

## Annex B

Sent: 12 January 2021 13:39

To: [redacted]@gov.scot>

Cc: [redacted]@gov.scot>

Subject: Charity Position on NACCP

Hi [redacted]

Following a recent conversation with [redacted] of The Alliance I am writing to offer 'Affa Sair' as a participant to the reformed NACCP to represent the lived experiences of over 500 (and growing) chronic pain patients in Scotland.

I have attached a document outlining the history of Affa Sair to easier explain what we have achieved since our inception in 2015.

In brief, we share experiences and offer support to each other in our closed Facebook Group, there are 537 members predominately from the North East of Scotland, though in recent months we are attracting members from outside the region. Before Covid we also held face to face meetings in Moray College in Elgin where accommodation was provided by NHS Grampian in their community hub.

Our aim is to relieve the needs of chronic pain sufferers and one way is to help chronic pain sufferers learn to accept and live with their conditions as best they can.

If invited to join the NACCP, Affa Sair would bring the experiences and problems of the group to the committee. We are currently the only fully independent chronic pain charity in Scotland run entirely by chronic pain sufferers. We have no political allegiance and no ties to any other chronic pain group. We appreciate the best way to help chronic pain sufferers is to work with the Scottish Government and its advisors and to engage in a two-way street of education and listening by looking to the future of chronic pain services in Scotland. We know there is a place for both medical practice and patient self management in helping people cope with their struggles. We recognise resources are finite and that there must be ways to encourage sufferers to look at alternative coping mechanisms such as meditation, gentle exercise and lifestyle change.

I have also attached an article from the British Pain Society, written by myself, outlining my own personal battle with chronic pain so you can see I have had many years experience of the problems associated with chronic pain.

You can find out more at [www.affasair.org](http://www.affasair.org) or I would also be happy to speak direct if you have any questions.

Chris Bridgeford – Chairman

LOGO

19 Knockomie Gardens, Forres IV36 2TN

Due to health restrictions please call before 2pm

Scottish Ministers, special advisers and the Permanent Secretary are covered by the terms of the Lobbying (Scotland) Act 2016. See [www.lobbying.scot](http://www.lobbying.scot)



Landline: [redacted]  
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# affa sair

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## self help for chronic pain sufferers

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**Affa Sair** (Scots for “Awfully Sore”), is based in the North East of Scotland and is open to chronic pain sufferers and their families/partners from anywhere in Scotland and beyond.

**Affa Sair** started as a closed Facebook Group, formed by chronic pain sufferer Chris Bridgeford in 2015, in an attempt to break the isolation of chronic pain sufferers in the north east of Scotland. Since then the group has grown to 537 <sup>[Jan 2021]</sup> members from all over Scotland.

In 2019 the charity Affa Sair (SCIO) SC049728 was established, to formalise how to relieve the needs of pain sufferers. Specifically, to assist in the furtherance of knowledge about chronic pain conditions and to provide a strong presence for chronic pain sufferers and to educate the public, politicians, media, organisations and NHS Staff on the plight and needs of chronic pain sufferers

Some comments on chronic pain from **Affa Sair** members:

*“This illness has robbed me of my life. I’m 54 but feel like I am just existing. No-one would choose to live this way. I have found great help in support groups as fellow sufferers can understand and empathise. It’s hard to travel to attend groups in person so groups like Affa Sair are a lifeline.”*

*“There really is a shortage of trained staff in the chronic pain field. The waiting times after referral are incredibly long, we need to be seen and helped much quicker.”*

*“Living my daily life with pain has made me suicidal at points because I cannot cope with the pain I am in. I once asked to be referred by my GP to the pain clinic but was told it would be a pointless exercise.”*

*“The pain is constant and often at night it’s the worst. Finding the balance between medications to ease the pain and being able to think clearly is a constant battle along with people’s understanding.”*

*“I don’t want to be weak and helpless but I am. On my worst days I can’t move, even breathing causes excruciating pain, yet still people think I’m faking the pain as they only see me when I think I can cope with the world. I wouldn’t wish this in my worst enemy.”*

*“I never know when I have overdone it until it’s too late, most days I actually do very little now. I feel isolated and depressed. I have considered suicide. I hate feeling like a burden to my husband.”*

All of our support work is done on-line as chronic pain sufferers have immense difficulty getting out and about. Members discuss their condition without reproach and pick up hints and tips from other sufferers together with articles and documents researched by the group. There is also an open Facebook page giving general information about the charity and a website [www.affasair.org](http://www.affasair.org) where the charity provides advocacy and further support using shared research, facts and personal accounts. We also have our Twitter and Instagram feeds and a new You Tube channel.

“**Affa Sair** SCIO” gained Charitable Status in 2019 following 4 years as a campaigning and support organisation. The charity’s purposes are to relieve the needs of chronic pain sufferers by:-

- Providing a strong presence for chronic pain sufferers and to educate the public, politicians, media, organisations and NHS Staff on the plight and needs of chronic pain sufferers
- Providing an on-line location for chronic pain sufferers where they can freely discuss their condition and learn from other sufferers together with articles and documents researched by the group.
- Encouraging NHS Grampian to provide and maintain suitable Pain Services at Dr Gray's Hospital in Elgin
- Assisting in the furtherance of knowledge about chronic pain conditions.
- Ultimately, we aim to provide a strong presence for “Chronics” throughout Scotland and to educate the public, politicians, organisations and NHS Staff on the needs of chronic pain sufferers.

Chronic Pain is defined as continuous long-term pain of more than 12 weeks or, after the time that healing should have occurred after trauma or surgery. It affects 20% or 1.09 million of the population of Scotland. This is roughly equivalent to instances of heart disease, diabetes, major depression and other long-term illnesses.

Chronic Pain patients, on average, consult their GP five times more frequently than those without chronic pain.

Chronic Pain conditions globally, and in Scotland, are by far the greatest cause of disability. Chronic Pain was accepted by the Scottish Government as a distinct diagnosis in 2008, and its management prioritised.

**Affa Sair** has taken part in the numerous consultations and surveys including:

- 📖 Pain Management Remote Healthcare Pathway – Clinical Advisory Group - 2021
- 📖 The Alliance - My World, My Health Workshops - 2021
- 📖 The Alliance - Chronic Pain Reference Group – 2020
- 📖 Primary & Secondary Care chronic pain services in Moray and the way forward - April 2020
- 📖 New World Health Organisation ICD-11 classification of chronic pain survey by a research team at the University of Marburg, Germany - August 2019
- 📖 Chronic Pain Report recently produced by the Scottish Access Collaborative – 2019
- 📖 SIGN Public Performing Network – 2019
- 📖 NHS Grampian Public Health Directorate on Pain Management Resources – 2019
- 📖 Work and Pensions Minister re PIP Assessments – 2018
- 📖 Submissions to the Health Committee on Clinical Governance of NHS Boards – 2018
- 📖 Scottish Public Health Network Report on Adult Chronic Pain Needs Assessment – 2018
- 📖 Meeting with the Public Health Minister in November – 2017
- 📖 ISD Chronic Pain Waiting Times Consultation – 2017
- 📖 The Language of Pain Project with Glasgow School of Art - 2016

The charity is extremely grateful for the continued support of both our local MSP Richard Lochhead and local MP Douglas Ross. Both politicians have attended **Affa Sair** events and meetings and ensure that the plight of chronic pain sufferers is brought to the attention of Holyrood and Westminster Parliaments.

In October 2019, our Chairman presented a report on Chronic Pain Services in Scotland to the Public Health Minister at a meeting of the Holyrood Cross Party Group on Chronic Pain. A further meeting with the Minister was to be arranged this year in the North East of Scotland. With current Covid restrictions though this has not been possible. Meanwhile, **Affa Sair** continues to work with the many Government Departments and Working Groups connected with chronic pain.

The largest concern for chronic pain sufferers in Moray, and indeed in wider Scotland, is the ever-increasing waiting times for both first time and return appointments. In 2011, 89.8% of new patients were seen with the National Waiting Times targets of 18 weeks<sup>[1]</sup> but this has slumped to only 60.5% in 2019 pre-covid.<sup>[2]</sup> Source [1] Parliamentary Question S4W-05262 [2] Public Health Scotland.

NHS Grampian are consistently at the bottom of league tables for waiting times in Scotland. **Affa Sair** is also concerned at the lack of staff and resources in the NHS Grampian Pain Service resulting and the lack of a full multi-departmental team pain service at Dr Gray's Hospital in Elgin. The only way for Moray sufferers to get a full Pain Clinic Service is to travel to Aberdeen – a return journey of up to 150 miles (often by public transport) for some Moray patients.

The recent COVID-19 crisis increased the use of the “Near Me” Video consultation system by NHS Boards so chronic pain sufferers can be consulted in their own homes. Although this system has been around for a number of years it's use has increased exponentially since the Covid Crisis. It is essential that this service continues in all NHS departments and areas. We worked with Government Officials in promoting the continued use of this service and also see the new eConsult service being rolled out across Grampian as something which will benefit chronic pain patients.

**Affa Sair** would like to see a national Pain Service instead of the current system whereby each NHS Board decides what services their Pain Clinics offer. At present not all 14 Health Boards have a Pain Clinic. Only seven offer treatments such as lidocaine infusions and pain-killing injections whilst others do not – NHS Fife offer neither. This has led to a postcode lottery for chronic pain sufferers in Scotland. Chronic Pain Sufferers are unable to travel any distance due to the intense pain they feel. In many cases every little bump on the road causes them intense pain, leaving them completely exhausted after any journey.

**Affa Sair** is a wholly independent charity working purely for the benefit of chronic pain sufferers. We very much see the need to work constructively with the Scottish Government and its advisors to gain the best for all chronic pain sufferers. We feel strongly that any interaction with the Scottish Government should be a two-way street of listening and education where shaping the future is of the highest importance.





# A life of chronic pain and about 'Affa Sair' ('awfully sore')

Chris Bridgeford



I was aged about 11. We had gone on a family day out to visit a beloved uncle's aged mother in a luxuriant home in the City of Aberdeen, North East Scotland. It had been a good day out. Everybody in good form. I remember sitting quietly in a corner playing with Lego, as was my wont. My legs were becoming uncomfortable; something that was happening at night more and more. That feeling of dread came over me where the pain got worse and worse and made me cry.

## Big boys don't cry

Eventually with the pain increasing, I started sobbing. Huge breathless sobs while hugging my legs, that had everyone looking at me. My uncle's partner and his relatives had concern on their faces, my mother soon asking, 'What's wrong dearie? What's the matter?' Then, after a few shushing sounds, 'Oh, it's

just his growing pains', explaining away what was becoming a nearly nightly secret. I had learned not to make too much fuss about it as the pain was just brushed away as nothing unusual. This was the first time they had erupted in the daytime. I didn't have access to the light and dark blue checked scarf which I furiously tied tighter and tighter around each leg at a time in the loneliness of night. This had the joint effect of causing its own pain and seemingly cutting off the pain to the rest of my body.

In 1978 I was at home in my parents' house, a teenager of 18 shortly to be 19, when I tried to get up off 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. I had not long started work in a local Bank, University denied because of the expense, despite grants being available. A job in the Bank in those days was seen as a rung up the social scale. Thank goodness in the end I endured the 19 years there, so I got the final salary pension; but that was a long time in the future and thankfully well into the past.

I tried to get off the couch when, wham! — a blast of pain from my lower back to my toes put paid to any attempt to move. After a dreadful night of painful screeches and a seemingly never-ending climb of the stairs, I was escorted to the family general practitioner (GP; just across the street) who helpfully suggested I should 'get a skateboard'. Little did I know then that the pain was still to be going on 42 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.

I spent 6 months in Raigmore Hospital in the nearby city of Inverness on a 32-bed 'Nightingale' ward. With that came this new-fangled treatment called Hydrotherapy. Five days a week I was ambulated across to the Physiotherapy Department in the new building going up around the old crumbling single-storey blocks. It was like a day out from the ward. Other than that, I spent the time in bed getting to know the staff really well and beginning years of insomnia — to have tea in the middle of the night with the young nurses. The Ward Sister was a wonderful woman called Mary Campbell. She came from 'The Islands', on the west coast of Scotland, with that wonderful lilting accent. The patients and staff did what they were told

### A life of chronic pain and about Affa Sair ('awfully sore')

when she was around. The ward was absolutely spotless. Everyone took a pride in their job and the ward — their ward. Over the next 10 years or so I saw the decline of hospital standards first-hand, despite moving to the newly built multi-storey flagship hospital that is today wracked with outbreaks of Norovirus in both winter and summer, a huge bullying scandal resulting in changes to the Board and Senior Management, and of course Covid-19. But I digress.

After 6 months in hospital, with a diagnosis of Ankylosing Spondylitis, an inflammatory condition which was then nicknamed 'Bamboo Spine', I returned home and began a life of constant never-ending pain, depression and accusations of lying. I lost count of the number of times I was told by arrogant, overbearing consultants of the time that I didn't conform to what it said in the books. It was also clear that colleagues and acquaintances didn't accept the truth and seriousness of what I was saying. Nobody understood what I was going through.

After leaving hospital, I continued to travel the 26 miles to outpatient appointments under the auspices of the Rehabilitation Department. I was under a strange fellow who was also a Lay Preacher in his spare time. I was introduced to him when he came to me on the ward and measured me lying down and standing up — without a word of introduction. I had no idea who he was or what he was doing. The ward comedians kept telling me (a young 18 year old) he was the undertaker! His first idea was to give me a 6-week course of Radiotherapy. I kid you not. After discussing it with me and my Father, it was decided to go ahead. They proceeded to radiate my left knee twice a week for 6 weeks. It made no damn difference. They say it was a small dose, but I wonder if that would be done today. I was then strapped into a back support for years. As I grew older, I started to rebel, especially when the pain wasn't getting any better. I simply stopped going. I lived on a diet of anti-inflammatory medications which also didn't do anything to help. Time and time again I was disbelieved and told I was imagining it or making it up. The same old story when it comes to people suffering with chronic pain. Eventually, I was seen in a Gothic-style Victorian Psychiatric Hospital in Inverness and given a course of amitriptyline, a then new-fangled psychiatric drug that was being trialled for dealing with pain. I hated them. I had a raging thirst and put on loads of weight. I eventually stopped these too, and just drifted about the NHS with the GPs not interested enough to investigate what was really wrong, until I needed to have an aortal-femoral bypass in 1995 at the tender age of 36.

### You don't matter

My career was badly affected without any Disability Workers Rights in those days. I was deemed as 'supernumerary staff',

meaning it didn't matter if I was in the office or not as I was deemed not to make a difference. I was sidelined into being the office typist. Thankfully, a new Manager arrived and recognised my potential. He and his wife are now firm friends, and his wife gives me weekly Reiki treatments and valued emotional support. Head Office decreed 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 in the management suite, thankfully next to the lift. Despite his support, it was very difficult living a life of not being valued. The isolation of chronic pain had begun.

My parents also didn't understand what was going on with me. They chose to believe what the consultants said, as was the norm in those days. A Doctor and especially a Consultant was treated like a God. I closed my bedroom door and retreated into myself when I returned from hospital and didn't open it again until I left to be married about 10 years later. Without my wife, I would not be here now. She was actually my next door neighbour but we had no contact with each other then, as she was 5 years my junior. She joined the Bank where I worked and we became friends. What first attracted her to me was her complete disregard for my disability. If I annoyed her, which happened a fair bit, she simply took my crutches to one end of the office and left me at the other! Others used to avoid touching them if they were in the way, hanging off a filing cabinet. Not Rosie, she just happily moved them.

Also in the mid-80s I became a radio presenter on the local radio station because of my interest in home computing. I presented a weekly Computer Show to begin with but moved on to a 3-hour Saturday night show and joined a line-up of presenters for a Sunday night show dedicated to album tracks. It was great. I could be myself. No one saw the crutches on radio.

In 1987, we got married. We were advised by the lay-preacher consultant not to have children as there was a 50/50 chance of me passing on my illness. That was not true, it turns out, and is a regret. But in reality it would have been a tremendous struggle in later life. Cats took the place of children. Less work but just as smelly at times!

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. 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 AS, 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.

## A life of chronic pain and about Affa Sair ('awfully sore')

I eventually had to retire from work for medical reasons after 19 years in the Bank of Scotland. It was no coincidence that when the Senior Manager who supported me was transferred, I had had a mental breakdown, then ended up in hospital with a large aorto-femoral clot which led to emergency surgery to save my right leg, an angioplasty to save the left and a mesh graft to hold my abdomen together.

There then followed years of surgical hernia repairs with the last one in 2004 nearly taking my life after losing nine units of blood, needing two operations the same day and a bowel resection to boot. By now I had two mesh inserts, something that is causing a huge scandal in Scotland now in 2020. Tales of women, and a few men, enduring agonising pain with their mesh implants, being told they were removed when they weren't, and resulting in Dr Veronikis from America shaming the First Minister and Scottish Government by withdrawing his 18-month offer to come to Scotland and train people in mesh removal here for free. One of the Scottish Government's own mesh experts had already warned them of what he described as a 'professional conspiracy' to prevent Dr Veronikis coming to Scotland after he said talks were going nowhere.

In the early 2000s, my diagnoses had been changed to a Complex Neuropathic Pain Syndrome becoming Complex Regional Pain Syndrome with allodynia (ultra-sensitive to touch, sound and light). My medication drastically changed from anti-inflammation to neuropathic medicine, including opiates and Pregabalin.

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

Unfortunately in 2004, after a catastrophic accident in what was by now a recurring repair operation in my abdomen due to my previous bypass surgery, I needed to have a bowel resection and lost nine units of blood, nearly dying in the process. More depression followed (understandably) but in 2015, after having come out of the depression, due in large part to continual Reiki treatment and the never-ending support of my wife, I formed the chronic pain support group — 'Affa Sair' (Scots for 'awfully sore'). I had found my voice now after years of feeling too ashamed to speak out and be honest about what I was experiencing and feeling.

So what is it like to live a life where pain never ends, where there is always a base level of pain which can rise to unfathomable heights, blurring your very existence as a rational

being? After many years of label-collecting (Sacroiliitis, Ankylosing Spondylitis, Complex Neuropathic Pain), the current diagnosis is Complex Regional Pain Syndrome (CRPS). It certainly makes sense to me but clearly not all Pain Consultants agree. Does a label matter in reality? That is a question for another day. It certainly makes no difference to the pain.

**A day in the life of a CRPS sufferer**

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 16 of them. Oh, and because you've picked up Diabetes on your 42-year journey with chronic pain; 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. Back to the half-awake state you go, concentrating on the radio breakfast show; something to take your mind off the oppressive, all-encompassing layer of pain coming from seemingly inside and outside of you at the same time.

Two hours later, your wife long gone to work, a gentle paw on the nose wakes you up. After a few minutes, a not so gentle feline attack on the legs makes sure you know it's time to get up. You slowly stagger to the bathroom followed by your feline ginger friends.

While the water warms up, you sit down to brush your teeth — it does hurt everyone, doesn't it? No? Oh well then, I suppose the unpained don't need to spray their mouth and teeth with local anaesthetic (xylocaine) before they clean their molars! If your face isn't too sore you can shave — nervously, still sitting down. You then need to place the stool in the shower, as long ago you had to give up standing as the pain in your feet, knees, legs and hips was too severe. That job done, you enter the shower and sit facing the stream of water. A shower used to feel good and relaxing — now it's 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, even with the special towel softener you use.

Eventually dressed and awake, after a rest following your tiring morning ablutions, you make your way downstairs to get breakfast, careful to avoid the streak of a ginger feline intent on getting fed. You look warily at the letterbox in case there is that brown envelope from the Department of Work and Pensions (DWP) inviting you to prove again that you're ill and not a scrounger on the State. They don't seem to understand the



## A life of chronic pain and about Affa Sair ('awfully sore')

meaning of 'chronic' and are unwilling to believe your Doctor, with his years of training and experience. It took 2 years of fighting to restore the mobility payments you had first been awarded 30-odd years ago.

You need to feed the cats first or you'll have a rebellion on your hands. 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, and then you get to your chair with its cushion of high-density foam and eat your breakfast, accompanied with more oxycodone and paracetamol. You've become used to the oxycodone now and the paracetamol just takes it over the analgesic plateau.

At least your hands aren't too bad today, so no need to put on the gloves which give you that modicum of a cushioning layer. Your knees and shins are killing you, though, so it's time to break out the medicated plasters laced with a local anaesthetic. 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 instead of the cold, searing, stabbing pain with a life of its own.

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 good 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. Your health care practitioner 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.

After a mid-day meal and pills (only two this time and maybe another oxycodone), you can do some web browsing or more TV watching, followed by a 2-hour sleep before your wife is home. At last, some human energy to interact with. Time to eat a meal — if the pain allows, with the garnish of another five pills. You used to be a competent cook but now it's something simple like a quick stir-fry, a pre-prepared stew or good old mince and tatties, guaranteed to last a couple of nights.

Three or four hours later, the pain has you so exasperated and exhausted it's time to go upstairs again. More pills — seven of them — and so into bed. It's the most comfortable place in the house so you relax, surf the web, 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. Drift off to sleep if you're lucky about 2:30am. Four hours later, interspersed with periods of painful wakefulness, it starts all over again. . .

Unless, of course, it's one of the now many bad days with the added experiences of worsening pain. 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 a dangerous amount of extra oxycodone and diazepam (Valium) will have any effect on it. The temptation to take more is always there. But it's too risky, so you be responsible and take just what the Doctor advises. 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 your own 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.

Along with the increased pain comes irritability. Woe betide the feline friend who annoys you now that the pain has gone berserk. The TV is in danger of being shattered when the escapist entertainment maddens you. The slightest annoyance is likely to set you off, better you just keep your mouth shut and don't say anything to anyone.

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 TV 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, stuck in a chair as the depression takes over and kills all humanity left inside you. You know there are things you could be doing, feeding the poor cats, feeding your poor wife; feeding yourself; but you just can't get your act together. 'Why bother?' you ask yourself.

With all this pain you become 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. 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 and the truly dangerous side-effect of never-ending pain takes over. 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? Death looks a better option at times to those with never-ending, invisible, often disbelieved pain.

## You are not alone

In 2015, having come through another depressive episode, I began to realise that I was not alone. Due to the isolation chronic pain puts on chronic pain sufferers, I decided to launch a simple Facebook group for chronic pain sufferers to vent their frustrations, share their experiences and support each other. I wanted a simple down-to-earth name for this part of Scotland using our colloquial language. Hence 'Affa Sair', (Awfully Sore) a private Facebook group for chronic pain sufferers, was born in 2015.

So, what gives me, an elderly man from a wee village in the North East of Scotland, with no tertiary education or high-flying career, the right to tell my story to the un-pained in our society and lecture government advisors and publicly funded organisations and chronic pain experts. Well, having spent over two-thirds of my life in chronic pain and having been whimpering on the floor, in bed, or screaming in agony for long periods of time, or trying to hide the hard-to-describe pain from my wife as I cannot bear to see her sparkling, mischievous eyes saddened and worried by my suffering, gives me that right. I hold my 'lived experience', to coin a favourite catchphrase of the Scottish Government, to the equal of anyone or any organisation.

Since 2015, my pain has got progressively worse. I take over 30 pills a day. My last real-world friend moved to England many years ago. In early 2016 I became a victim of the Conservative Government's cull of disabled benefit claimants. My ability to move around has gotten worse; I even struggle to make it to the door of my GP's office (despite what the DWP say). Thanks to a condition called Allodynia — which many chronic pain sufferers put up with — every touch hurts. There are days the very air hurts. Then there's the weariness and 'Brain Fog'. The Brain Fog is what it says it is. A fog descends on your brain and every thought is lost in an impenetrable cloud. Your thought process just seizes up.

I was hospitalised during the Covid crisis with extreme pain caused by severe serotonin syndrome, which caused such a massive headache that I was blue-lighted to both the local hospital and the major hospital in Aberdeen. Serotonin syndrome is caused by the antidepressants many chronic pain sufferers are given, not only for depression but for pain control. That's another problem with chronic pain, the medicine given to help can often cause damage. I woke up after being intubated, not knowing where I was, without clothes, my walking sticks and (worse of all) my glasses! That may sound horrendous, but for me the person who suffered the most was my wonderful wife. She came home from work (in the county hospital) to me lying on the floor rambling deliriously. During my period in hospital, she could not visit due to Covid, even when I was

admitted to the County Hospital where she works, on the day after my discharge from the main Hospital, with Angina attacks. It is worth stressing here that the staff in the hospitals were fabulous and looked after me extremely well despite the Covid crisis. They were in different roles and wards than usual, rushed off their feet, but acted in a highly compassionate and professional way. A credit to the frontline staff of NHS Scotland.

But things are not all bleak. I am now as content as any of the 'un-pained'. Setting up the group has done me the world of good. I have my confidence back. I'm doing what I feel I was always supposed to do. I understand my condition so much better. Myself and my GP work as a team looking after my health and learning together. I have accepted my condition and no longer look for a cure, nor do I feel angry or despair at the loss of a planned-out lifestyle. Of course, anxiety and depression does rear its head from time to time, but now I have the members of Affa Sair to help me through the really hard times.

## Pain doesn't care about deadlines

I was delighted when asked to contribute to Pain News by the Editor, Rajesh Munglani, following Annie Lennox' revelation of her battle with chronic pain and her sadness at the way chronic pain sufferers have been left in agony during the Covid crisis, their pain-relieving treatments cruelly stopped, with some having to travel to England to pay for private treatment unavailable in Scotland. Of course, I had a deadline, not harshly imposed, thankfully as it turned out. As I write this I am just recovering from another foray into hospital with, you guessed it — pain.

This time it was my gut which bore the brunt. It has been recognised that CRPS and other pain conditions like Fibromyalgia affects the gut, often causing IBS and similar conditions. Now, many people in my life have claimed I'm full of a certain substance. It is true.

Chronic constipation brought on by a diet of necessary opiates (don't get me started on that one) had me self-administering an enema a few nights ago. I thought I'd sorted the problem for that week but no, body-doubling abdominal pain started at 9 pm and continued through the night. By 4am I was alternating between sobbing, screaming and moaning. My wife and I were already facing a family tragedy that week and the last thing I wanted to do was disturb her and end up in hospital. I had to give in, though, so forcing her awake she called NHS 24. It took 4 hours and lots of frustration to eventually get an ambulance to take me to A & E. I was there about an hour when I got a simple injection and the pain disappeared after 10 minutes. 12 hours of intractable gastric spasms have laid me low, but if you're reading this then I made my deadline.

## A life of chronic pain and about Affa Sair ('awfully sore')

Anyone with a chronic pain condition will have been given a main diagnosis. That is not where the story ends, though. All the other bits and pieces that accompany the diagnosis make your life a continuing nightmare. Things such as dry eyes, skin and mouth, Isolation, the aforementioned constipation, mental and emotional conditions, any of which would warrant a visit to the GP or hospital and treatment in their own right, culminate in a truly difficult life with a greatly flawed system for helping 1 in 5 of society. The solution is not endless reports and talking shops but true compassion, understanding and practical help that begins with listening to the real experts — the patients themselves.

**Affa Sair** (Scots for 'Awfully Sore') was formed in 2015 as a private Facebook group in an attempt to break the Isolation of chronic pain sufferers. At Affa Sair we aim to provide a strong presence for chronic pain sufferers and to educate the public, politicians and NHS Staff on the plight and needs of chronic pain sufferers. In 2019 we gained Charity Status. Our Charity Number is SC049728.

Affa Sair has taken part in the following consultations and surveys:

Primary and Secondary Care chronic pain services in Moray and the way forward — April 2020;

The Alliance — Chronic Pain Reference Group — 2020;

New World Health Organization ICD-11 classification of chronic pain survey by a research team at the University of Marburg, Germany — August 2019;

Chronic Pain Report recently produced by the Scottish Access Collaborative — 2019;

SIGN Public Performing Network — 2019;

NHS Grampian Public Health Directorate on Pain Management Resources — 2019;

Work and Pensions Minister re PIP Assessments — 2018;

Submissions to the Health Committee on Clinical Governance of NHS Boards — 2018;

Scottish Public Health Network Report on Adult Chronic Pain Needs Assessment — 2018;

Meeting with the Public Health Minister in November — 2017;

Meet and Greet with First Minister — June 2017;

ISD Chronic Pain Waiting Times Consultation — 2017;

The Language of Pain Project with Glasgow School of Art — 2016.

The Charity's purposes are to relieve the needs of chronic pain sufferers by:

- Providing a strong presence for chronic pain sufferers and to educate the public, politicians, media, organisations and NHS Staff on the plight and needs of chronic pain sufferers;

Providing an online location for chronic pain sufferers where they can freely discuss their condition and learn from other sufferers together with articles and documents researched by the group;

Encouraging NHS Grampian to provide and maintain suitable Pain Services at Dr Gray's Hospital in Elgin;

- Assisting in the furtherance of knowledge about chronic pain conditions.

**Chronic Pain was accepted by the Scottish Government as a condition in its own right in 2008**, and its management prioritised. This prioritisation has been sadly lacking in recent years. A large proportion of the Affa Sair Charity is campaigning at Holyrood — the seat of the Scottish Government.

In 2016 Affa Sair became a member of the Holyrood Cross Party Group on Chronic Pain. Cross Party Groups in the Scottish Government provide an opportunity for Members of the Scottish Parliament (MSPs) to engage with external stakeholders on a particular subject and should not be confused with the Parliament's committee system. This gives Affa Sair a voice at the heart of Government.

The modern progressive Scottish Government allows for much greater public questioning of Government Ministers in the debating chamber and so with the help of MSPs has featured in many Parliamentary Questions to the First Minister at First Minister's Questions (the Scottish version of PMQs) and to the Health Minister and Public Health Minister at Portfolio Questions. In Scotland, Chronic Pain is classed as a public health matter and therefore is the responsibility of the Public Health Minister, who in turn reports to the Health Minister. Before Covid, arrangements were being made for the Public Health Minister to come to the North East of Scotland to meet with the Affa Sair Trustees following a report submitted to the Health and Public Health Ministers and various MSPs on the state of provision for chronic pain assistance in Scotland. Affa Sair will ensure the meeting goes ahead as soon as Covid allows — possibly virtually, although the Minister was keen to meet personally with NHS Grampian Management and Affa Sair.

There have been various Advisory Bodies on chronic pain set up in the Scottish Parliament. Since 2007, 11 such groups had been formed. In 2017, these morphed into the National Advisory Committee for Chronic Pain (NACCP). Some members of the NACCP have featured in all the previous groups. The controversial NACCP does not have the

**A lite of chronic pain and about Affa sair ('awfully sore')**

confidence of Affa Sair or of chronic pain sufferers. Indeed, under a Freedom of Information Request in 2018, the Scottish government were unable to quantify any changes resulting in practical help for chronic pain patients by any of the advisory groups. The advisory groups' output consists of publication of guidelines and strategy and a failed attempt at the development of a minimum core dataset and quality performance indicators to enable the measurement of clinical activity and outcomes in 3 of the 14 NHS Scotland Boards.

What is needed is an advisory body made up of patients with 'lived experience', the current buzzwords flying around political circles. There seems little point in politicians listening to only one panel of experts. That is no way to glean proper impartial

advice. Without another advisory group, the unelected NACCP makes de facto policy despite the protestations of high-ranking officials and politicians.

Chronic pain patients desperately need proper help in securing treatment for their life-stealing conditions, not reports or surveys. There is no national Pain Service in Scotland. Each Health Board is responsible for setting up its own Pain Clinics and services. This has resulted in a postcode lottery of services for patients with treatments like pain-relieving infusions being denied in some areas while available in others. Affa Sair will be entering into discussions with the Scottish Government and health organisations to ensure that this unjust system is replaced as soon as possible.