My Personal Experience

Charles Balcombe

Webinar October 2022

I would like to start by explaining how I got to this place. My relationship with chronic pain started in 2013 when I developed sciatic pain. My GP eventually sent me to a surgeon who sent me for an MRI and I was told I had a ‘bulging’ disk causing my pain. I was told this by a man in a white coat with a lot of letters after his name who exuded a huge amount of confidence and said: “it will be very easy – I will nip in there, take out this bulge, zip you back up, send you home and you will be back playing football withing six months. This sounded wonderful, and I walked out of his office thinking it made a lot of sense, so let’s go forward with the surgery. I had the operation in April 2013. I went home, went to sleep and woke up a few hours later in agonising pain and burning. I found I had lost control of my foot and thought I would never be able to walk again. I went back into hospital where they found that my disc had re-herniated. So they re-operated and I recovered the use of my foot but from then for about nine months my right leg was sunburn red in colour. This was the start of a very unhappy six years when I tried, failed and floundered to deal with my pain.

 During this time I lost an extremely promising career and many relationships including some close family members. I became depressed and isolated and stayed in my bedroom for much of the time. I became heavily dependent on oxycodone and diazepam and I am not ashamed to say that I often used alcohol for the pain. I would wake up in the morning and think I would do anything and everything to get rid of the pain. To jump forward to 2018: my life had fallen apart to such an extent that I decided to try to end it. Even though at this time I was unable to think clearly; the medication and indeed the suffering made it difficult to form thoughts I remember thinking quite clearly that this was a logical decision because I had exhausted all the other options that appeared to be available. I mean the options provided by the healthcare system: I had been to three ‘ologists and specialists and been given every medication and seemed to have exhausted everything that might help to relieve my pain. I tried to apply logic to the situation and concluded that if the healthcare system hadn’t worked I had no other choice but suicide. But I am happy to report that – otherwise I wouldn’t be talking to you tonight – that for various reasons that I didn’t do this.

 But this started a process where I knew something had to change. I had been through this crisis and didn’t want to repeat it. I had been granted a second opportunity and I knew I had to do something with it; to harness this and make a positive change. I didn’t know at that time what that change would look like; I had very few ideas and didn’t really know what I was doing. But I had two targets: the first was to take less medication – that wasn’t driven by the knowledge I now have about them and their dangers. The second was to move my body more; even though I didn’t at that time know about the benefits of movement I just thought “ you’ve been locked in your bedroom for five years and can you just move more?” I was able to achieve these things albeit slowly although it was very painful on multiple levels. Stopping opioid medication after several years is not easy or pleasant and in the short term pain becomes worse. Movement seemed very scary at the time and even walking out of the front door I perceived as be very threatening. But as I was able to continue with these two things I started to notice a reduction in my pain. I would go for a five-minute walk one day and after a month that would turn into a ten-minute walk with a friend. I was able to engage in social activity and get myself fit with exercise. I told you about my pivotal moment in 2018 and contemplated suicide, but I also had an epiphany when I took stock and said to myself: “you started this process in 2013 believing that the way to reduce pain was to take painkillers and to stop moving when you feel pain. But you have done the reverse of that and improved your quality of life from a place about nine months ago where you didn’t want to live but now you are happy, going on dates and finding enjoyment in life”. And it was all because I had done things that I had believed were not the way to go when I started this process.

 And this opened my mind to the potential limitations in healthcare (which I am not slamming) but also on a societal level because I realised that this couldn’t be unique to me and there must be millions of other people with these belief systems and who had gone down a similar path to me. In many ways I was better off - I had access to private healthcare at times and able to access some resources that other people weren’t. But I began to think that so many people who were suffering could be helped in the way that I had been able to help myself.

I picked up my first book about pain around this time as I was intrigued to discover what other people were saying. -And then I found books such as *The pain-free mindset* by Deepak Ravindra and *The painful truth*  by Monty Lyman. The latter was mind-blowing for me; Deepak’s book had more of a medical slant but reading *Th*e *painful truth*  was almost as if Monty had been watching my life for the preceding six years and seen all the ways I had struggled, and the science behind why I had been suffering and why I was seeing improvement. I had been confused; I was happy with the way I had improved my life but I didn’t really understand it until I read these books and had someone explain to me why I was getting all these benefits.

So it was at that moment I decided to start the work I am now doing now. The company I started is called Paind. I looked at the numbers of people with chronic pain and my journey and I thought that there must be something that we can do to deliver this new understanding to them. Clearly, despite the best intentions of many clinicians and the desire of people with chronic pain and their loved ones to improve their quality of life it wasn’t really working and probably getting worse. The numbers of people with high impact pain, especially youngsters, are getting worse.

I will try to simplify the problems I met on my journey; these are problems that we all face, I speak about them from my own perspective but I would love to see solutions provided for them.

There were three: The first concerns me as an individual. I was born in 1987 and had my first operation when I was 26, but I went into it with 26 years’ worth of false beliefs about and false narratives around pain. So it was not just my first encounter with the healthcare system that was the problem, but everything before that.

 The second is the healthcare system – I don‘t want to sound critical of it as it does some wonderful things, but a lot of the beliefs that I had as a lay person seemed to be shared by the clinicians I encountered. There was a point in my journey when I started accessing private healthcare. I was doctor-shopping and trying to find someone with a new view on things. I saw countless but hardly any of them had any vestige of the approach which I now believe to be the right one – an approach no doubt shared by the clinicians in this group, but I didn’t encounter any of them during my years of suffering. That really should not be the case. Not only is it problematic that there are so few clinicians that really understand pain, but when you are growing up the only people you trust more than your own parents are doctors. So if the clinicians you encounter in primary care have the wrong beliefs it’s difficult to see how the individual patient can change theirs.

 The third problem is with society in general. For the individual living with pain, as long as they live in a society that stigmatises pain, especially where there is no underlying pathology, we can’t make any meaningful progress in reducing the numbers of people living with it – or even helping one suffering person – without some understanding of pain. The same stigma still attaches to pain as was applied to mental health fifteen or twenty years ago when people were looked upon as psychologically weak or deficient in some way if they had such problems.

\*https://www.paind.com

There have been great strides in that regard recently with employers making provision for mental health in contracts.

 I hope that in coming years chronic pain is treated in the same way, but at the moment we live in a society that views people with long-term pain in a very suspicious way. And that attitude of only half believing someone only amplifies the pain.

I don’t know how many clinicians we have on this call and it’s not for me to suggest how healthcare can improve. But for a lay person coming across the stat that in six years at medical school there are thirteen hours of pain education it is very concerning. I have also discovered that learning about chronic pain is not compulsory; I found that terrifying but it did at least explain why some clinicians had some of their beliefs. But I would like to ask you: how can we change that? Does it involve petitioning to get more into the curriculum? How can learning about chronic pain be made compulsory? But bringing about change individuals and society shouldn’t be overly -complicated as it is a matter of raising awareness. We have seen a paradigm shift into a new way of treating chronic pain going forward and I hope we will see a snowball effect; the more clinicians embrace this, the more people there are like me and Louise talking about their lived experience and how we have been able to use pain science to reduce our pain and improve our quality of life, the more that will snowball. I would like to see pain science introduced into the school curriculum, perhaps at AS level biology and that would have a profound impact on the number of young adults who report fibromyalgia or CRP in their mid-twenties. Deepak Ravindran has done some work on that in his local area which is very inspirational and the kind of thing that needs to be done as the earlier we can talk to people and raise awareness around the science of pain that would be really impactful for the next generation.

But I am concerned about what we are up against. I saw an advert for a pain-killer in a tube station today which was problematic on so many levels; everything about it was wrong and it was projecting incorrect beliefs into people looking at it. I can say that now because I know a huge amount more about pain than I did a few years ago; but a few years ago I would probably have gone and bought that painkiller. So there is a lack of regulation and oversight over the kind of material that big pharma can produce. We have to be aware that on a societal level we are constantly being impregnated with incorrect beliefs; and although I am aware that what we believe today to be correct may change tomorrow, we have to change belief systems on a societal level. I can only speak from the perspective of my own beliefs and experience but I would submit that our beliefs affect the way we respond to things. And this is a major problem for people living with pain. If you go into a situation when you are feeling pain with incorrect beliefs – if for instance I were to sprain my ankle the response I would have made with my previously limited understanding was ‘ouch, that hurts, I should stop moving’ which would be an appropriate response to injury. But someone living with chronic pain, having made that response, may end up immobilising for years, becoming isolated and depressed; putting their body into this inflammatory environment. But they are totally unaware of this because they don’t have the right belief system. They think they are making an informed, logical response to that pain but are only amplifying things. If they could be told on day one that this is mistaken and why not moving and becoming isolated is only making things worse, that would allow people like me to make a different response. But that information just isn’t there. So how can we get this out to the people that need it most? – and shift their belief systems towards a better response?

For me, responding appropriately has been a skill that has taken me a couple of years to acquire and I’m now quite good at it, but I still struggle from time to time as pain is so unpleasant. But now I know what it means I find the response much easier.

Paind

There are three parts of the business that we are working on: the first is building communities both on- and off- line to enable people with chronic pain to reach and network with one another. And that is really powerful. Social isolation is such a common response to pain and we are trying to create an environment in which that response can be changed. Offline communities like Betsan’s StitchLinks are very important and it is not just about creating another Facebook so people can chat online but trying to harness the power of social connection as a way to reduce or even resolve pain.

 We are also hoping to deliver on another area: pain inspired healthcare. I used to call this pain informed healthcare but I don’t feel qualified to judge what is and is not well informed. Pain inspired healthcare is that which is provided by some of the clinicians on this call and those I met at Rydal who wake up in the morning with the humility to accept that our understanding of pain is changing rapidly - the landscape has shifted even since I started to try to teach myself about it – and to accept that a lot of their practice to date may be outdated. This may be difficult; a lot of the pain medicine consultants that I have encountered have trained and practiced in a certain way for 25 years and have built a career around things which may now no longer be the way to go. So it is going to take a lot of humility for them to move forward. So within this pain app we want to create a body of clinicians who embrace this new philosophy.

 The third thing we at Paind are trying to do is to impact on the belief systems I have spoken about with education. Clearly we are not the first people to try to help people with chronic pain but for whatever reason nobody has been able to do it in a scalable way which reaches a reasonable number of such people. We hope to do this by producing high production value content and by using social media like TikTok to reach those youngsters, whose pain and numbers may be made worse by social media, and create bite-size bits of education that we can feed them through our app to enable their understanding of what pain is and, perhaps more importantly , what it isn’t.

From my basic understanding of pain science and how I have tried to apply this to reducing my own pain, one of the most important shifts for me was to start considering myself as my main primary caregiver. I had spent years searching for solutions from clinicians and someone who would make my pain go away. It was all things that would be done *to* me. That is a model of healthcare created by consumerism and capitalism in the sixties and seventies when we had this feeling that for anything that ails us we can go to our doctors and they can make it go away. I noticed a marked change in my ability to manage my own pain when I looked in the mirror and said this has to start with *you.* The feeling of self-worth, self-confidence resulted from changing from a ‘done for you’ model to … not a DIY model, but encouraging people to be their own primary caregiver with the addition of pain inspired healthcare. But that is a huge shift for people to buy into because it creates a cognitive dissonance between the view that I can go to a doctor and have my pain taken away to a place where actually I can do some of this myself. The bridging of that gap is something I would like to explore as it can be daunting for a lot of people.

Discussion

*What an inspirational and indeed moving description of your pain journey that was. I don’t actually like that term pain journey but I can’t think of a better one, and you certainly articulated it brilliantly from a patient’s point of view. From a totally different one I have had a long-term condition which is very slow in progress and pain has been very mild but constant, and never severe or debilitating at any one time. I agree 100% about the need for re-education and the paradigm shift that we all have to go through in order to understand and take control of the situation we are in. We are used to being told what to do; as patients we are trained by the NHS and even the private medical system to be patient to receive and be passive in the receipt of our treatment. I has been interesting that in the last 20 years there has been high profile lip service in the NHS to patient involvement. They* say *that your treatment is a partnership and a collaborative process whereas in fact you take what you are offered or go your own way. From a patient’s point of view it’s when you can click that switch and become engaged and start to do something however small helps them we can make a terrific difference.*

The basic principle of when you have a persistent pain is pain that is there the whole time and how often can you access healthcare. It is a very simple equation; and what do you do with the rest of your time. Whether we call it self-management or a patient-first approach - whatever the limitations of healthcare may or may not be – there are still hours of every day when you are on your own with your pain and you need to be … you might get some of those tools from healthcare but there still has to be a shift in the mind to accept that it has to start with me and can’t be wished away by someone else.

*That was a great talk and very inspiring. It could be very educational for pain professionals but it shouldn’t have to be after all these years, and I kept wondering why you had to find this out for yourself and hadn’t received any appropriated guidance from any of the clinicians you sought help from. I got into pain medicine in the mid-seventies and ideas of treating the mind as well as the body were already well established, and had been coming to us for years, mainly from America; John Bonica having started the science based pain movement together with John Loeser, Bill Fordyce and others in Seattle nearly 20 years earlier. But still, after all this time, far too many people are having similar experiences of the healthcare system to yours.*

 *John [Loeser] : – do you have any cause to view the present situation with anything other than despair and pessimism?*

*I don’t believe in despair and pessimism. The American Chronic Pain Association1 incorporates everything that Charles has been talking about in terms of people learning how to overcome their chronic pain. It is a good source of information online.*

 *Charles - I thought you gave a very inspiring talk and I wish there were more people like you who have solved the chronic pain problem through their own endeavours, because the health system in your country and mine obviously doesn’t have the training and education to address this issue. Part of it is the failure to recognise that mental issues are as important as physical ones And I can say this as a surgeon: if someone could put a barrier around surgeons so that no patient could get to them until they had been assessed from a multidisciplinary point of view and we could reduce the amount of surgery …*

1 <https://paincommunity.org/listing/american-chronic-pain-association/> It is interesting that this was founded by a pain patient and appears to be very similar to Paind, and is not clinician driven

*When you started your journey you had an acute pain from a disc pressing on a nerve which didn’t go away so you ended up with chronic pain. Opioids are known not to be suitable for chronic pain but you ended up stuck on oxycodone*

I consider myself lucky in the sense of the terms we use now, neuroplastic and nociplastic2. My journey started in 2013 with the disc problem but by 2016 I would say that 99% of my pain was neuroplastic and involved everything else: the depression, the isolation and opioid induced hyperalgesia. It involved absolute misery, but where I am today, although I still have a lot of pain attributable to the damaged nerves and how I respond to that depends on my pain levels. You mentioned oxycodone: I tried to explain to my parents who had gone to hell and back with some of the issues around that; thinking that they could come into my bedroom and find ……I tried to explain that the term pain-killer implied something that probably doesn’t exist but they still don’t understand

*So opiates are appropriate for acute pain like a broken leg but there is this other thing that is morphs into that doesn’t respond*

 When we are thinking of these resources online on how to deal with chronic pain … one of the problems is the societal thing; while loved ones of PWCP don’t understand these basic things – not things you should have to learn in medical school – that shift really needs to happen. I think there are more people that have been able to embrace this and talking about lived experience than there were a few years ago and I do really hope there will be a snowball effect.

*There is a book you should read:* A Whole New Life *by Reynolds Price who is a professor at Duke University in North Carolina. He has undergone an experience very similar to yours with surgery and terrible chronic pain and a biomedically dominated healthcare system until he finally learned strategies for managing his own pain.*

*…*Very much so. I didn’t come across this concept until 2018. I had started taking it in the acute phase and it worked exceptionally well at reducing my pain. But by 2013 I was in a totally different kind of pain. It was still alleviating a lot of that kind of pain – or rather it was alleviating some of my misery, which was very dangerous.; but if all someone has is to take at the time is something which is alleviating whatever kind of pain it is – in my case it was neuroplastic – it is very hard not to become addicted.( I know there are differences between addiction and dependency but I am not going to go into them now) It seemed to be the only thing in the world that was making things better but I didn’t comprehend that it could be making things worse.

*You took a holistic approach and talked about pain reduction and resolution. At the moment my lived experience of working in a pain service and of our profession is that at times we are a bit conflicted about whether we want talk about pain reduction and resolution, or rather about living well with pain from a more sort of purist perception of pain acceptance. So if you are in a sort of pain reduction kind of camp then you fit more into the interventionalist side and if you are in a more holistic one you will fit more into the live well with pain side. And for someone like me from a holistic background but who wants to talk about pain reduction there is a kind of no-man’s land between them.*

[2 What is nociplastic pain? | Pain Management Today (medicinetoday.com.au)](https://painmanagement.medicinetoday.com.au/2021/july/regular-series/what-nociplastic-pain)

When I last saw Deepak Ravindran I pulled him up on the name of his book *The pain-free mindset.* I suggested that in calling it that he was advocating the view that pain should be eliminated. Of course I knew that that was not what he was getting at and this was the outcome of discussion with his publishers. When I talk about pain reduction and resolution it’s not the day-to-day pain that alerts our alarm system it is chronic pain that people are struggling to reduce or resolve, which is not a bad thing to hope for. With a holistic approach and the right input that output should be reduction and resolution. As I have been sitting in the same position for some time I have significant pain in my right leg but this isn’t chronic pain but the result inter alias of sitting too long. I very much advocate getting rid of pain but that’s not a place we should strive to be in but that’s not an argument against trying to reduce and resolve chronic pain.

*I wanted to talk about my own experience. I am now 65 and I have had chronic back pain since I was 18. When I was 19 I started training in dentistry and over the years with the posture involved in this, six days a week and 40 patients a day, the pain got worse and worse and more debilitating. Eventually after 20 years it led to lumbar and cervical disc prolapse which cut short my dental career. I did not have surgery for either of these and I was extremely lucky in my rehabilitation with some brilliant physios and osteopaths who worked on my belief that movement would make the pain worse and basically told me to move. And exercise keeps pain levels down and fitness up and improves everything which the cocktail of analgesics I had been taking failed to do.*

Movement is a non-negotiable part of everyday life and although I do exercise now and enjoy going to the gym for several hours a day I tend not to use the word exercise as it can be quite daunting or confusing for somebody living with chronic pain. A few years ago if someone had told me to exercise I would have thought it totally illogical. But you know the difference between walking down the street with your shoulders back and your chest up and going around hunched: that is a snapshot of how we move through the world and talk to our CNS and our whole being about how secure and safe we are at that moment. Perhaps ‘making yourself stronger’ is better and enables you to say to yourself – I am a bit stronger than I was yesterday, I walked a bit further …. That and growing confidence was for me a huge part of my ability to reduce my pain.

*I used to be a physiotherapist but I now work as a health coach and I think there is a need for health coaches to have a good knowledge about pain and the way pain is a whole person thing within one’s environment. This could be one means of getting that information across.*

 *Secondly I have been researching the meditative, creative and social benefits of knitting and its therapeutic potential. One of our most significant findings has been the importance of being successful at something. I used to be a community physio visiting people who couldn’t get to the department often with long-term pain who were sitting all day because they had no reason to get out of their armchairs and had nothing in their lives that they had been successful at, and knitting was something they could be successful at in a chair or eve in bed. This gave them the motivation to try something else they might be successful at, and gave them a springboard to get out of their inert state. It doesn’t have to be knitting – it can be anything however small that they can make a success of.*

Health coaches or pain coaches could play a massive part in improving the landscape and go forward. We could argue that one issue with the healthcare system is the siloed approach which doesn’t tend to lend itself to a holistic view. Some of the best clinicians I have encountered in the last few months are the ones that have stepped away from this to embrace a holistic approach. The coaching role gives that flexibility, and is a model that allows for someone with lived experience to become a coach – it doesn’t have to be someone with many qualifications – someone like a sponsor in Alcoholics Anonymous

 I so agree with your second point. I spent years locked in my bedroom not accomplishing anything; feeling worthless and that nobody would want to spend time with me.

 *I joined you a bit late this evening because I had been talking to a patient who had had a nasty injury with compartment syndrome and major surgery several years ago and ended up with neuropathic pain. He has had every treatment in the book including spinal cord stimulation, various injections and the whole range of medication. He is probably at a similar stage to where you were, and I was wondering if you could go back in time what could have been said to you at an earlier stage, or what could clinicians have done earlier that would convince you that the lessons you eventually gave yourself were valid.*

It's a very good question and a tricky one to answer because I remember that certain concepts of pain science were introduced and my suffering was too great to process them some of the time. They weren’t delivered in very helpful ways like ‘the pain is all coming from your head’ which was supposed to introduce me to the role of the brain. But the powerful basic things which helped me to change my mindset were videos such as The nail in the boot [ see *A Tale of Two nails* Rachel Zoffness [A Tale of Two Nails | Psychology Today](https://www.psychologytoday.com/us/blog/pain-explained/201911/tale-two-nails) ]

It shouldn’t take exhausting all other options to find these things out.

 For a clinician to be seen embracing uncertainty – a doctor who says I don’t have all of the answers - may seem worrying for a patient; but if they do pretend to have all the answers the patient is always going to want to come back for more. I wish some of the ones I saw hadn’t promised me a silver bullet.

*It doesn’t help that every clinician you see says something different, probably because they are all from different specialities. But you cling to everything you are told because you are desperately searching for* the answer. *If you were told at the beginning that this might be something that we can’t actually ‘fix’ but we can help you towards a better quality of life you are just going from one referral to another, in the hope that this one will at last tell you that this is what is wrong and how they can fix it, but of course it doesn’t. You are just going through that ever-revolving door, and end up as I did with hospital files about a foot thick and on huge doses of opioids. If we got the message about moving etc early on it might prevent this.*

*You may need opioids in the acute phase but when it transitions to chronic you need this other stuff*

If you wait to bring in a psychosocial approach till when pain transitions this way we will always have a system when the bio is prioritised however appropriate it may be, and the attitude that we should only change our approach if we fail to relieve pain by treating this broken leg or whatever. Even before this happens we need to treat the bio, psycho and social equitably and not bring n the latter two when the first fails.

 This is a massive challenge for physicians but we must find a way.

*Rather than calling it biopsychosocial which of course puts the emphasis on the bio if we could we turn it round to psychosociobiological that would go a long way.*

I think I would be very peed off if I were a pain consultant – or another discipline – if having trained and built a career round doing things in a certain way and then some evidence emerges of a new way forward I would have a bitter pill to swallow, And it would take a lot of humility to face that future uncertainty. So this is a major challenge for the healthcare system.

*Things do change a lor in medicine; we gave up tonsillectomies and new drugs come in but this is different and involves a big change in mindset.*

*I wanted to respond to what Tim was saying [about going back in time] If the doctor had said to me “sorry, we have tried everything and you are going to have to put up with this pain. It’s terrible for you but I want to help you find ways to cope with it” then that would be the best thing a GP or pain consultant could have said to me as a patient, because they were showing that they cared and that they believed me. And then all the other things that Betsan and Charles were talking about. And this sort of support would be the best thing a doctor could offer.*

*I just wanted to pick up on one things: the healthcare system which is clearly in need of compete re-jigging in terms of conditions that exist on the edge of formal medicine as we used to know it. And although there are many of us moving towards that it is difficult to maintain within the current framework. And that is something we have to be aware of: the necessity to work around the fringes of medicine*

*I am pain consultant and also a pain patient with chronic neck pain. In my practice I tell patients that I cannot cure your pain but I can reduce it and help you manage it. I have tried to reduce the amount of medication people are on. The other day I saw a patient with 200µg per hour of fentanyl on board. I tried to tell them that they were going to have to reduce this and look at alternatives but they just didn’t want to listen. Such patients reject my offer of help because I am not cooperating with them. This is an issue that needs to be addressed.*

 *I have cervical pain and I have not had any surgical procedure. My main pain management is this: [head rotation] and I do it every five minutes, even in the clinic, and I tell my patients that this (movement) is the answer to some of their problems*

 *[…inaudible…] in the community. I think most pain consultants don’t want to go into the social aspects, although a lot may be moving in that direction. This may be because of the way the system is structured .*

Regarding your patient on the fentanyl: I remember when I was first told that painkillers could be producing more pain and I needed to reduce them it seemed totally illogical as I had thought that if painkillers killed pain I just needed to take more painkillers. So it comes back to awareness and getting the message out there about how these pathways work. it’s common for people to feel confused and offended when they are told to stop taking their pain medication.

*John Loeser quite rightly chided me for giving way to despair and pessimism but I would like to ask … I have been out of the clinical field for many years now… I would be interested to know whether you, Charles, or anyone else, do see any grounds for optimism about the situation, in particular the sort of advice patients are getting from clinicians including pain specialists? I started this group more than twenty years ago very much with the awareness of the polarisation between the ‘needle jockeys’ and the ‘tea-and-sympathy brigade’ and the necessity of reconciling and integrating these approaches. So can anyone reassure me that there has been some improvement in this respect? Or anything in the education of pain doctors which could alleviate my sense of despair?*

II do see grounds for optimism and this is why I started my current work and developing an app to help people with pain. I see this as a snowball which is starting to become big enough to soon make a lot of difference to a lot of people. I hope I am not overoptimistic as I am new to this party but the timing is right for a paradigm shift.

*In terms of the question about are things getting better or are there new things developing, I worked in pain management in the 90’s and evolved pain management programmes and we learned to teach the sort of techniques you have been talking about to other clinical psychologists specialising in pain. Self-efficacy – horrible word – can make a huge difference.*

 *The problem with hope is it’s all very well to tell someone to have hope but you have to guide that hope into something a person can do. Sometimes you have to challenge people and ask: what else do you think you are going to do? And they say: what is there? So you could suggest pacing their medicine and their exercise. Or look at other role models like soldiers walking to the North Pole which needs more effort but you have to start gently and build up.*

 *But I wanted to come onto the role of trauma behind pain; some of you may remember my EMDR talk and the ways we are discovering ways of getting into pain being in effect a message from the body about a completely unacceptable or unbearable situation which can’t be put into words. NMDR is a way of allowing the mind and body to speak to reveal that pain and in some cases take it away. So this is something which is coming in – it does better in case studies rather than RCTs . And that has given me hope.*

*We actually use EMDR in our unit and it works very well in certain types of patient. There are so many different things available; we need to coordinate and or efforts for instance towards reduction of opioids.*

*There are lots of reasons to be optimistic about things but of course that is not enough on its own and requires action. A lot of the things that have been said are good and true and there has been a paradigm shift in understanding. All these things are important but one thing I wanted to emphasise. I don’t like the idea of self-management and the implication that this is something people will have to do on their own. When we are at our best we do things together. And to some extent a lot of things that we do … but there is so much suffering to deal with that it defeats medical professionals. But actually it is in our own hands as communities. We talk about getting back to doing things socially and doing things that are meaningful to us as groups together. And the whole emphasis on this and empowering ourselves as communities and sharing stories … the social aspects of this are hugely important. When I sit in the pain clinic and people come to me who have waited months and nothing much has been done and they are on more and more drugs and I tell them that I am sending them to see our wonderful psychologist who does NMDR and all these things; and we have a trauma-informed pain management programme and they wait for that at least, but there are resource. So if could say that there is a community you can join and they will support you and you can do things together, and reach out to people who are socially isolated; that is something I need as a pain consultant and I think it would help my patients so much. Moving forward, powering the community and powering people to do things for themselves and putting tools in their hands – going down that route is a big source of optimism*

*I am a lot more optimistic now mainly because we have examples of people who are living well with pain and people can see that this is possible*

Website of Paind: [www.paind.com](http://www.paind.com)

Instagram: @paindofficial (recommended for keeping up to date)