

# Self-management – abandonment or empowerment

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The situation for chronic pain sufferers in Scotland is now at an all-time low. Like everywhere in the United Kingdom, NHS Scotland has had to concentrate on the Covid pandemic and so chronic pain sufferers have found their Pain Clinics closed and treatments such as lidocaine infusions halted without confirmation when they may start again. This has driven some patients to travel to England and access private practice there to get their infusions for a total cost of around £1,000 a time. Some Pain Clinics, including in my own region of NHS Grampian, have been offering virtual consultations using the 'Near Me' System – a medical version of Zoom.

In my part of the world, this is a very welcome and long called-for innovation. The main Pain Clinic for NHS Grampian is in Aberdeen. A round trip of 150 miles for me. Thankfully, in the first year of Affa Sair's existence a pain service was reinstated at our district hospital in Moray, saving patients from my immediate locale having to endure the 3-hour return journey, often by public transport. However, for any procedure recommended by the clinicians, sufferers are still made to travel to Aberdeen. Even worse, lidocaine infusions are not available in NHS Grampian because the clinicians there say they don't find any evidence for their efficacy. This is grossly unfair to the estimated 95,000 sufferers in the Grampian region as the treatment is available in 7 out of the 14 Scottish Health Board areas.

It is beyond doubt that during Covid, chronic pain sufferers will be at the bottom of the list as usual for any improvements in their treatments. Eight months in, Scottish Pain Clinics are only carrying out virtual consultations – no treatments for people suffering out of control pain whether Covid rages or not. It strikes me that to leave people suffering so much in the 21st century is completely immoral. I find it incomprehensible that professionals with a vocation for healing allow the faceless government advisors and NHS managers to put policies and budgets ahead of well-being. Such is the influence of these clandestine characters that people in total despair find themselves denied appropriate help available to the rest of society.

It is a sad truth that people not in chronic pain find it impossible to understand, or in some cases, believe how vicious it is.

The two phrases currently being forced on sufferers in Scotland are 'lived experience' and 'self-management'. I don't see the need for the first when the terms 'patient' or 'sufferer' tells it as it really is. What is included in 'self-management' is never explained but it has become the current buzzword when treatment is mentioned.

It would seem the term 'sufferer' is too brutal and negative for politicians so the gentler 'lived experience' is used to give a cosy, unchallenging feeling. The politicians and advisors don't want any brutal realism spoiling the numerous workshops and committees making decisions that have excluded the opinions of actual pain sufferers.

The 'self-management' phrase may be self-explanatory but the Scottish Government, their Advisors and other proponents of the ideology have never explained what treatments it covers. Until its meaning is explained, how can we judge its usefulness in helping over a million Scots suffering intractable pain which they wake up with and then try to go to sleep with every day and night until they die?

In my personal lifelong journey with pain – 42 years of continuous pain one day after another – I have had no real help from the NHS apart from ever more potent pharmaceuticals. Opiates are currently thought of as the devil's work by the medical profession. This is the same profession (spurred on by the chance of lots of money from the huge pharmaceutical companies in America) which told us the drugs were a wonderful way to control the pain. What happens in America soon happens around the world, of course. For me, in my long journey with chronic pain, it is a personal decision on the good and bad of opiate use. I do not think they should be used as a first line of defence for chronic pain, but neither should they be forcibly removed. The long-term way to help a chronic pain sufferer is through information not prohibition.

So, what sort of methods could be included in Self-Management Treatments?

The treatments I have used throughout the years are Reiki, Alexander Technique, Acupuncture, Meditation, Counselling and Psychological methods including Psychiatry. They all have one thing in common – they cost money. The most expensive of these was Psychiatry at £75 an hour, some 10 years or so ago. Nowadays, the more common private Psychology sessions come in at £150 an hour. Reiki and Acupuncture treatments currently start at £40/50 an hour. These are just not affordable for chronic pain patients reliant on hard-won benefit payments which can be withdrawn on a whim. I have also used equipment and aids (all at a personal cost) such as Infrared Lamps, TENS units, heat pads, CBD Oil and capsules, Musselflex Gel (Green-lipped mussel extract) and Capsaicin cream, various shaped pillows, expensive mattresses – anything to give me even a moment's relief. None of the treatments and very few of the aids are available free of charge on the NHS.

Manchester University PhD Medical Student Joe Parsons and I are currently working to develop a Self-Management Programme which will have the respect of chronic pain sufferers, by not making the patient feel cast aside. Initially, those taking part must have face-to-face contact with the programme instructors and this contact must be carried on at intervals throughout the programme. Outwith the initial and follow-up 'in-person' sessions, the remainder should be available virtually so that patients do not increase their pain in travelling long distances. A question and answer system should be provided so patients can ask individual and private questions. These questions need not be answered immediately but a reply guaranteed within a certain amount of time.

We feel a successful self-management programme should include the following.

### Meditation/mindfulness

These sessions should be available online with standardised video or audio files to reduce cost and ensure these resources are available long term. The same should be done for treatments like Yoga, Tai Chi and basic physiotherapy exercises.

### Physiotherapy

Individualised physiotherapy regimes would be developed in an individual session with a physiotherapist. This can reduce the long-term reliance on repeated physiotherapy referrals. The idea would be to have this initial consultation with provisions of what to do if you feel like the physio is too much (how to reduce the intensity of the exercises) or what to do if you feel like you can do more (how to increase the intensity). This would ideally be followed by online consultations initially monthly and then slowly decreasing the regularity until there is a biannual

in-person physio appointment. As much as this results in continued physiotherapy, it reduces time and cost with repeated referrals and hopefully the patient will benefit in a way which means they no longer feel they need the help of the other pain management services.

### Psychotherapy

It is crucial that there be an individual psychotherapy session. This is very important in identifying those who could receive genuine benefit from psychological support. It is also key for so many patients to feel heard, particularly by medical professionals. This should be in the form of a casual chat so that it ends up being patient-led, as this will not only allow the patient to feel heard, but it will allow the psychotherapist to identify any potential areas in which they can help. This needs to be designed to ensure that the patient realises the psychotherapy is part of a full treatment regime and is not a way of suggesting that the pain is 'all in their head' – frequently heard from many chronic pain sufferers not fully understanding what the health professional means.

### Alternative therapies

Alternative therapy sessions where patients discuss their experiences with and have the opportunity to access treatments such as Acupuncture, Chiropractic, Reiki, Alexander Technique, Wim Hof method and Hydrotherapy.

### Diet

A session with a dietician can be important as chronic pain sufferers may genuinely benefit from certain exclusion diets, but it is important that the dietician can confirm which of these diets are beneficial and which are nonsense. In addition, the dietician would help to prevent issues with comorbidities.

### Peer advice

It is imperative that those taking part get help from sufferers who have battled chronic pain for many years. An initial coping technique session could be done as a group discussion forum. As with the other disciplines in the programme, online reviews must be available.

### Navigating the benefits system

Benefits advice sessions to discuss government benefits and other potential sources of income and support for individuals with chronic pain is a necessity as remaining employed is often incredibly challenging. The current tests are ridiculous and humiliating for people who have genuine health problems. This could potentially be provided by Citizens Advice staff and also feature in the 'Peer advice' section.

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**Hobbies**

A facilitating passions session where we determine what people's passions are and how we can ensure that they can maintain these even with health complications. If people don't have passions, we can have sessions where creative outlets such as drawing, painting, writing, computing and crafting can be experienced.

**Pharmacists**

A medication forum run by a pharmacist would be useful in discussing the mechanism by which drugs work, their successes in different people and in different conditions so that patients can be more informed in their drug choices. This will give the patients room to discuss their own personal experiences with these drugs so that peers feel that they are not just getting statistics but a more personal touch on the experiences a cocktail of drugs can bring.

Whether you are an advocate of self-management or not, it is clear that an efficient and successful programme needs to be available within our NHS. Otherwise patients will take a scattergun, often futile approach to improve their health. Many patients will be led down dark avenues by unscrupulous con-artists looking for a fast buck from desperate souls. With professional advice denied them, patients could well end up taking dangerous drugs disguised

as supplements and interfering with the efficacy of prescribed medications. Only budgets and the unscrupulous will benefit from pain sufferers being cast adrift from NHS services they pay for through their taxes.

There have been welcome changes recently in the make-up of Scottish Government Advisory Groups. First, the National Advisory Committee for Chronic Pain has included patient representatives for the first time and have also invited three new third Sector groups to sit on the Committee, The Centre for Integrative Care based in Glasgow, SAMH (Scottish Adult Mental Health) and I'm really honoured to say – Affa Sair – my own charity. I, and many others, have been hugely critical of the NACCP in the past, but we welcome these new developments and certainly Affa Sair looks forward to working progressively with the NACCP to better help Scottish Chronic Pain Sufferers.

Second, a new Chronic Pain Reference Group has been formed under the leadership of The Health and Social Care Alliance (The Alliance). The Alliance have managed to form together a group of chronic pain sufferers from all over Scotland from which five representatives and five deputies have been chosen to bring the members opinions and comments to the NACCP. This is in early stages with Terms of Reference still requiring to be formalised as I write but inaugural patient representatives have been chosen to serve for a period of 2 years.