Back pain management programme

Expert patient talk

My experience of the back pain management programme by Rachel Thomas

Introduction

I started to suffer from episodes of severe back pain when I was 16 years old; it is a measure of how things have changed in terms of medical diagnosis, understanding and support in the intervening 30+ years that my GP’s opinion back then was that the roots of the problem lay in my being “a girl, and therefore not built to lift things”.

As time passed, the periods of time between these episodes of pain shortened, and the pain itself became more intense and disabling. I was beginning to have to take sick leave for longer and longer periods, was visiting an osteopath, and casting around for prescription or over-the-counter pain relief that had any worthwhile impact. I also, without realising it, was starting to decide not to do things based on the actual pain, but also on the fear of the pain and of its worsening.

In 2009, I was hospitalised for the first time, and as alarming and distressing as it was; it turned out to be the ‘silver lining’ I needed as I entered the world of modern, common-sense back pain management at Addenbrooke’s Hospital.

I know what I cannot do; now I want to find out what I can do

This was my response when asked what I’d like to get from the programme. In fact, I came to see that my perceptions of what I could and couldn’t do were either incorrect or seriously flawed, such as “I can't do strenuous exercise”, or, “I can never relax”, or, “My back is very fragile, I must live a reduced life around that fact”.

My pain is always very bad

Completing the pre-programme diary showed me there were in fact times when my pain levels decreased, often during times when I was doing something I enjoyed that relaxed me, such as listening to music. I began to learn how tension feeds pain.
**Tension feeds pain**

This is one of the most important lessons I learned from the programme: pain makes you psychologically tense; pain can be extremely depressing; pain feels isolating.

All of these psychological states mean that we will be adding still more muscle tension to that which we are already experiencing due to our back conditions. This is an **irrefutable** fact; how we feel psychologically affects how we feel physically. It is crucial for us to practise concentrating on finding what triggers a more relaxed state. For example, I find it is not possible to feel tense whilst watching birds feed on the bird table. It can be something as simple as this, and is likely to be personal to you.

**I have had a flare-up/setback; I am a failure**

You will be told on the programme that flare-ups are common, set-backs rather less so. I was re-admitted to hospital at Christmas, 2010 (I attended the back pain management programme in May of that year) when a cough I’d had for several weeks lead to severe back spasms. I felt I’d let everyone down, my consultant included. He reminded me that the programme wasn’t a guarantee that I’d never have flare-ups or set-backs, but if I continued to utilise all I’d learned, I should recover far more quickly from each episode. This was indeed the case. I was able to return to work the week after I was discharged from hospital, a huge improvement on the weeks I’d have had to take off under similar circumstances previously.

**I’m fed up with doctors; there must be a cure for this**

I realised that on many occasions, I’d come away angry from a doctor’s appointment because I hadn’t heard what I wanted to hear. For instance, I had requested “an operation to fix my back”, but it was thought to be too risky. I was not ready to accept that it was time I developed a more mature and rational approach. But eventually, I’d just got to accept it is how it is, and to find out what sources of help were actually available to me to enable me to manage my symptoms. Remember: if your doctor could cure you, he or she would.

**What do you expect?**

It is very likely that, by the time you get referred to the BPMP, you will have lived for a long time with back pain and its impact on many, if not all, areas of your life. By the time I was referred, I had lived with increasingly severe pain for more than 25 years. Put simply, if I left my car in the garage for even five years without turning the engine over or working on it in any way, I should not expect it to spark up first time of asking. Why would your body be any different? You will have been holding back, limiting movements, tensing muscles, adapting the way you walk in so many subtle ways you are not even aware of in your attempts to protect yourself from increased pain. You will need to start to unpick this by trusting what you are told and shown on the programme.
Pacing a problem?

People who suffer back pain come from different backgrounds, can be any age, have different interests, be single, be married with a family.... In fact, apart from living with pain, in my experience, there is only one thing we all seem to have in common, and that is real difficulty in accepting the idea of ‘pacing’.

That applies to me, too. It is a hard message to convey to myself as well as to any other person I meet on the programme, but the fact remains, if we choose to ignore pacing ourselves in our daily activities, we have to take responsibility for the fact we are consciously opting for a risk of increased pain.

No-one understands

As with back pain, so with everything else you could think of in life, you cannot expect people to understand what chronic back pain is like unless they have experienced it themselves. Trying to get people to understand shouldn’t be your goal, and will only get you down and waste energy. The goal should be to get those around you to accept your situation at those times you need to explain it, or ask for help with a task. It is much more likely that you will get that acceptance if others see you taking appropriate, confident care of yourself; I have found that the more confident I feel in managing my own condition, the less I actually need to feel ‘understood’. I also have found others are very interested to hear what the BPMP is all about (and the bit about the gym is always a surprise!)

It’s pointless, it’s too late

If you think it’s pointless to try, or too late to make a difference to your situation, then that is because the depression and lethargy generated by living with pain has put itself in the driving seat of your life, and is speaking for you. It is not a medical fact that you cannot make changes that ease your symptoms, nor is it a medical fact that, even after many years of living with pain, a significant difference can’t be made to your quality of life by absorbing the lessons learned on the BPMP.

I do hope you found my talk helpful, and that the programme as a whole gives you a life-long toolkit that you can dip into time and time again. Whilst this isn’t a fairytale of instant cures, it is nevertheless a major step towards putting you back in the driving seat of your life, getting long-held fears into perspective, and putting something other than pain at the centre of decisions you make. I wish you much improved health and happiness and confidence for the future.
We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Help with this leaflet:

If you would like this information in another language, large print or audio format, please ask the department to contact Patient Information: 01223 216032 or patient.information@addenbrookes.nhs.uk