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Physician, heal thyself

Mindfulness – the Art of Presence

Pain Patient Pathways implementation

Report of the First English Pain Summit

Online Pain Management Programme

Interdisciplinary nature of the PMPs



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Pathway through Pain – online pain management programme

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Pathway through Pain is an online pain management course. It is currently being piloted by a number of NHS trusts and offered to patients as part of a portfolio of pain services. It is already proving an effective tool for improving patient self-management skills, with significant improvements reported in terms of health, disability, anxiety and depression. Results for these can be seen at <http://www.pathwaythroughpain.com>



My interest in online courses for patients started when a few years ago I saw a paper demonstrating the efficacy of an online cognitive behavioural therapy (CBT) programme for depression. Two thoughts struck me: the first was to be amazed that you could achieve results by interaction with a piece of software; if CBT could be done by a computer, the change was clearly something relating to the process that the patient was engaged with, aside from the magic and skill of the therapist.

This was news to me because I had always thought there was an element of charisma and persuasion involved. I had worked with a number of really impressive psychologists who seemed to get great results, and less good folk who got moderate results. (In addition, I recall a whole issue of *The Psychologist* focusing on the subject that nobody dared mention: the importance of the therapist in outcome. The conclusion confirmed that the therapist mattered.) But here were data suggesting that it could all be done by a software program – very interesting!

The second thought that struck me was that if online treatment worked for depression, where CBT had been shown to be effective in general terms, then why couldn't it work for chronic pain management, where there was similarly convincing data?

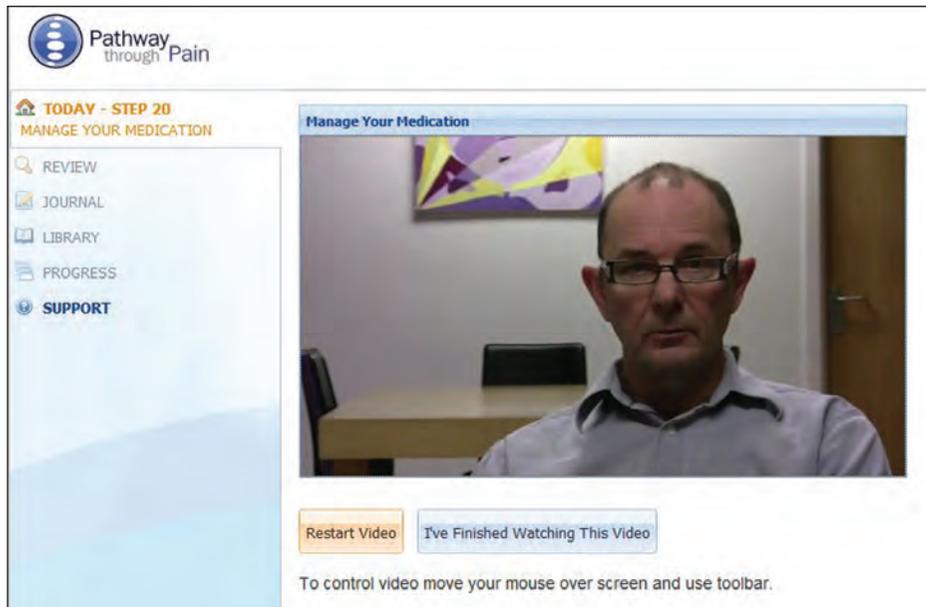
Working with Wellmind Media, a publisher of online health programmes, the possibilities of an online approach suggested many potential advantages. Here was an opportunity to properly educate patients about the complexities of chronic pain. We could use technology to prompt and nudge, we could measure outcome using various validated computerised tools, and there was the possibility of the provision of access for those not able to attend groups or therapists face to face. So why not develop an online course encompassing the best elements of our conventional programmes in a package delivered through the internet?

The naysayers immediately came up with a number of problems and pitfalls, mostly related to the percentage of patients with access to the internet who would have the necessary skills to negotiate their way around such a package, but working on the basis that even if it was a small percentage of folk who could access the course, it would still be worthwhile.

The conversion of this roughly hewn idea to a working and sophisticated online course is thanks to the hard work, ideas and experience of Wellmind Media. As the development started, what rapidly became clear was that my own ideas of how we might translate the complex and comprehensive components of a pain management programme (PMP) into a usable format, were based on an outmoded scientific educational experience that just would not suffice for an online package aimed at a general public of mixed educational attainment, and who needed to be kept interested if they were going to complete the whole course. In addition, it became clear that the user interface had to be totally bullet proof; it had to work with one click, and never lead you up a blind cul-de-sac.

The eventual format of 24 short video-based modules of about 20 minutes each, felt very different from the traditional medical learning paradigm of my studenthood, but we were able to include many other aspects that I considered crucial, such as inclusion of whiteboard teaching on pain mechanisms, ideas about acceptance and a diary facility to jot down thoughts and feelings as part of the cognitive modules. We also included a series of guided audio meditations for relaxation

Pathway through Pain – online pain management programme



Charles Pither leading a module on the course.

and mindfulness, which had already proved their value with Macmillan Cancer Support and its online community. The guided meditations have proved very popular with participants and seem to be used predominantly to self-manage during pain flare-ups and help with stress and sleep problems.

The area that caused us the most angst was how to deliver the stretch and exercise programme. Our concerns were getting the balance right between the person who could cope with the Mr Motivator-style TV exercise regime, versus the person severely disabled and barely able to get to the general practitioner (GP) surgery. In the end, we kept it really simple, focusing on the general not the specific.

The technology development team also designed fantastic VAS 'sliders' that give the participant the opportunity of scoring their pain along with a number of other modalities whenever they login. This enables participants to track any improvements while they progress through the course and to consider what

aspects of pain management are working especially for them.

After a year of work, and a great deal of glitch sorting, we finally started recruiting volunteers over the internet to pilot the programme, provide feedback and help us to make improvements.

Even from the earliest days it emerged that people really did engage with the online course. Patients (if they are that) like it, and if they start it, on balance they complete it, taking on average of two months (perfect!). They slide the sliders, press the buttons, do the tasks and write heartfelt comments in their pain diary, and most importantly give things a try in their daily lives. Maybe this is a key advantage of an online course: it is accessed by people while in the reality of a typical day and so gets them practising pain management in the here and now. It seems that they really do feel that they have a relationship with a trusted friend and experienced counsel, and many report those same 'Ah ha!' moments we know from our face-to-face experience.

We have discovered that the best way for the online course to be delivered is within the auspices of a multidisciplinary pain clinic. This is not surprising. Look at how much you get from your online Etruscan ceramics distance-learning programme, then add in supervision, chat and a regular call from your tutor and you will do better. Anchoring the course within a specific clinic not only allows us to personalise it with screens specific to the unit, but also allows the course to be integrated into the other modalities of the treatment package.

The marvellous feature from our perspective is that the program generates its own outcome data. Once a user completes the course, we have data from numerous self-evaluation questionnaires measuring changes in various domains. No need for postal questionnaires, face-to-face follow-up, or that tricky telephone call; we have the data, which is shared with the participant and their clinical referrer.

We now know that those completing the online course make, on average, a 20%–30% improvement in health, mood, confidence and general function. What is more extraordinary is that participants' physical function and walking distance also improves. Completion rates are above 60% (which, believe me, is good for this type of protocol), with many more people than not making a worthwhile change.

But the real point is this: it costs less than £150 per person, less than the monthly cost of few medications. We can agonise over treatment efficacy and ponder about whether the person is ready for change, but at such a low price it just might be the most cost-effective treatment that can be offered to a chronic pain patient.

For the future we need to know more about who can get most from the course, as well as more fine-tuning of the course content, but that an online course can help those with persistent pain to make key changes to their mood and function is now not in doubt.



Feedback from participants Deborah King, Participant

As a sufferer of chronic pain for over 20 years I began the online Pathway through Pain program with great scepticism. Doctors and so-called health specialists had always promised so much and disappointed so often. How could an online course help? The Pathway through Pain program helps you by changing your long-held views about pain and by teaching you to help yourself.

In the first week, I was still a sceptic; as each health specialist presented a short video on the programme, I always looked up their profile on the internet to check out their credentials, but soon began to realise how fortunate I was to be given help and advice by such a range of well-qualified, respected consultants, doctors, physiotherapists and so on.

I had always thought that 'there is no simple cure' to back pain and strangely this is why I really believed in the health care specialists I was introduced to on the programme – they agreed with me! However, while they do not offer a cure, they do offer practical advice that is easy to follow, simple to fit into your day-to-day life and realistic.

As you can only complete so many steps of the course at a time you have time to practice each exercise you have covered that day. This could be a psychological exercise like relaxation or a physical one like gentle stretching. All these methods and exercises I had tried before but it was only when I changed my beliefs about pain and put all the tools the program offers together, that I began to see positive, lasting results. By the middle of the course I was eagerly awaiting the time when I could access the next steps of the program.

For the course to be successful, you will need to have an open mind and be prepared to try all the suggestions and see if they work for you; even if you don't think they will work, they may!

By the end of the online course I had really changed my way of thinking and this helped me to change my life. I still have some pain but I have now joined a gym, go swimming regularly, go for long walks and have planned a long flight to see my son in America, all things I couldn't have even hoped for last year.

Elizabeth Dutton, Participant

Two years ago, I had a fall skiing and fractured a vertebra. Although X-rays and MRI scans showed the fracture had healed, from that point on I suffered from chronic back pain. None of the interventions I tried had any noticeable effect on the pain and increasingly I began to feel like a 'victim'. The pain, which intensified during the day, had a negative impact on my working and domestic life and increasingly restricted social activity.

I had more or less given up hope of ever getting to grips with my pain when I discovered the Pathway through Pain course. Doing an online course did not immediately appeal to me because I, probably like most people, was used to a



more hands-on approach. How wrong I was! On the contrary, the course is designed in a way that is accessible, supportive and, most importantly, motivating. Having started it, I was hooked!

The online course has given me practical tools for dealing with my pain including exercises, relaxation techniques and meditation. These, combined with new knowledge and perspectives about pain and pain management, have empowered me to take greater control over my life. This means that although I still have occasional pain, I have the confidence to deal with it.

Being liberated from pain in this way, I have a much more positive outlook. My husband says I'm a lot easier to live with and I have even taken up gardening again. One of the key lessons I have learned is pacing myself, particularly in relation to work. I am self-employed and need to spend long periods of time sitting at a computer. Whereas in the past I used to sit for hours writing reports, I now take regular breaks, away from my desk, often using these breaks to take short walks or do stretching exercises.

For more information about the online course please visit: <http://www.pathwaythroughpain.com>