would be a yoga mat, the book, the CD, possibly something to put underneath your head like a book or a yoga block. We encourage people to use a blanket, we encourage them to use a chair, sometimes we use belts, but they weren't anything special – they could just be dressing gown belts. So you'll have most of the equipment at home already. Compare it to an MRI scan or something like that to find out exactly what kind of functional problem there is – but, actually, we're offering functional solutions.

Evans: That's Anna Semlyen talking to Pain Concern's Christine Johnson. For further information on that research, the book and CD developed for the trial, and how to find a qualified teacher, go to the Yoga for Backs website. That's [yogaforbacks](http://yogaforbacks.co.uk), no gaps, yogaforbacks.co.uk.

As I say in every programme, that whilst Pain Concern believes the information and opinions on *Airing Pain* are accurate and sound, based on the best judgements available, you should always consult your health professional on any matter relating to your health and well-being. He or she is the only person who knows you and your circumstances, and therefore the appropriate action to take on your behalf.

Now, chronic pain is described as a bio-psycho-social phenomenon, meaning it affects and indeed is affected by biological, psychological and social influences. Its treatment using the biomedical model is now well-established, but is the social domain of pain given the same emphasis? Participatory-action research is the approach to research in communities that aims to empower participants through seeking transformation of exposure to similar others, reflection on self and consciousness-raising. Sorry, but that's gobbledegook to my small mind, so what's it mean? Gareth Parsons, who's a clinical nurse specialist in pain management, now a Senior Lecturer at the University of South Wales, is passing on his experience to student nurses... and me.

Gareth Parsons: Unlike conventional research where a participant would normally be viewed as maybe a passive subject who's trying out a drug treatment or, in a qualitative piece of research, as somebody who's being interviewed, just as you're doing to me now – participatory-action research involves groups of people discussing their lives and coming to some kind of new form of knowledge based around that discussion.

Evans: So that's the theory. Gareth's been using the method in his own PhD research to find out whether the lives of patients of chronic pain would benefit from collaborating with

each other in their own learning communities. The participants for three such learning communities were recruited from a pain clinic and a general practice in South Wales. Now, over the last few years of making these **Airing Pain** programmes, if there's one thing I've learnt, it's that there are plenty of experts in pain management for us to turn to. So what could we lay members of the pain community – the patients – add to the wealth of knowledge that's already out there, Gareth?

Parsons: I've worked in a clinical practice in pain for seven years before I came here, I teach students about pain management, I've written a book on the subject... so in a way, you might say that I'm an expert in pain, but my knowledge of pain is *theoretical*. If we think about chronic pain as being an entity in its own right, then the only people who really have expertise in it are those who have chronic pain. Everything else is theoretical: we don't really know what it's like. We might know how to help people or we might have some ideas of how to help people, but we can't help people if we don't acknowledge the fact that they are the experts.

Evans: What'd you mean by acknowledging pain as something in its own right? I have a condition, it's called 'fibromyalgia'.

Parsons: When somebody has a condition, of whatever sort, one of the symptoms of that condition might be pain. And if you view pain as just a symptom, then you're going to try and treat that symptom without looking at the whole person. I believe that when somebody has pain, it affects them at a personal level: it affects who they are and [I believe] that people in pain are different to how they are when they aren't in pain. That means that people with different conditions who have pain have something in common with each other. To say to somebody 'you've got fibromyalgia' or 'you've got osteoarthritis' or 'you've got a bad back' or 'you've got trigeminal neuralgia' is to categorise them into their condition and is to ignore the impacts that condition, and the problems that arise from that condition, impose upon them in their lives. So somebody with chronic pain is restricted in what they can do in their lives: it affects them in lots of different ways.

Not everybody's affected in the same way, but there are similarities. And as an expert in pain, I've been taught a lot about how to manage the symptom of pain. A lot of that comes from treating acute pains, which largely involves physical treatments on a biological entity. More recently, we're coming to think about pain as something that has psychological dimensions. There are treatments out there now which explore cognitive aspects of pain, behavioural aspects of pain... and they've been shown to be very effective. But an area of pain which is overlooked is the social aspect of pain. When people are learning together,

they're leaning in a social context and that social aspect, I think, has been overlooked in research.

Evans: What do you mean by social aspect – which social aspect?

Parsons: If we go back to where I got the idea for my research from, first of all. When I started off as a clinical nurse specialist, I was working in a district general hospital. I was an acute pain nurse and a chronic pain nurse. We were developing a chronic pain clinic and we were looking at interventions that I could do as a nurse in the chronic pain clinic. So it wasn't just about giving people drugs and giving them injections, we were trying to explore other things as well. And one of the things that we were interested in exploring was this idea of mindfulness – I guess you could think about it as relaxation therapies, but a bit more than that as well: body consciousness, being aware of what your body's doing. So we put on classes for people – we called them 'relaxation classes', but they were really more about the idea of mindfulness.

What I found was that the patients who were taking part weren't really listening to us when we were instructing them on how to do relaxation techniques – they were too busy chatting to each other. We thought, first of all, that this was a bit of a – you know, what's going on here? We thought it'd evaluate very badly because people weren't really picking up their relaxation lessons, they weren't really putting them into practice. But they kept coming back and they kept coming back and they wanted more and more. Initially, we just did a 6-week programme – people come for a couple of hours once every 6 weeks, [but] they wanted more and more.

There was something about the social interaction that was going on. The social interaction wasn't intended – what was intended was that I would be the expert teaching people how to relax, because I'd done a course on relaxation therapies and mindfulness. So I was going to share that expertise with them. They circumvented that; they broke the rules and interacted with each other. That made me think there's something going on here, there's social interaction. It evaluated very well. This was a time of GP fund-holders and GP fund-holders were telling us that their patients liked it and they'd like to do some more because they were willing to pay for it. So that started off a germ of an idea: it's not what we were offering them that was helping them, it was the interaction with each other, because we were doing it within a group.

So that started off my idea that there's something about people sharing stories within a group. In my role as becoming an educator, one of the educationalist theories that I came across was [by] somebody called Paulo Freire. He wrote quite a famous book called *The*

Pedagogy of the Oppressed. He was working in Brazil at a time when, if you couldn't read and write, if you weren't literate, you couldn't vote. So he was training people who couldn't read and write to read and write. And in doing so, they were getting the vote, they were becoming empowered. So he linked the idea of educating people to the idea of liberation from some kind of oppression.

So that was one area that I was interested in: people becoming conscious of their social condition and thinking about how sharing those experiences amongst each other enabled them to develop what Freire called 'consciousness-raising'. As you explore your life, you develop awareness – you become conscious of how your life is limited. That's the first action in becoming empowered.

Evans: I've heard similar expressions with the term 'disability'. [**Parsons:** mm-hmm] What does 'disabled' mean – is it a person's physical condition that is disabling them, or is it society's attitude and reaction to that person that is the disabling factor; who is disabling who? And that's the same as oppression, I guess.

Parsons: Yes. When I started off, my idea was having chronic pain imposed physical limits on somebody – not just physical limits, because it's a bio-psycho-social problem, I recognise that, so it also imposed limits in terms of their thoughts and their behaviours and their ability to interact with other people. I thought it was being pain that was the oppressor, [but] through doing my research and working with my co-participants, I've come to realise that that's only part of the story and the other part of the story is, as you say, the way people respond, the way people behave towards people who have pain, contributes towards their pain.

So, the social interactions that they have with others, creates a situation which contributes to their oppression. But people aren't aware of this and the people who are oppressed – the people in pain – also buy into this through their lack of consciousness and they are also involved in oppressing themselves and also oppressing other people with chronic pain who aren't like them.

Evans: So who is the oppressor: the pain, the person with the pain or the person without the pain?

Parsons: This is the interesting thing, because a lot of these interventions that were designed to help people in pain or with any chronic illness, if you take diabetes, for example, they are all about encouraging self-management. If you look at the writing on self-management, it talks about it being empowering. So the idea is that nurses who work with

people with diabetes are involved in empowering people with diabetes. Or people who go to cognitive-behavioural therapy for their chronic pain are being empowered by the therapy.

Now that's nonsense – because you can't empower somebody else. The only person who can empower somebody is yourself – only you can empower yourself. Now what you can do is create a set of conditions which allow people to become emancipated – similar, I guess, to slavery. If you look at what happened in America, when slavery was abolished, black people were still oppressed. Getting rid of slavery didn't stop people being oppressed. In a way, you could say that pain is like slavery, in that it's a condition which people might say that's oppressed them, but the reality is, it's the attitude towards people who are in pain and also the attitude that people in pain hold about themselves and their abilities, which is the oppressor.

Evans: Going back to what you said about you being the expert talking to the group of patients [**Parsons:** yes] and them basically ignoring you [**Parsons:** yes] and finding each other [**Parsons:** yes], I've been in that situation [**Parsons:** mm-hmm] through the Expert-Patient Programme [**Parsons:** yes]. I found when I did that, that actually there was nothing much new that I hadn't read in the books because I'd done a lot of reading; I knew all the theory as well, but the real benefit was being in that group and being allowed to smile with other people in pain, where pain actually doesn't become the focal point of the meeting.

Parsons: Now that's interesting, because that's similar to what I found in my study. If you think about it, the reason why people are being brought together by me is because they're in pain. But when we actually got together, although we talked about pain and we shared stories about that, we also talked about a lot of other things as well, including, what the weather was like and what was on the telly and what books I'd read, what their hobbies and interests were. Because these topics weren't about pain, I wasn't initially interested in those, but I came to realise quite quickly that was important – this sharing, this being able to open up to each other and tell people things. They were sharing things with people who were relative strangers that they couldn't share with their family or their friends or their GP, because it would sound ridiculous. They've never felt able to share those things because they thought they won't be believed – 'oh, it's just so-and-so moaning again about their pain'. They've learnt to keep quiet about it.

One of my participants described the fact that she didn't like to think of herself as Mrs Never-Well. This meant that she was always guarding what she was saying. She didn't explain to her husband or to her children how she was feeling; she tried to hide it from people. When she went to her doctor, it was 'how are you, Mrs So-and-so?' – 'I'm fine, thank you, doctor.' That's her first response, even though she's got a problem. Within the groups, there became

a kind of joking about this: 'I'm fine, but...' This way, they had to develop a means of communicating with other people in order to get their message across about their pain. It was a defence mechanism, really, but it was also a way of controlling the communication that they had. It was a way of them placing themselves in charge of the communication with others so that they could dictate... they were subverting their relationship, their communication with their GP.

Evans: That's a really interesting point again, because I found one of the worst questions that I could be asked is 'how are you doing?' And normally, I'd say 'fine' – if you're asked 'how are you feeling', the last thing you want to say is 'I feel total rubbish. I'm glad you asked. Let's go through it together.' Nobody wants that.

Parsons: No. And I actually use this as a scenario with my students. I give them the example of they've somebody in a supermarket they haven't seen for a long, long time. And they ask them how they are, and their friend talks about their bad back, and half an hour later, they're still telling them about their bad back and the ice cream's melted and the children are playing up and the husband's walked off and gone and sat in the car, tooting the horn, waiting for them to come out... Anyway, they finally manage to get away from their friend. The next week, they see their friend in the supermarket and they have a choice, because their friend hasn't seen them: do they go up and say hello again or do they dodge down the aisle and hope that their friend hasn't seen them? You can imagine what the response is from the students and it's a normal human response, because when we ask people how they are, we're not interested in how they are, we want to tell them how we feel. It's just a part of the social glue. It's another way of saying hello.

Evans: What major outcomes have come from your research, do you think?

Parsons: There were two full learning communities that were sustainable over time and we were able to work through a 10-week process together. Both groups had a problem with communicating with healthcare professionals and others. And how they dealt with that; how they realised that and they had to take some kind of ownership of that communication. They talked about the hard life of having chronic pain; they talked about going through cycles of having to repeat treatments when they saw new doctors, that they knew wouldn't work, but they had to do it because if they didn't do it, they would be viewed as being non-compliant, which, as one lady put it, was the death knell – as soon as you're labelled as non-compliant, that's it, you're out.

One of the other things that they came across was accepting the need to make adjustments. They were kind of fighting the need to make adaptations in their lives – they were trying to

carry on as they were before their pain. When they had good days, they were overdoing it and then suffering as a result, which we all know, I think it's been called 'activity cycling' or various other [Evans: Boom and bust] ...boom and bust kind of approach to things.

An example would be, because these were all ladies in this group, they were talking about doing housework – how their husbands didn't notice that the house hadn't been dusted for a week, so why did they have to do it every single day? Why were they so hard on themselves? So they talked about ways that they could maybe make allowances for themselves, forgive themselves for not doing so much.

And then other learning community, they looked at ways that they could learn to adapt to their pain – not the same as making adjustments – it was about coming to some kind of accommodation with their pain, some kind of understanding as to how they could fit pain into their lives. Whereas, they'd been fighting it before and maybe they had to sort of realise that it wasn't going to go away and they had to adapt to having pain. And the participants worked at individual ways of doing that, but in a shared, collaborative way.

So that is a new thing, that people can come together and teach each other about that without having an expert come in and tell them how to do it. Doing it in an informal way, in a way that seems disorganised, because when we sat down at the beginning of an evening, we didn't know where we were going to end up two hours later. From the point of view of an outcome, if I think about my research question, which was 'can you set up learning communities with people who have chronic pain?', then yes, you can.

I had this wonderful idea that I would be able to recruit about 10 people and have them come every evening for 10 weeks and keep them there all together. I soon learnt, quite early on, that that wasn't feasible: I had a high drop-out. One group, I ended up with about six people; another group, I ended up with five. But what was interesting was instead of the drop-outs killing the communication, they actually contributed towards it. So people who left actually made the people who stayed think 'why am I staying? Why am I interested in this?' They made comparisons to the people who left – 'what is it [that's] different about me to them?' So it helped them explore themselves and develop their own self-awareness: 'am I open to this [while] they're not?'

Evans: Going back to the point you were making about participatory-action research, that when you came into it, you [were] the theoretical expert [**Parsons:** mmm] whereas the patients were actually the expert [**Parsons:** yes], was it right that *you* should be doing the research, or perhaps should the patients have been doing the research?

Parsons: Ideally, participatory-action research should be something which is thought of by the participants, designed by the participants; [something that] participants take part in. They also take part in any analysis of the findings and in the actual production of a discussion and conclusion and further research.

Evans: So guide me through this: if a self-help group [**Parsons:** yep] wanted to set up research like this [**Parsons:** yes], how would they go about it?

Parsons: They could either do it all themselves just for the fun of it, I guess, or just to generate their own knowledge; or they could approach an academic and say, 'we have a problem [and] we'd like you to help us explore it'; or they could become the academics themselves. That would be the ideal.

Evans: But what would the benefit be to the participants?

Parsons: The whole point of participation research is it's not about benefits for anybody else; it's about benefits for the participants. They would learn more about themselves. They would learn more about their lives, perhaps gain in confidence, gain in self-esteem, produce something meaningful to themselves, be able to explain things to other people...

Evans: So it's removing the oppressor.

Parsons: Yeah, because it's all about raising awareness; raising consciousness; empowering yourself. And when you're empowered, you're less likely to be oppressed.

Evans: That's Gareth Parsons, senior lecturer at the University of South Wales. Don't forget that you can still download all editions of *Airing Pain* from painconcern.org.uk or you can obtain CD copies direct from Pain Concern. If you'd like to put a question to our panel of experts or just make a comment about these programmes, then please do so via our blog, message board, email, Facebook, Twitter. All the contact details are on our website, and once again, it's painconcern.org.uk. On the website, you'll also find details of *Airing Pain's* companion magazine *Pain Matters*, which is available as an online subscription or direct by post.

Okay, to end this edition of *Airing Pain*, I'll leave you with maybe a controversial thought to take away and discuss at your own learning community: does what Anna Semlyen now say just apply to yoga?

Semlyen: Low-tech healthcare has to be the future, really. We've got to go towards things that are both effective and cheap and yoga fits those two categories very, very well. It allows people to be their own healers and isn't that a fantastic thing that you can choose to be?

Contributors

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