

Information for Patients

Controlling your pain and the problems this brings



It seems like the most logical thing in the world to try to do. Indeed, most pain services in the NHS and beyond are often very focused on getting control over pain, and use a huge range of different methods to do so. You may have experienced many of these. Control measures might include the medications that you have had and the different ways you've been asked to take them. Then there's acupuncture, TENS, and the various types of injections and surgeries that are offered to many. All in the service of trying to bring pain levels down, or get rid of pain, or indeed to get it to a level that it can be managed.

Getting control makes sense – doesn't it?

And why not? It seems that if only the doctors can intervene then things will be ok, be better than they are at the moment. And it seems to make logical sense, that if the pain can be controlled, then you can get back to all the things you've not been able to do since the pain got worse. We read lots every week in the news about the marvels of medicine and how it can help cure people of things or at least get them back to a healthier life. So why should pain be any different? After all, this is a physical condition and that's what doctors are there for, right? **Pain interventions = Pain Control = Relief = Better Life.** Right?

You also see a certain message all the time on TV and the radio. Phrases like "Battling to overcome", "fighting the disease" "not giving in to it" and "getting control over it" are used to describe our relationship to illness, as if we have to "win the fight" in order for things to be better.

So far, so logical.

All this would be perfectly reasonable, if it were not for the actual experience of many people living with chronic pain. If we look at the lived experience of many, we often don't see the logical outcome we would expect from trying to control, or get rid of, or fight the pain. Many people report that while they get initial pain control or relief using a new medication, or injection, this relief does not always last long, and there is a gradual return to the pain levels felt before.

Sometimes there can be better control, with the result that folk can get back to doing more and feeling less distressed by the pain. However, after a while the effect of the intervention gradually becomes less for many. This can have a psychological effect on people when hopes have been raised that their pain can be controlled to a greater extent than they had previously thought. Hopes can be dashed if pain returns.

Does any of this ring a bell for you? What has been your experience of trying to get longer term control over your pain?

When pain is controlled a little better, this can often be a cue for people to get back to the many things that they have stopped doing. Often people feel the need to get lots done during a "window of opportunity" that less pain gives them. This is very understandable and simply human nature. What often happens as a result, though, is that overdoing activity leads to more pain as we get our bodies to do more than they are used to, or have been able to do in a long time. So we end up with more pain, less control and feeling like we are "back to square one". This can be a common end result of trying to get more control over pain, and an unintended consequence. If this has happened to you, it's not your fault.

A different type of “Boom and Bust”

What can often follow is an attempt to get back the control that you experienced, even though it did not last long. Sometimes this results in a raising of hopes, a focus on the next thing the doctor has to offer, some period of relief and a gradual return to the same pain levels as before. This is a type of “**boom and bust**” that is often less talked about in chronic pain, and can result in more distress and disability than might otherwise be the case. And the more we try to control things that aren’t that controllable, the more focus there is on that control. Keeping away from things that cause pain, using too much medication, having thoughts about how frustrating things are, and feeling low about what is happening and anxious about the future can be the result of these attempts. And think about all the energy that goes into all of these attempts at control. Many often find that their experience of pain gets worse, not better, as the suffering generated by trying to control pain increases. Strangely, pain ends up being back in control despite all the effort. If you end up making decisions about what to do based on how your pain is, who’s really in charge?

Before we know it, our attempts to control pain lead to more and more suffering as we try more and more things to succeed in our efforts.

Does this sound familiar? Don’t take our word for it. Look to your own experience to find out whether your attempts to control pain have been successful or not.

If you’re struggling to get your head around the idea that controlling pain might not work, this would be understandable. You might want to take some comfort from the fact that a lot of scientific research with people who have persistent pain has shown that the more effort we put into controlling pain through avoiding things that cause it or make it worse, the more problems we have in actually getting control.

Why is control such a problem?

Part of the answer lies in the fact that as humans, we are not very good at accepting the idea that some things are not under our control. Especially unpleasant things. We are used to figuring things out. It's in our genes to look at a problem and find solutions. And out there in the world there are lots of examples of how well we do this. However, it is often different for our internal problems, and despite medical advances there are many conditions which are long term in nature and where there is no control or cure. This often "does not compute" in our minds, and we go back to trying to control or get rid of the bad experience or situation. And so the problem goes on.

Is there an alternative to control?

So if your experience is one of more pain and suffering despite (or because of?) the effort put in to keep it at bay, what are the options for you? What on earth is there left to do if pain control is not the solution? A way forward, we believe, is to look again at that word "acceptance".

Acceptance as an idea can often throw up lots of strong emotion, often to do with "giving up", being "taken over" by the pain, or just "lying down and taking it". Of course when this is felt to be the suggestion, it generates huge upset and often a renewed effort to struggle on, keep pushing and "never be beaten" by the pain. This puts us back at the start of our conversation about the pain. So the word "acceptance" is often not a good one.

Rather, we wonder if people can be open to the simple idea of recognising that there are some things that are beyond anyone's control, and that this might include persistent pain. And in recognising this, rather than giving up, we might in fact be able to see more clearly some of the efforts we have come to make in trying to control, and consider the tantalising prospect of reinvesting that energy into the things we want to do, we can do, and which might give our lives more meaning than before.

This might sound quite scary, that pain is not controllable. But is it any scarier than the thought of continuing to battle it for the rest of your life?

Are you willing?

This so-called “acceptance” is not giving up (quite the reverse in fact), but rather showing a “willingness” to have things in our life that we can’t control. Even more than this, it means considering the possibility of deciding who you are, who and what you want to be, and whether it might be more possible to get back to doing some of the things that make you, you, even if this means taking your pain with you, rather than trying to do all you can to leave it behind first.

Imagine all the energy you currently use to control your pain. Thinking about how to steer your day to avoid more pain, trying to avoid others or telling them exactly how you feel so they’ll understand, all the attempts to figure your problems out in your head, and all the possible medical routes for that final cure. Imagine “cashing in” all that energy into a bank account.

How much “money” would you have? And if you had choice, how would you really like to spend that “money”, if all that investment in controlling the pain has come to nothing? We might be able to help you at the pain clinic “reinvest” your efforts and reduce the distress and suffering that your may be experiencing.

We would wish you to appeal to your own experience in deciding what to do next, not this writing. If control over pain, or continually fighting or battling it is not working for you and letting you lead the life you want, is it worth considering an alternative?

Even if that alternative doesn’t seem to be the most “logical” thing to do?

