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self help for chronic pain sufferers

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NICE vs SIGN

There was great consternation and fear among the 1.09 million chronic pain sufferers in Scotland earlier in the year when NICE (National Institute for Clinical Excellence) released their new guidelines for dealing with chronic pain. Headlines screamed from various newspapers and magazines saying that chronic pain sufferers were no longer to be given any pain killers but were being told to exercise and self-manage their pain instead. For once, the headlines were actually spot on and NICE have indeed come up with guidelines that leave chronic pain sufferers in permanent agony. The better news for Scottish pain sufferers is that the NICE guidelines do not apply here, so many of the fears, amongst this already poorly treated section of the community, are unwarranted.

It's the same old story that when the media speak of the "UK" they invariably mean England. It's a sad fact of life on the island we share, that this error, is never corrected or even given a second's thought. Since 1999 with the formation of the Scottish Parliament and devolution, some of the most important aspects of Scottish lives such as Health and Education are no longer under Westminster's purview.

In Scotland, SIGN (Scottish Intercollegiate Guidelines Network) produce the guidelines for medical treatment. SIGN 136 is their guideline for specifically dealing with chronic pain. Every pain consultant, health professional, physiotherapist or nurse work under the SIGN guidelines. Only where SIGN have no guidelines on a subject should the NICE guidelines be taken into account.

So, how different are the guidelines.

For a start there is a subtle but telling difference in the intent of both guidelines. The SIGN guidelines emphasise that "The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan." The NICE Guidelines clear instruction in the first line of their explanation state "When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account ..."

On comparing both documents my impression, as a chronic pain sufferer of 43 years, is that the NICE Guidelines are far more imperious than the SIGN Guidelines.

Both documents stress the need for a person-centred assessment to find what contributes to the pain and how it affects the person's life. SIGN 136 goes on to stress that "A compassionate, patient-centred approach to assessment and management of chronic pain is likely to optimise the therapeutic environment and improve the chances of successful outcome." In other words "listen to the patient" something my own GP often says but which sadly many patients report just doesn't happen.

For me, the different ways in which each guideline deals with the pharmacological management of chronic pain is telling. Though NICE strongly advocates that chronic pain sufferers not be given any painkillers (even paracetamol) to help with their devastating levels of pain, SIGN 136 recognises that strong Opioids, NSAIDs Paracetamol, and Lidocaine can be considered in the treatment of chronic pain. There are caveats of course but they seem very sensible to me. For instance, if the painkiller does not cause a reduction in the pain it should be stopped. Nothing wrong with that, as long as it is the patient who decides whether or not there has been a reduction in pain levels.

The overall feeling of the NICE guidelines is not to treat chronic pain sufferers as there is no cure and money will just be wasted because the sufferers need constant treatment. SIGN 136 has a more compassionate approach recognising that although there is no cure for many chronic pain conditions, a reduction in someone's suffering is a good thing and should be the aim of the treatment. It's hard to believe that anyone would think otherwise but in the real world, those in charge of budgets don't use compassion to balance the books. It is clearly felt that having to repeat a pain treatment over and over means it shouldn't be used. Why?

There are many other conditions which need treatments to be repeated time after time yet in the case of acupuncture, both Guidelines see no benefit in using it long term. I can vouch for the fact that acupuncture does indeed work and reduces my pain greatly. It only lasts for a week or so though but for someone like me, that week gives me an escape from the endless torture. Knowing my condition will last till the day I die, I see no reason to only use it once in my (hopefully) normal life span. The NICE guidelines go as far to say acupuncture should be “made up of no more than 5 hours of Band 7 healthcare professional time or is delivered by another healthcare professional with appropriate training and/or in another setting, for equivalent or lower cost.” Clearly the important factor here for NICE is the cost to the NHS. What about reducing suffering, or is patient welfare low down on the list of considerations? Smacks of a wish for private healthcare.

Exercise and exercise therapies are also recommended in the SIGN guidelines but importantly not to the exclusion of help from pain-reducing medicine. After all this time in chronic pain, I know it is not good for me to sit in a chair or lie in a bed all day. There are times when I need to do that but moving about stops my connective tissue seizing up and causing even more pain when I do have to move. I can also vouch that trying to become a gym bunny doesn't reduce the neuropathic pain nor does losing weight. However as the chronic pain sufferer will invariably pick up other conditions along the way, it is best not to get into the trap of lying there, moaning and groaning all the time! Everything in moderation is the best way to survive the cruel pain-filled life.

One other method of reducing the pain that I and many other sufferers use is TENS - Trans cutaneous electrical stimulation. These devices emit electrical pulses through pads placed on the skin which scramble the pain signals reaching the brain. NICE bluntly state: “Do not offer TENS to people aged 16 years and over to manage chronic primary pain because there is no evidence of benefit.” While SIGN 136 recommends that “Transcutaneous electrical nerve stimulation should be considered for the relief of chronic pain. Either low or high frequency TENS can be used.”

It is worrying though to hear tales from chronic pain sufferers of instances where less senior and newly trained health professionals seem to put so much sway on the more widely reported NICE Guidelines. It is beyond expectations that the British media and other bodies will take the different structures of the Scottish, Welsh and Northern Irish health services into account. Clearly the Scottish Government and Health Bodies need to promote the SIGN Guidelines far more than they do. Yes, there are pamphlets and websites available but unless people are told they are there the information will lie in the back of a cupboard or shelf collecting dust or lost in the myriad of information that is cyberspace. It's hardly conducive to a good relationship with your Doctor if you have to take the SIGN 136 Guidelines to every consultation. We at 'Affa Sair' will make sure that the SIGN Guidelines are known to our members and hope that other chronic pain charities and groups do the same to make sure pain sufferers north of the border are not unfairly treated.

Chris Bridgeford is chairman and founder of the Scottish Charity 'Affa Sair' – Scots for 'very sore'. Charity No. SC049728. In May 2021 the charity had 547 members. 'Affa Sair' is a member of the Scottish Government's National Advisory Committee on Chronic Pain and takes part in many chronic pain surveys and consultations. Their website is at www.affasair.org