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affa sair
for sufferers of chronic pain
www.affasair.weebly.com

Please find enclosed documents on the chronic pain group called “Affa Sair” an on-line support group for people suffering from chronic pain conditions.

Most importantly - we are not looking for any money.

All we are looking for is your support in publicising the work of the group in any way you can.

- ⊕ You could spread the word among your friends and colleagues.
- ⊕ You could display the enclosed poster.
- ⊕ You could display the included postcards.
- ⊕ You could visit our webpage www.affasair.weebly.com and read the articles and information there .
- ⊕ You could join in the discussions at www.facebook.com/groups/affasair.
- ⊕ If you are in the media you could publicise our group.



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The “Affa Sair” Group – an on-line meeting place for chronic pain sufferers www.facebook.com/groups/affasair & www.affasair.weebly.com

I established the “Affa Sair” Facebook Group to offer support to people suffering with chronic pain, their partners, friends and anyone with an interest in the condition. The group has become popular and there is now also a website for folk who do not want to join Facebook but are interested in reading documents and articles relevant to chronic pain sufferers.

The group’s primary aim is to highlight the life of chronic pain sufferers in the Grampian Health Board region. Official statistics show there are 95,000 sufferers in the Grampian Health Board region; 17,000 in Moray alone. However, as the group has become more widely known on social media, we are delighted to have members from all over Scotland and the world.

Built for people with chronic pain by someone with chronic pain, this group provides a trusted space for real people to talk about real problems without fear of judgement, or medical jargon.

Members are encouraged to leave tips on how to deal with a life of pain on a daily basis and to just have a good moan to each other about their experiences. Our lives should not be defined by our condition. We are allowed to have fun at times. We do not need to be serious and miserable all the time so the comments are sprinkled with a good dose of humour.

Remember you are not facing this alone, and no matter what a bad a day you are having, there is someone else out there whose day is worse. So by bringing joy into someone else’s life through the group, you might just make the world of difference.

If we, as members, truly invest ourselves into this online community, we can speak together for those who feel they have never had a voice before. I can take our experiences and feelings to the Grampian Health Board, local health professionals and politicians.

We truly are the forgotten of the many sections of community needing help from our health service. It's time we made our experiences and our opinions known.

We badly need a pain service re-established at Dr Gray's Hospital in Elgin.

It is horrendously difficult for us to endure the 140 mile return journey to Aberdeen and, in some cases, making that journey is simply impossible. Some of our members face a five hour round trip on public transport to access the pain clinic.

I fully realise how difficult re-establishing such a clinic would be. The Health Board had promised a clinic in Elgin by the end of 2015 but this date has already been pushed back. Even the new current date of February is very unrealistic, so I would like to see a pain specialist or practitioner making the journey from Aberdeen Royal Infirmary to Elgin to hold the clinics there, until a permanent solution is in place. This would save the Health Board paying out travelling expenses for the patients.

I've suffered from chronic pain for 38 years now and have only just realised I am not unique in my experiences with the health service thanks to the Affa Sair group members. I had found it very hard to find the relevant information relating to my condition and even harder to get the advice I need, or the answers to my questions from local health care facilities, so had to rely on self-research on the internet and social media. The Affa Sair group pulls this information into one on-line location.

There has been a cross-party chronic pain group in the Scottish Parliament for 12 years. But I was shocked to find we have no political or Health Board representation from the North East of Scotland on it, which is a disgrace. This volunteer-run cross-party group, despite their best efforts, has been unable to achieve little, if anything, for North East patients, as there seems to be no support from Grampian Health Board. The group's main achievement has been to set up a new Pain Centre in Glasgow which was open to patients from all over Scotland when it was launched. Of course, for us, if the journey to Aberdeen is too much, Glasgow just isn't realistic. It pains me to notice that this new facility itself is now in danger of being closed. If this happens Scottish patients will again be forced to have to travel to Bath for the care they need. A journey too far.

To be fair to the medical profession, science has moved on considerably since I was first affected. Like practically every other pain sufferer, on many occasions in the past I wasn't believed and at one memorable consultation, was told I probably had some psychological problem. That was in the 1970s, but it disgusted me to learn that some patients are still not believed to this day and are still being told "it's all in your head."

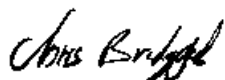
This has got to change - right-minded medical experts are starting to realise that pain is not just a symptom but a disease in its own right.

I have yet to find someone in our group who has seen posters on chronic pain conditions in our medical centres, yet, patients are bombarded with information on other diseases and conditions. The public need to be made aware of our existence and our problems.

Life can be very difficult for the chronic pain sufferer who not only has to put up with the never-ending pain, but also comments and supposedly helpful advice, which only degrades our well-being. "But you look fine" is a common one. "Well, at least it's not cancer" is another one. Though still a dreadful disease, thankfully many forms of cancer can be cured these days. Very little funding has been allocated to chronic pain services though the many conditions causing it last your whole life. There is no cure.

My own diagnoses is Complex Regional Pain Syndrome. I also have Diabetes, Sleep Apnoea, Cardio and Peripheral Vascular Disease after having had an Aorta/Femoral Bypass when I was 36. I have attached documents to let you better understand how chronic pain affects me along with this introduction to the group.

I am truly grateful to you for taking the time to read this information.



Chris Bridgeford
Chief Administrator
Affa Sair Group

An Ordinary Day in the life of a Chronic Pain Sufferer

a personal tale by Chris Bridgeford

You slowly become conscious into that dreamlike state somewhere between sleep and wakefulness. Then, wham, the pain hits like a sledgehammer. It feels like you've been plugged into an electrical socket - everything jangling. You don't want to move but you must. You need to swallow down the morning pills, all 16 of them. 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 somewhere inside of you.

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 its time to get up. You make your way to the bathroom.

You need to place the stool in the shower first, as long ago, you had to give up standing for a shower because the pain in your feet was too severe. You sit facing the stream of water which used to feel good and relaxing. Now it's like little needles attacking your skin. You can't bear this attacking your back which is why you face the stream of water. Now to scrape your face with the razor. It's ok if you don't press too hard. Time to get dry. Wrap yourself in a towel just to take the surface water off but then you need to use a hairdryer as the towel is like a sheet of sandpaper on your skin.

Dressed and awake, you make your way downstairs to get breakfast. You look warily at the letterbox in case there is an envelope from the DWP inviting you to prove your ill and not a scrounger on the State. They don't seem to understand the meaning of "chronic".

You need to feed the cats first or you'll have a rebellion on your hands. Feline friends appeased, you get to your chair with the air cushion 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 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. Good thing is, you can use your MacBook today - the track pad and gloves don't agree. Your knees are killing you though, so its time to breakout the medicated plasters. These are laced with a local anaesthetic and are incredibly cold when put on. They do seem to calm things down after a wee while.

You can only use three at a time so if your shoulders are bad, your stuck. That's when the TENS machine comes in handy. It doesn't do a damn thing to cure the pain but the electrical impulses it causes gives you something else to feel. A regular controllable pulse instead of the cold and searing never-ending pain.

Time to do some housework to pass the day.

If its a normal day then you can do some ironing, usually sitting down. Then maybe a quick Hoover downstairs. This is where it gets dangerous. If you're having a good day after a few bad ones, you go berserk. Doing 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 seem incapable of doing that no matter how many times you're advised or your wife tells you to look after yourself.

Fast forward to the evening after a mid-day meal and pills (only 3 this time and maybe another oxycodone). Your wife and pillar of strength is home. At last some human energy to interact with. Time to eat again with more pills (5 this time) accompanying your tea.

Three hours later the pain has you so exasperated and exhausted its time to go upstairs again. More pills – 7 of them - and so to bed. Its the most comfy place in the house so you relax, surf the web, read a bit. Maybe an extra oxycontin 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.

And it starts all over again

Bad Days – when the pain become a ravenous monster

A personal tale by Chris Bridgeford

Worsening Pain

The pain seems to have a mind of it's own and goes into overdrive. The pain rampages around your body; depriving you of rational thought, movement and speech. Only a dangerous amount of extra Oxycodone and Diazepam would have any affect on it. It's frankly too risky, so you 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 you but surrounds you as well. You are in your own pocket of reality, filled with a nagging unrelenting hurt. Sometimes you're lucky and its just your legs that are threatening to explode. Sometimes it becomes a guessing game with bits of you spontaneously erupting into an area of searing agony.

Irritability

Whoa 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.

Lack of interest

Even the programmes you like or the book you were enjoying does not appeal to you today. You just sit there, lost in your own thoughts, oblivious to those around you.

Lack of motivation

You know there are things you could be doing, feeding the poor cats, feeding you poor wife; 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 cant 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 really would miss you?
- Would it not be better if you weren't here to be a burden or annoyance?



a community group for chronic pain sufferers

www.affasair.weebly.com

www.facebook.com/groups/affasair

www.twitter.com/affasair

Then the sharp, gripping, stabbing tendrils of cold pain spread from the spine to the shoulder blades leaping to the ribs in the front of the body; at once you bend over wailing in agony, unable to keep this pain a secret.



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"My illness is invisible, not imaginary."



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It is easier to find men who will volunteer to die, than to find those who are willing to endure pain with patience.

Julius Caesar



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A group for chronic pain sufferers; their partners, friends or anyone interested in chronic pain.

The group aims to highlight the lives of “chronics” and to have a pain service re-established at Dr. Gray’s Hospital in Elgin.

Members leave tips to deal with daily pain and just have a good moan to each other about their shared experiences.

For further information please contact
Chris on 07783 047430
or
Jeni on 07951 518710

You can also email us at:
affasair@gmail.com



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Membership Rules

1. Any problem with another member please take it to an ADMIN. Please do not take matters into your own hands and start arguing with another member publically on the group as these posts WILL be removed and possibly the member along with it.
2. Please type replies to other members in a polite manner so the message cannot be misconstrued.
3. If a member is venting about their illness and pain please support them in a positive manner, if you don't like what another member has typed and have a complaint then again please take it to ADMIN not the member. A lot of us suffer from depression so always try and put yourself in their shoes and think before you type.
4. What you read in the group stays in the group. Please do not discuss another member's private problems to the general public, the group is meant to be a safe haven full of trusting and trustworthy people.
5. If you have a problem with your pain, illness, family then please vent away as it really does help you and is far better than bottling it up.