

A new pain management programme designed for sustainable self-management

Joe Parsons and Chris Bridgeford



Joe:

For the past 8 years, I have suffered with chronic back and neck pain, and after seeing more than 30 different medical professionals, there is still a great deal of uncertainty about the cause of my pain. Scoliosis, Scheuermann's disease, ankylosing spondylitis, Marfan's syndrome and Ehlers-Danlos syndrome have all been suspected or diagnosed as well as several suggestions of growing pains and one suggestion of fabrication. Searching for a diagnosis felt so important to me. Every time scans would return clear I would be faced with the same dilemma that faces so many chronic pain sufferers: why am I devastated that nothing is wrong with me?

All that I have sought for so many years is to feel that my pain is validated, that I can put a name to it and that I can finally use it to help explain the way I feel to those around me. The lack of diagnosis left me with an inability to explain the pain to others so I set about writing a book with the hope of explaining what life is like for a chronic pain sufferer. I have interviewed tens of chronic pain sufferers to try and give a more representative view of life in constant pain.

However, every individual to whom I spoke inspired me to write a new section. One inspired me to write about the

specialists one might expect to see as a chronic pain sufferer and to detail the examinations and treatments one might receive, to make referrals less intimidating. One inspired me to write advice of how loved ones of those with chronic pain can provide constructive support. One inspired me to write about the biology of chronic pain and the mechanisms behind different analgesics and anti-inflammatories. Currently I am 150 pages in and have so much more to write and I hope that in a few years I will be able to share the book with the general public to raise awareness of all things chronic pain.

During the process of writing this book, I had the privilege to meet and interview Chris Bridgeford regarding his experiences of chronic pain. Chris however is no ordinary chronic pain sufferer (not that there could ever be such a thing); he runs a chronic pain support group and charity in Scotland called Affa Sair (or 'Awfully Sore' in Scots) which provides emotional support and education to chronic pain sufferers. Chris spoke of negative experiences that he had in pain clinics, of frustrations that he shared with clinicians about the lack of access to necessary resources such as psychological support and advice about benefits applications for those disabled by their pain. Having been under the care of two pain clinics myself here in the United Kingdom, I had similar sentiments and I set about researching pain clinics across the United Kingdom to determine the services that are available. Some provide extensive physical, psychological and occupational support, while others cannot access enough funding to provide anything outside of guided mindfulness and a couple of group exercise sessions. A postcode lottery is an understatement. Among clinicians I interviewed for my book, those who specialise in pain management agreed on the best centres in the country consistently and admitted that services were lacking in so many areas.

Given the issues with existing pain management, I toyed with the idea of developing a pain management programme but thought better of it. My thought process following the pattern 'I am a PhD student, I don't have the time. I am not a doctor, I don't have the expertise'.

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These excuses disappeared when the new National Institute for Health and Care Excellence (NICE) guidelines were announced in August 2020. Patients are to be encouraged to self-manage and will be pushed away from pain services. So I set about asking myself 'What is self-management?' and where can I get support for this. After reading hundreds of articles from patient voice to the International Association for the Study of Pain (IASP), I realised that self-management is two things:

- A beautiful concept;
- An empty statement.

Self-management has the potential to allow patients to take control of their lives if supported correctly; however, the support available to patients is found fragmented across tens of different websites and is often buried pages-deep into Google search results (where realistically no one is looking past page 1). Even if patients are able to trawl through and find all that is available, it is still insufficient to support the complex array of patient needs that come under the umbrella of pain management.

So I began making a list based on my own experience and the experience of those I had interviewed. What support do you want in your daily life? Physical therapy, psychological support, benefits and welfare advice, dietetic advice, education on drug mechanisms and side effects, relationship advice, coping techniques, guided mindfulness and so many more came out. That same day, I began writing an outline of an ideal pain management programme and contacted Chris to ask if he would like to be involved. Chris agreed and has subsequently become a dear friend and a great mentor. Over the past 6 months, we have developed a pain management programme that we propose to be standardised across the United Kingdom. Even more importantly, the programme would be delivered in a secondary setting so that patients can learn vital self-management skills without needing a firm diagnosis of the cause. I wasted 8 years of my life hoping someone would help teach me to manage my pain, and we hope that this will not be an issue faced by chronic pain sufferers again. There is no reason for patients to have to wait for a firm diagnosis before they learn to manage their pain. Maybe if patients learned earlier, their dependence on National Health Service (NHS) services would be reduced, which is the ideal situation for the patient, clinician and finance department.

A Christmas list of clinicians and services however would, understandably, be laughed all the way to the shredder by the NHS as it would not be financially viable within pain services in their current form. Therefore, all aspects of the new programme were costed using NHS Reference Costs (where

possible) and subsequently have gained the support of NHS Future Finance Leadership, though admittedly comparing costs against other programmes precisely is proving challenging as NHS finance departments all run very differently depending on the Trust they are in. However, we are confident our programme will reduce costs compared to existing pain management services.

In addition, a lack of clinical insight is likely to see the proposal veering back towards the shredder; therefore, a team of physiotherapists, psychologists, pharmacists, dieticians, rheumatologists, pain consultants, occupational therapists, benefits and work advisors and chronic pain sufferers has been assembled to advise on the programme and to ensure that the programme provides the best possible support to patients. We hope this programme will allow self-management to move from being a term associated with abandonment to one associated with empowerment.

Despite our extensive team of advisors, more guidance is always welcomed from clinicians and pain patients like those associated with the British Pain Society and thus any comments that you would like to make regarding the programme, we would be very grateful to hear, so please send them to joseph.parsons@postgrad.manchester.ac.uk



Chris:

I'm nearly two generations apart from Joe, so it is a disappointment that his experiences of trying to get help from the NHS for a chronic pain condition are so similar to mine. We both share experiences of disbelief (though consultants are generally far more open than they were in the 70s, and actually speak to the patient at the bedside these days), hours of painful prodding and poking asking if it hurts while you openly

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swear and cry a lot, exploratory deep digging expeditions for unexplained reasons (possibly training opportunities for junior doctors) and endless diagnoses. One main difference is medication. In my day more and more new powerful pills were handed out, these days they are taken away whether they actually work for the individual or not.

One of the most concerning problems for me is what the Scottish Government is proposing for the 1.09 million pain sufferers in Scotland – the move to self-managing their conditions. Although the Scottish NHS has saved my life more than once, they have had very little effect on my chronic pain condition, so I quite welcome the idea of self-management as long as I do not have to pay for such treatments like a private patient. So, although self-management is the current mantra from Scottish Government advisors and politicians, they do not say how the patient is going to be able to access such treatments. It looks like they see the move to self-management as a way of cutting the cost of dealing with chronic pain to the Scottish NHS and landing the sufferers with the full cost of their own (often private) treatment.

Joe and I came across each other when he approached the Aberdeen Pain Clinic when he started writing his book, and they in turn passed his request to me as Chairman of 'Affa Sair'. I do so love it when the universe makes connections.

So here we are, two people generations apart and also,

- One an Englishman,
- One a proud independence-seeking Scot.

Yet both of us share a need to fight for the good of chronic pain patients wherever they live in the British Isles and beyond.

Parsons-Bridgford pain management programme

The programme will last approximately 25–30 hours depending on how many of the optional one-to-one sessions patients request, and would likely be completed in 5 hour days over 5–6 weeks with sessions split into approximately 90 minutes each. The session would be delivered to groups of between 5 and 20 and would be available on-demand online for patients registered to the programme to ensure that those who are housebound or happen to be ill at any point during the programme do not miss out.

The programme would be a referral from the primary care setting where general practitioners (GPs) could enable patients to manage their pain while other secondary or tertiary examinations are being undertaken.

Patients will be asked which aspect of the programme's one-to-one support they feel is most essential to their self-management and their programme will begin with this. Not only does this help patients address their most important needs but it also ensures that patients feel autonomy and feel able to guide their own treatment. Pain management programmes are plagued by drop-outs, and thus, we feel that this choice is more likely to engage patients in the programme.

All sessions will also benefit from additional materials on a centralised chronic pain website which will be explained in the sections below.

The programme will comprise the following sessions:

Physiotherapy

Patients will receive 1 hour of one-to-one physiotherapy support to help develop an exercise regime within their capabilities that can be scaled up or down depending on how the patient feels on any particular day. This will reduce patient dependence on physiotherapy support from within the NHS and will enable better physical self-management.

A bank of hundreds of physiotherapy exercise PDFs and videos will be available on the centralised chronic pain website with explanation of their biological effects, how to scale them and who should/should not do them. With this patients will be able to choose to further their rehabilitation and even look for additional ways to improve their fitness.

Psychotherapy

Patients will receive a 2-hour individual psychotherapy session to identify those who may have large psychosomatic aspects of their pain and those who are at risk of mental comorbidities such as depression and post-traumatic stress disorder. This will help to inform clinicians of which patients could benefit from long-term psychological support. This session aims to reduce costs of mental health referrals by identifying patients who can benefit from support and treating them promptly, rather than waiting for much larger issues to arise. In addition, with the crucial role of psychology in pain presentation, this session will be important for improving patients' attitudes towards their pain, which frequently couples with subjective improvement in symptoms and quality-of-life.

A key point regarding this session is that patients will receive educational material in advance of the programme that will also be available on the centralised website, to better explain that psychology does have enormous impacts on pain and that psychotherapy is not a suggestion that it is 'all in your head'.

Occupational therapy

A 1-hour individual session with an occupational therapist will be used to discuss methods of improving the workplace environment for individuals to reduce the impact of work on their condition, for those in work. For those hoping to return to work, it will be used to discuss potential appropriate jobs or mechanisms of support by which patients can return to the workforce more easily. For those unable to work, this session will be used to determine how the home environment could be improved to ease symptoms of the patient, including information regarding grants that are available for disability home improvements.

This session aims to help patients feel more comfortable in the workforce or at home and to maintain or regain a greater degree of independence. In addition, enabling chronic pain sufferers to remain in, or return to, the workforce will have positive economic impacts.

Information regarding grants, training and more disability-friendly workplaces will be available on the centralised chronic pain website.

Pharmacy

A 3-hour group session with a pharmacist will be used to discuss the efficacy, mechanism of action and potential side effects of different analgesics, anti-inflammatories and other chronic pain-associated drugs, for example, anti-depressants. This is essential for educating patients that drugs do not provide a guaranteed cure and that certain drugs are not appropriate for certain pain. For example, a patient with Crohn's disease will be negatively affected by the constipating effects of opiate pain relief.

This session will allow patients to identify potential medications that are appropriate for their condition but more importantly it will prevent patients pushing clinicians for prescriptions that are inappropriate to their condition. Not only does this improve patient safety but it also prevents patients from developing negative opinions of clinicians 'denying' them drugs, further increasing the likelihood of patients cooperating with clinicians.

Patients will be able to opt-in to an individual 1-hour session with a pharmacist to discuss their specific medication. This will help patients to understand why previous medications have been unsuccessful, how they can avoid side effects and what medications may be the best choice in future.

Information about the aforementioned mechanisms of action, efficacies and side effects will be available on the centralised chronic pain website.

Dietetics

A 2-hour group session with a dietician will be delivered to help patients understand the role of diet in pain and how it should be used to avoid comorbidities such as diabetes and hypertension. In addition, a number of fad diets and exclusion diets are recommended across the Internet for pain patients, so the dietician will also seek to address the scientific merit in these diets and explain whether or not they are of any benefit, and more importantly, whether or not they are safe.

With the information gained in this session, patients can understand how better to use their diet to manage their condition and they can understand whether any exclusions could be beneficial to them or if any of their previous or current diets need to be stopped as they are likely doing more harm than good.

To supplement this information, videos of cheap, healthy meals will be provided on the centralised website. These meals will range to fit various dietary requirements and exclusions. Videos will also be provided detailing useful kitchen equipment for patients with chronic pain conditions to help allow patients to maintain or regain the capacity to cook comfortably.

Acceptance and commitment therapy

Six hours of psychologist-guided, group ACT will be provided to help patients identify negative thought processes and behaviours and to help them address how they can alter these so their mental state has reduced impact on their physical health. With better acceptance of their condition(s), patients will be able to understand the importance of self-management and may be able to reduce their clinical dependence.

Mindfulness is commonly recommended in the management of chronic pain and proves highly beneficial for some and ineffective for others. However, it is often recommended alongside ACT, and thus, mindfulness exercises guided by several different instructors will be provided on the centralised website so patients can access these resources at all times, not solely within the programme.

Coping techniques

A 3-hour, psychologist-led session discussing coping techniques will be used to discuss coping techniques with scientific backing, for example, breathing techniques, and for patients to discuss their coping mechanisms with one another. This may enlighten patients of better ways to deal with flare-ups and will hopefully reduce the impact of pain on their relationships.

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Breathing exercises and similar coping techniques will be demonstrated and described on the central chronic pain website.

Facilitating passions

A 3-hour session led by patients with 'lived experience', also known as those who have been in pain for a long time who have developed beneficial, healthy self-management practices. In chronic pain, patients often lose their passions; my own condition prevented me from continuing to play basketball which was my greatest passion. However, by now attending more games, I have managed to develop a sense that this passion of mine is still in my life. This is important for patients as maintenance of their passions, in some form, despite potential deterioration of physical state, can be crucial for maintaining a positive mental state.

For patients lacking in passions or hobbies, chronic pain-friendly hobbies will be detailed on the centralised website as well as methods by which the impacts of less friendly hobbies may be reduced, for example, how to reduce the impact of sports on joints with effective warm-ups, joint braces and so on.

Complementary therapies

A 2-hour session will be used to discuss complementary therapies that are not commonly provided by the NHS but that may provide benefit for pain such as acupuncture and chiropractic. The literature-based evidence for these methods will be discussed and how they can be accessed within or outside the NHS will be explained.

Ideally savings from the programme compared to existing programmes will be used to offer small grants to patients so

that they can try therapies such as acupuncture before committing to spending large amounts of their own money on receiving these treatments.

Family and friends session

A 2-hour group session with friends and family of patients within the programme will be used to help better explain the mind-set of patients and how loved ones can provide constructive help.

An optional 1-hour session for individual patients and their loved ones will be available for specific discussions regarding how individual patients can be helped and how problems generated by the patient's condition can be addressed to help maintain healthy relationships.

Extras

Currently, the format of any extra sessions is not complete, but it is likely that optional sessions of chair yoga, sleep hygiene, relaxation techniques, social sessions between patients on the programme and virtual reality methods will be added to the programme. Suggestions of further additional sessions would be greatly welcomed.

It is our hope that this pain management programme will be provided both online and in person by teams of clinicians specific to different areas of the United Kingdom. With this programme, we hope to improve standardisation of care delivered by pain management services and to provide more comprehensive patient support for their self-management. This service will preferably be provided in the secondary care setting so patients are able to learn to manage their condition while other investigations are ongoing, rather than having to wait until a dead-end in their diagnosis or treatment to receive self-management guidance.