

Whit a sotter!

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Whit a sotter I'm in. For those of you who don't speak the language I should translate it to 'What a mess I'm in!'

Now that it's 2023, I'm celebrating the 45th anniversary of being diagnosed with chronic pain. It's been quite hellish and exhausting since the beginning of the year.

I always expect a worsening of my pain levels in the winter but it seems to have been continually bad since October or so. Life has carried on as usual, of course, but any good times have been pushed into the background with a darkening gloom of increasingly painful body parts and frustration of nowhere to go for help. The usual daily battles of chronic pain were interspersed with flares that lasted longer and longer with it all merging into a long, dark, solitary passage of pain.

Even when things seem dire they can always get worse, of course. All made more difficult with a background of increasingly depressing stories on the state of the once enviable National Health Service (NHS). Whichever side of the border you live in, we're all aware of the media reports on the destroyed NHS. While politicians battle over whether the English or Scottish Health Service is worse, it's the patients who are suffering. When you have an invisible condition like chronic pain, the problem is made much worse as there's no free-flowing blood or bones sticking out to convince already stressed and exhausted health workers how bad a state you are really in.

An exhausting menu

Knowing the problems even my wee local health centre and small District General Hospital face, I recently put up with ever-increasing abdominal pain for hours before I gave in and phoned for advice and help. Unfortunately I negotiated the menu system wrongly and picked the option for medical emergencies – as I presumed the pain that had me doubled-up and screaming fitted the bill. The call handler (well known for her – let's say – argumentative style) answered with 'Do you need a Doctor?' I gave a mangled breathless response of saying 'Well, not necessarily a Doctor . . .' meaning I was

happy to speak to a clinician as I well know from my wife's work and years of my own experience that other clinicians are just as knowledgeable and capable. Before I could continue through the paroxysms of pain, I was sharply told, 'This is the line to speak to a Doctor!' Well no, actually. The menu system says it is the line for 'medical emergencies'. This shows a clear need for the difficulties of a chronic pain condition to be explained not only to clinicians but also to gatekeeper staff who are, after all, the first point of contact for most patients.

Not having the energy (or breath) for an argument, I hung up, called back again choosing option 2 for 'Appointments and General Enquiries'. It takes 52 seconds to get through the menu system to the medical emergencies option and 1 minute 4 seconds to get to the Appointments and General Enquiries option. To get through the whole spiel takes 1 minute 24 seconds. Unless you're told they are too busy and your call disconnected, you find yourself in a queue, of course, and wait and wait and hope for a pleasant call handler – most of them are, to be fair. These times may not look long on paper but believe you me, when you're doubling up in pain, they do seem forever.

I did get through to a very pleasant lady on the general line who immediately got me a conversation with the triage team – just what I wanted originally. All I wanted was some advice on whether taking a muscle relaxant (Diazepam) would be ok with the abdominal spasms. His advice was that, considering the amount of pain I sounded in, I should phone an ambulance – so I did. They arrived within half an hour and thought I'd be better off in hospital but warned that they could be stacked for up to 3 hours. However, they suggested that if they got their control to phone A&E, my wife (who had gotten home from work in the NHS by now) could take me to the District Hospital and we would be seen. Not wanting to have the ambulance out of action for so long, we decided she would take me. Sadly, control didn't phone ahead and so there was a 2.5-hour agonising wait in A&E reception.

Should've stayed at home

In the A&E department, I was put on a trolley and stayed there for the next 14 hours after which I was sent home, as there were no beds in the hospital. First of all adhesions were blamed, a chest x-ray was done instead of abdominal x-ray,

and eventually constipation was diagnosed ('No sh*t, Sherlock', as the saying goes) and an enema was given. Not the most comfortable night, no sleep, no relief, but regular attention from the conscientious nurse. Frankly, I should've stayed at home, used the enema kit I had at home and just screamed at the walls. For those who say I should stop the opiates – well, no, tried that and pain is unbearable even for me being used to it after 45 years. What I should have been doing is taking more care and using more laxatives and stool softeners. I've now got the health centre to instruct the pharmacist to put docusate capsules in my dosette box to ensure I take them every day. It's these simple joined-up schemes that make a huge difference to the patient. Problem is that it seems the patient has to come up with the answers themselves.

Is there anybody there?

To add to all the excitement a new joy has come my way – restless legs syndrome – so weird and painful. But where to get help? Thing is, I know there's no quick cure and there seemed little point in battling the health centre menu system, so I just waited for my regular 5-week phone call from GP. I'm lucky and grateful to get that these days as it saves waiting around in the health centre while the Doctor is always running behind schedule as he says and knows how uncomfortable it can be for me in the waiting room. So, it's Mr Google again. Now, I know many clinicians frown on patients googling the answers but frankly there is nowhere else to go. I suppose I'm fortunate that with all my time researching and helping other chronic pain sufferers, I can tell the bad from the good, but it's a far from ideal system that we've descended into. So, after ordering a bottle of magnesium and slapping it on, the problem does seem to be under control. Ironically, on speaking to my GP on his regular call, I found he uses it too for leg cramps after gym training. Well – as the saying goes, what's good for the goose is good for the gander!

In the last couple of years, I've also been affected by hip pain and have even had steroid injections to help. No joy. While it's gotten worse and worse over the winter, a long-time forgotten pain problem also came back to haunt me. A legacy of having ankylosing spondylitis as a teenager is the observable narrowing of the spaces between my sacroiliac joints where lower back pain has gotten to ridiculous levels again. The hip pain is piriformis syndrome, trochanter syndrome or, to put it bluntly, a damn sore hip with numbing pain down my leg. This is so bad now that every night, without fail, I'm woken to a numbing-piercing pain from hip to knee and sometimes ankle and the dreaded low back pain from AS joining the rest of my painful skeleton, musculature and nerves. What to do?

I've tried the recommended exercises from Mr Google and YouTube to no avail. There is a long wait time for real-life

physiotherapy here, with a phone call being the usual option given. You can only attend physio for 7 weeks at most now. Some 30–40 years ago, I used to go to the now sadly mothballed local cottage hospital every week for physiotherapy until the early 2000s. Those were the days. Just think how much bed-blocking and other problems could have been lessened if cottage hospitals had been allowed to stay open.

DIY is a necessity

Nowadays we're encouraged to live well with pain. That's all well and good. But when the pain is day after day, the fatigue has you unable to think and there are no real-life treatment facilities in reach – that's not an aim that's any good to most people.

I do fully accept that good mental health is crucial to coping with a life of chronic pain but again, how do you get that help without battling the stressful obstacles to reach a sparse and underfunded service on the NHS? Well, in a rural area like mine, it's a matter of DIY. I'm a long-time meditation user and enjoy the benefits of Reiki and Acupuncture but the pain lingers on. I'm convinced it has a consciousness. It hides away from the areas that are treated just to appear again later in the day on the untreated body parts. The last recommendation I got to improve my mental health was through a diabetic consultation which led me to an online 'chat' with a bot. No help to me – just more frustration.

There are a huge amount of resources available online but humans need human contact.

Insults don't help

Every part of the NHS seems to work independently of the others while, up here anyway, the NHS Boards blame the Government, and the Government blames the Boards. If only the politicians in both Scotland and the rest of the United Kingdom would work together to get the NHS back to a working health service, patients might get some of the help they need. Here especially, the opposition parties do nothing but literally shout more and more childish insults across Parliament, conveniently forgetting the pandemic, and hurl meaningless statistics about. All this does nothing to help patients but has the effect of demoralising staff and frightening patients away. What would it be like if health care was taken out of political point scoring and our supposed representatives worked together to ensure the people they are supposed to serve get the best care available – free at point of use?

I'm exhausted; with no choice but to battle on – on my own.

As I said at the beginning, 'Whit a sotter I'm in' – but is it me or the country?