



affa sair

registered charity SC049728

a community for those in chronic pain

www.affasair.org

affasair@gmail.com

19 Knockomie Gardens

Forres Moray IV36 2TN

Telephone: 01309 673626

Mobile: 07783 047430

Email: affasair@gmail.com

Web: www.affasair.org

LIVING WITH CHRONIC PAIN - UPDATED

Way back in 1978 I was at home in my parent's house, a teenager of 18 shortly to be 19 when I tried to get up from the couch I was lounging on. A bolt of pain shot down my lower back and leg and my whole body went into paroxysms of pain. Little did I know then that the pain would still be going on 45 years later. That was the first of many days where I could hardly take one step in front of the other; nights where I could not get to sleep for the agony and many times when I was accused of pretending.

A few months later I was diagnosed with Ankylosing Spondylitis an inflammatory condition which was then nicknamed 'Bamboo Spine'. After six months in hospital I returned home and began a life of constant never-ending pain, depression and false accusations. I lost count of the number of times I was told by the arrogant, overbearing consultants of the time that I didn't conform to what it said in the books.

As the years went on, illness began to overtake my life with one drastic event after another. The pain began to spread around my body till every bit of me was affected by it. After the initial diagnoses they even tried irradiating me with a short course of radiotherapy on my right knee. Nothing changed, but who knows what damage that has done to me. All manner of anti-inflammatory medications were tried, anything new and experimental. I was a mystery clearly and "didn't conform to what the books said". My ESR rates (the indication of inflammation) were always low but I had the HLA27 marker in my blood – an indicator of Ankylosing Spondylitis, so the diagnoses stuck. They just gave up on me and reached for the pad to sign me off work when I appeared at the Doctors. My career was badly affected without any Disability Workers Rights in those days. I was deemed as "extra-numerary staff" meaning it didn't matter if I was in the office or not for working out staffing levels. I was not allowed to be promoted though my performance reviews were exemplary and I was now working as the assistant to the Senior Manager with my own office space, thankfully next to the lift.

I eventually had to retire from work, for medical reasons, after 19 years in the Bank of Scotland. That same year I had had a mental break, then ended up in hospital with a large clot which led to emergency surgery to save my right leg being amputated and an angioplasty to save the left, and a mesh graft to hold my abdomen together. There then followed years of incisional hernia repairs plus two mesh implants, with the last surgery in 2004 nearly taking my life after losing 9 units of blood and needing two operations the same day accompanied with a bowel resection. That same year my diagnosis had been changed to Complex Neuropathic Pain Syndrome with allodynia (ultra-sensitive to touch, sound and light). Somewhere along the long line of clinical letters and discussions it became Complex Regional Pain Syndrome.

My medication drastically changed from anti-inflammatory to neuropathic medicine including opiates and Pregabalin.

Five years later I picked up Diabetes, was living in constant states of anxiety and was also labelled with peripheral and cardiovascular disease. 3 years later, 3 mini strokes entered my medical history swiftly followed by sleep apnoea, IBS, faecal incontinence, mouth and tongue problems and then Asperger's Syndrome. I was now taking over 30 pills a day.

It's been an interesting life.

Coming out of a bout of depression I set about creating Affa Sair to bring other chronic pain patients together as the isolation I was in had a huge effect on me. I quickly realised I wasn't as unique as I thought. For those who don't speak Scots or Doric "Affa Sair" translates as "Awfully Sore".

So much for the history. What is it like to live day to day with an illness with no outward signs, no bruising, scarring (well just a couple of big ones from abdominal surgery and gall bladder removal), discolouration etc.

Let's start at the beginning of the day.

You slowly become conscious into that dreamlike state somewhere between sleep and wakefulness. Then, wham! The pain hits like a bolt of electricity-laden, stabbing, fire. You don't want to move but you must. You need to swallow your morning pills, all 21 of them. Oh, and because you've picked up Diabetes you also need to test your blood sugars and take your insulin injection. Both things wouldn't cause much pain, if any, to one of the 'un-pained' but they sure as hell hurt your compromised central nervous system. Nowadays, in 2023, I've moved to a continual glucose monitoring device which has been quite a game changer. Back to the half-awake state you go, trying to concentrate on the radio; something to take your mind off the oppressive, all-encompassing layer of pain coming from seemingly inside and outside of you.

Two hours later, your wife long gone to work, a gentle paw on the nose wakes you up again. After a few minutes, a not so gentle feline attack on your legs or worse, nose, makes sure you know it's time to get up as the monsters want fed! You slowly stagger to the bathroom followed by your feline carers.

Whilst the shower warms up, you sit at the sink to brush your teeth but first spraying your mouth with local anaesthetic (xylocaine) to dull the pain on your tongue and mouth. Then if your face isn't too sore - time to shave, gingerly. You need to move the stool to the shower and sit facing the stream of water. A shower used to feel good and relaxing a long time ago but is now like a stream of sharp needles attacking your skin. You can't bear this on your back which is why you face the stream of water. Time to get dry. You wrap yourself in a towel to take the surface water off; but you need to use a hairdryer to dry properly as the towel is like a sheet of sandpaper on your skin. Back to the bedroom and a welcome lie down to help get over the exertions of showering before you get dressed. The warmer the day, the better, as you can wear shorts to save trousers irritating your sensitive legs.

You make your way downstairs to get breakfast, careful to avoid the streak of a ginger feline intent on getting fed first. You look warily at the letterbox in case there is that brown envelope from the DWP inviting you to prove yet again that you're ill and not a scrounger on the State. They don't seem to understand the meaning of "chronic" and are unwilling to believe your Doctor with his years of training and experience and your full medical history. It took two years of fighting to fully restore the mobility payments first awarded 30 odd years ago - "indefinitely". These aren't handouts but were paid for through your nineteen years of full-time work when you dragged yourself to the office and forced yourself to battle with the pain just to prove you were as capable as the rest of the workers. Again, thankfully time has moved on and now in 2023, because I am Scottish, I no longer have to fear the DWP. Instead the Scottish Social Security system gives me the Adult Disability Payment.

You need to feed the cats first or you'll have a rebellion on your hands. So, feline friends appeased, you either get the breakfast tray made up the previous night or sit on the padded stool to put a simple breakfast together accompanied with more oxycodone. The 'experts' say they are dangerous and you'll be addicted but as there is nothing else that helps and you'll need them for the rest of your life anyway, you fail to see the problem. After all, they were happy to get you addicted to Pregabalin for about 15 years, a drug which causes tremendous harm both mentally and physically. The withdrawals were hell on earth but worth it. I can string words together again to make sentences and no longer live in a strange world of my own.

Your knees and shins are killing you, so it's time to breakout the medicated plasters laced with a local anaesthetic (lidocaine). You can only use three at a time so if your shoulders are bad as well, you're stuck. That's when the TENS machine comes in handy. It doesn't do a damn thing to cure the pain but its electrical impulses give you something else to feel. A regular controllable pulse under your control of instead of the searing, stabbing pain with a life of its own. There's always the infra-red lamp too and Reiki and acupuncture. These aren't available on the NHS though so they cost - a lot.

With fatigue subduing you again, you try to get lost in some televisual escapade for the best part of an hour. If it's a goodish day then you can try to do some light housework so you can pretend you're not totally worthless. This is where things get dangerous though.

If you're having a good day after a period of bad ones, you go berserk. You try to do every little thing you can think of just to prove you can do it and not be a burden. Those 'experts' tells you to pace, pace, pace. You're incapable of doing that no matter how many times you're encouraged to, or your wife repeatedly tells

you to look after yourself first and to hell with the dust. I don't know I've done too much till I've actually done too much as the pain level changes daily.

These days any spare time is used up running "Affa Sair" if the pain and fatigue allows but you have to spend at least three hours back in bed till your wife comes home. Time to eat your evening meal - with a garnish of another 16 pills. You used to be a competent dish or something guaranteed to last a couple of nights!

Three or four hours later, the pain has you so exasperated and exhausted its time to go upstairs again. It's the most comfortable place in the house so you relax, pain permitting and read a bit. Maybe an extra oxycodone to see you through the night, a peck of a kiss goodnight. No more intimacy in your life because you can't bear to be touched for any length of time. So, you open up the kindle and read for a while, then try a meditation and drift off to sleep if you're lucky about 2:00 am.

Four hours or so later, interspersed with periods of painful wakefulness, it starts all over again.

Unless of course it's one of the many bad days with the added experiences of:

A Pain Flare: The pain seems to have a mind of its own and goes into overdrive. It rampages around your body, depriving you of rational thought, movement and speech. Only an extra amount of Oxycodone and Diazepam will have any effect on it. It's too risky, so you try to be responsible and take just what the Doctor advises. The temptation to take more is always there. It can affect your whole body at once. You are just pain. It seems to come from within but surrounds you as well. You are in your own pocket of reality, filled with a nagging, unrelenting hurt. Sometimes you're lucky and it's just your legs threatening to explode. Sometimes it becomes a guessing game with bits of you spontaneously erupting into an area of searing agony.

Lack of interest and motivation: Life has no interest to you at times like these. What is going on around you, your family life, financial life, what's left of your social circle are dead to you. Even simple things like the programmes you like or the book you were enjoying does not appeal to you. You just sit there, lost in your own thoughts, oblivious to those and situations around you. You know there are things you could be doing, feeding the poor cats, feeding you poor wife; feeding yourself; but you just can't get your act together. Why bother, you ask yourself.

Sleeplessness: You're so tired and just plain exhausted that you long to go to sleep. The pain has other ideas though. You just can't get comfortable in bed; sleep is always just out of reach.

Twisting of sanity: Even when you thought it could not get any worse a spasm hits you and the pain shifts up to a forgotten level. You feel your very soul and mind are being attacked. It is so relentless. Your thoughts get more and more unstable.

Near-suicidal thoughts: Now comes the truly dangerous side-effect of never-ending pain. Will it ever end? Is there any point in continuing like this? Who would miss you? Would it not be better if you weren't here to just be a continuing burden or annoyance?

After 45 odd years though, you have learned one or two coping mechanisms. Distraction works well, fatigue permitting. It's great when you can get lost in your laptop honing the self-taught skills of photo editing, website designing and general problem solving. My new saviour is losing myself in intricate painting by numbers. Meditation is helping more and more and has become a daily occurrence so coupled with your Reiki training you can get peace for an wee while.

I've found that the best thing for me though is to concentrate on looking after my wife, our remaining cat, friends and Affa Sair. The age-old problem of disbelief has shockingly reared its head recently so, for me as a means of self-protection, I've chosen to cut the disbelievers out of my life. Life is hard enough without having to justify yourself to ignorant closed minds.

I now choose a peaceful positive life and to share my experiences with those who need a way to survive the endless onslaught of invisible chronic pain.

Chris Bridgeford, Affa Sair, Founder