

THE PROBLEM WITH PAIN SCALES

Whenever I ended up in hospital or a clinical appointment (which happened far more than I would've like), I was asked "How would you rate your pain on a scale of 1-10?" When I began to seek help for my chronic pain in the late 1970s, I never saw a problem with the question. However, as time and my own knowledge has moved on, it's clear now that the question is really inconsequential for gauging how the never-ending pain affects me and my circle of loved ones. I'm certainly not unique in my dissatisfaction with the overly-used 1 - 10 pain scale or even worse, the 1 - 4 scale I came across in Accident and Emergency the other month.

Everyone is unique in how their pain affects them. Even people with the same condition or label for the pain don't experience the same pain levels. Some people tolerate more pain than others all the time or dependent on how long they have lived with their pain, and so their pain score will be lower.

Although I am always in pain (and I do literally mean always - which in itself seems hard for the non-pained to comprehend) the pain levels can change immensely day by day and even hour to hour. This is caused by many things such as the weather, my mood and my stress level at the time. During an appointment for example I could be stressed and tired out by travelling to the appointment, especially if it's many miles away from home. This happens a lot if, like me, you live in a rural area. Travelling for about three hours is pretty common in my part of Scotland. At the time of the appointment my pain could be a 5 on their scale but when I get home it could be an 8 for the next couple of days as I recover from the journey.

Many people will be guilty of being influenced by how desperate they are for help by increasing or lowering the score. Some patients can be worried that they will not be taken seriously if they are having a good day and their pain level is low at the time. The clinician's own perception of the scale can also influence things. They may think that 4 is very low and not worth bothering about. Dangerously, all this misinterpretation could lead to an inadequate amount of pain relief or even the wrong treatment being given.

During an appointment you normally get the chance to discuss your chronic pain issues after you've rated your pain level. However when the pain scale is used on a questionnaire it becomes even more unhelpful. With no chance to discuss what you mean by picking a "3" doesn't give you an opportunity to make it clear how the pain makes you feel, what sort of pain you are experiencing, or how it affects your ability to cope.

In the 1970's, McGill University in Canada developed the McGill Pain Questionnaire which is now used worldwide. It has questions about the type and quality of pain that an sufferer may be experiencing. The university also produced a pain scale which shows different conditions on a line that ranges from the least to most painful conditions. This scale starts at zero (no pain) and ends with 50. It gives a relative idea of pain severity, such as a bone fracture to childbirth, cancer pain and many in between. Incidentally, this widely known Pain Scale was utterly dismissed by the main instructor at the Glasgow Residential Care Treatment Course some three or four years ago run by the Scottish National Health Service where Pain Clinics in Scotland can send their patients for three weeks. She said she had never heard of it and I vividly remember her stating the scale was dangerous by comparing different pain conditions with each other.

The Wong-Baker Faces Pain Rating Scale which features a series of faces representing what different levels of pain "should" look like is a wee bit more helpful. Under each face is a number, ranging from 0 (no pain) to 10 (the worst pain imaginable). Patients are asked to look at the faces and circle the number which best represents how their pain makes them feel.

Despite living with chronic pain since 1978, I don't really have a definite diagnosis – which isn't that unusual for someone my age. It started off as ankylosing spondylitis (and is proven by x-rays), then labelled as "neuropathic pain", "complex neuropathic pain syndrome", "complex regional pain syndrome" following serious surgery in 1995, with "fibromyalgia" now appearing to cover my symptoms. Whatever label you give it – it is devasting and has seriously affected two-thirds of my life.

After 1995, with CRPS being described by the worst pain imaginable on the McGill Pain Scale, I wasn't shy about giving my pain score a high 8-10. Then, a few years ago, "the worst pain imaginable" for me was changed when I needed to be put into a coma to cope with a serotonin syndrome induced headache which had left me incoherent on the floor at home for my wife to find.

What I've learned over four decades of pain is that it truly is subjective. Your pain is unique to you. No pain scale can reveal that without some sort of description of how it affects your ability to get through the day.

Not that I'm likely to be attending a pain review anytime soon, but in future I will bring along my own pain scale to try to get over what a day in chronic pain is like. Something like this:-

| 10 | Unable to Move | I am in bed or trapped in a room due to my pain. I need to be taken to hospital to get help. |
|----|----------------|--|
| 9 | Severe | I can barely talk, move or think of anything because of the pain. |
| 8 | Intense | Talking and listening are difficult. My pain is so bad it's hard to think of anything else. |
| 7 | Unmanageable | I am in great pain all the time. It keeps me from doing most things. |
| 6 | Distressing | I think about my pain all of the time. I've given up many activities because of my pain. |
| 5 | Distracting | I cannot do some of what I need to do each day because of the pain. I think about my pain most of the time. |
| 4 | Moderate | I am constantly aware of my pain but I can continue most activities. |
| 3 | Uncomfortable | My pain bothers me but I can ignore it most of the time. |
| 2 | Mild | I have a low level of pain. I am aware of my pain only when I pay attention to it. |
| 1 | Minimal | My pain is hardly noticeable. |
| 0 | No Pain | l have no pain. |



Chris Bridgeford is Chairman of the Scottish Charity - Affa Sair – Scots for "awfully sore". They currently have over 680 members, an information-filled website at www.affasair.org and a well-used private Facebook group where most member interactions take place.

Affa Sair is one of the charities on the Scottish Government's new Pain Management Framework. The charity has taken part in many consultations, surveys and webinars from universities and health organisations in both Scotland and England.