

affasair

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SUPPORT FOR CHRONIC PAIN SUFFERERS IN SCOTLAND

THE CURRENT SITUATION

Affa Sair is located in NHS Grampian who have long held the unenviable honour of being the worst region for waiting times for many years. This is despite the efforts made by the under-resourced dedicated staff of Grampian Pain Services. At present the waiting period for first time referrals to the Pain Clinic at Aberdeen and Pain Service for consultations only in Elgin, stands at 35 weeks — last year it was 42 weeks and six years previously it was at 31 weeks. Return appointments are now practically unheard of leaving many of the estimated 105,000 pain patients in Grampian in desperate states.

Like so many chronic pain patients throughout Scotland, some of **Affa Sair's** members report suicidal thoughts and attempts because of the lack of help. Group members have divulged their daily struggles with chronic pain specifically to help you realise how difficult the life of a chronic pain sufferer is. I have included their stories, together with my own in the Appendix which accompanies this report.

An FOI request earlier this year confirmed what we already knew, that the last 12 years of Government Advisory Bodies have resulted in no practical help at all for chronic pain patients in Scotland, with the exception of the creation of the National Residential Pain Management Programme in Glasgow. The Healthcare Quality and Improvement Directorate stated in their reply to our FOI Request that they are unable to quantify any changes to chronic pain patients from the workings of the Advisory Bodies.

The inclusion of the Strategic Planning and Clinical Priorities Unit in The Scottish Access Collaborative gives us little confidence in the eventual outcome of the report. Affa Sair have had first-hand experience of the workings of this unit which resulted in a written apology to the group from Prof Jason Leitch, then National Clinical Director of the Healthcare Quality and Improvement Directorate, for the failings. [see appendix] These included not replying to simple questions for six months, and expecting our group to arrange and pay for the meeting with the then Public Health Minister, Aileen Campbell, and her staff. In Prof Leitch's own words, the unit did not provide "... the level and quality of service that a representative of a third sector organisation should expect to receive". We found no indication of care or concern for chronic pain.

At Affa Sair we hear from members who have never been referred to a Pain Clinic. We do not know the reasons for this but wonder if the very existence of a Pain Clinic is widely known in some NHS Regions. Pain Clinics are a drastically under-resourced of course so perhaps some GPs feel it not worth clogging up an already broken system.

You will be well aware the amount of money given to chronic pain in Scotland 2019 is miniscule compared to the number of sufferers and to monies giving to other conditions. Just £27,000 (less than half a percent) of the Waiting Times Improvement Plan funding of £535 million is being put towards chronic pain conditions. 1

Locally, NHS Grampian was given £4.9 million in 2018 by the Scottish Government to reduce waits in several areas, but just a miserly £36,000 of that was spent on chronic pain. Despite NHS Grampian being permanently bottom of the league tables for chronic pain waiting times... 2

An email from The Directorate for Health Performance and Delivery on 23_{rd} September 2019 [see appendix] has recommended that far more resources be given to GPs and the Primary Care sector thus ignoring the valuable expertise of Consultants in Secondary Care and so being able to ignore the long waiting times for appointments with Pain Clinics.

The World Health Organisation states that 1 in 5 (20%) of people suffer from a chronic pain condition. With the current population in Scotland estimated at 5.45M by Population UK, it is estimated that 1,090,000 Scots are affected. Far more than the 800,000 oft quoted by government advisors. This is no niche disease. It is a cruel and devasting illness affecting a fifth of the population yet receives miniscule funding and no research into useful practical assistance for patients.

IMPROVEMENTS REQUIRED

INCREASED STAFFING LEVELS

The most vital improvement needed to Chronic Pain Services as a whole is for there to be an end to years of under-staffing with enough staff hired to reflect the large and growing number of patients requiring the expertise of the Pain Clinic staff. A national shortage of Pain Consultants has been allowed to build up, despite years of warnings, through inadequate policies, no-one assertively encouraging recruitment and a lack of resources being given to the appropriate Departments within the NHS.

Until more full-time pain consultants are available to be trained, we suggest there be an increase in less expensive Pain Nurses and ancillary staff to be used for follow up appointments. They would be a boon to the patients and would be able to build a rapport with them. These ancillary staff should always be full time and not just available for the miniscule amount of time Consultants are currently given in their overall workload. Each Pain Clinic should have at least one Psychologist or Psychology Nurse available as mental health problems are endemic in chronic pain patients resulting in many considering suicide as an escape from the daily torture of chronic pain.

INCREASE CAPACITY AT DR GRAY'S HOSPITAL, ELGIN

In NHS Grampian there is an urgent need to have the capacity of the Pain Service in Dr Gray's Hospital in Elgin increased so patients from Moray do not have to make a three-hour return car journey or up to five hours on public transport to Aberdeen. The current Pain Service does at Dr Gray's does not allow for any procedures such as infusions to be carried out. Nor are there physiotherapists or psychologists available. The Elgin Pain Service is purely for consultations. In conversations with Senior Management at Dr Gray's we know there is a willingness to provide an enhanced service but it appears Aberdeen are reluctant to help progress this.

SOCIAL MEDIA

Full use must be made of developments in social media so that patients who find it difficult to travel can access health professionals via video conferencing or private messaging services. Indeed, the first of the six Principles of the Scottish Access Collaborative Report on Chronic Pain 2019 states: "Patients should not have to travel unless there is clear clinical benefit".

COMPARABLE RESOURCES

Alleviating the problems of Chronic Pain needs to have comparable resources and funding in line with other public health concerns such as Diabetes, Cancer, Smoking and Alcohol. The obvious lack of care and compassion for chronic pain patients in health policy is a national disgrace. I fear nothing will be done until an important political figure is subjected to the horrors of an "invisible" condition such as Fibromyalgia or other neuropathic pain conditions.

SECONDARY CARE PATHWAY RESOURCES INCREASED

Following the recommendations of the SAC Chronic Pain Report, we do wonder if the Primary Care pathway is the best use of resources in helping pain patients. Training for Primary Care Doctors in chronic pain is woefully inadequate. It is an extremely specialised area in medicine. GPs are as their name suggests "generalists". They cannot be expected to understand the complexities of problematical chronic pain conditions. Ignoring the valuable expertise of Consultants in Secondary Care and so being able to ignore the long waiting times for appointments with Pain Clinics, will be detrimental to chronic pain sufferers. Trying to help pain patients within the timeframe of a typical GP appointment is clearly ludicrous. These patients endure 'invisible conditions' which rob patients of their lives, cause immense mental problems, suicide risks and untold misery.

Assisting With The Cost Of Complementary Therapies

While the individual nature of chronic pain conditions lends support to self-management, it is out with the financial capability of chronic pain patients. Complementary therapies are far too expensive for patients relying on benefits such as PIP, ESA and Universal Credit. Current prices begin at around £40 per session. For people in chronic pain one or two sessions are never enough. Significant discounts could be arranged. The Self-Directed Support system is good in principle but sadly, in Moray anyway, this is so underfunded that it is no longer fit for purpose. A decent SDS system should be established which gives chronic pain patient's access to individual budgets to be used to access private therapists. This will surely help free up NHS resources.

OPIOIDS CAN BE BENEFICIAL TO CHRONIC PAIN SUFFERERS

The Government and their advisors urgently need to stress that Opioids are useful and effective for some chronic pain patients despite the current zeitgeist on opioid prescribing. A blanket approach does not work for chronic pain conditions. Each case must be judged on its own merits. No patient should be forced to give up medications which have proved useful to them without consulting both the patient and the patient's GP.

Time and time again we at Affa Sair hear stories of patients being denied opiates on admission to hospital with hospital staff, untrained in pain medicine, going against the prescriptions of GPs who have long experience of their patients. GPs themselves are now reluctant to prescribe opiates to new chronic pain patients as, without a strong message from the government and its advisors, they perceive opiates to only cause high rates of addiction. Advisors in the UK have not carefully considered the clarification the FDA and CDC in America have had to issue in February 2019 concerning their previous advice on Opiate Prescriptions. [see appendix]

Whilst we appreciate the concern of addiction in patients without chronic pain, these concerns should not be used to deny opiates to the many long-term neuropathic pain sufferers whose only pain relief is through the use of opiates. This message must be stringently put across by Pain Clinicians at all levels, as patients are being greatly harmed by having their medications withheld or in some very concerning cases - stopped abruptly.

FACE TO FACE MEETINGS WITH GOVERNMENT MINISTERS

It would clearly be beneficial for Affa Sair to be able to speak to Ministers and Advisors face to face. It is extremely difficult for chronic pain sufferers to have to travel to the Central Belt. Travelling such a distance results in increased pain levels and episodes. There is also a large financial outlay to be considered as many chronic pain sufferers are unable to work and rely on hard-won benefits for their income.

With the constant problems in NHS Grampian requiring visits from the Health Sectary and other governmental representatives, it should be possible to combine a visit North to meet with Affa Sair representatives. North-East citizens deserve the same level of governmental input and opportunities as the Central Belt enjoys.

However, to prevent any delay to an initial meeting, I would be prepared to consider another journey to Edinburgh - despite the health and financial implications.

CHRONIC PAIN PATIENT REFERENCE GROUP

On 17th July in a reply to Question S5W-23816 Jeane Freeman stated that:

"Third sector colleagues are taking forward the establishment of a Chronic Pain Patient Reference Group"

Who is establishing such a group and why has Affa Sair not been invited to join. We are still the only patient-led campaigning group in Scotland with 433 members now. We have also been involved in numerous consultations and surveys, so feel we have enough experience in taking part in discussions concerning chronic pain patients. We are certainly known to members of the Strategic Planning and Critical Care Unit, the office of the Public Health Minister; Prof Blair Smith and Dr Paul Cameron from many of the advisory bodies and the disbanded Core Minimum Dataset project at Dundee University and Pain Concern.

Surely our geographical location is not seen as an obstacle to our ability to take part in such a reference group. There are many digital options available for us to be included in any group meetings.



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THE BACKGROUND TO AFFA SAIR

Since April 2015, **Affa Sair** has gathered 432 [Oct2019] members in its Facebook Profile. In 2019 a Trust was formed with five Trustees led by Chris Bridgeford, the Founder of the group. Charitable Status has been applied for.

Affa Sair strives 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; to provide 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; to encourage NHS Grampian to provide and maintain suitable Pain Services at Dr Gray's Hospital in Elgin and to assist in the furtherance of knowledge about chronic pain conditions.

Chronic Pain is continuous long-term pain of more than 12 weeks or, after the time that healing should have occurred after trauma or surgery.

- Chronic Pain is thought to affect 5.6% or 1 in 20 of the population of Scotland now estimated at 1.09million. 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 5 times more frequently than those without.
- 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 as a long-term condition.

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

- 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
- 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 in 2016

MEMBERS ACCOUNTS ON LIVING WITH CHRONIC PAIN

Life doesn't start each day, it's an existence some of us would prefer not to endure on most days. A restless night, little rest, restless limbs, jerks and spasms let alone no sleep which leads to depressive thoughts, over thinking what one did to deserve this hell, what really is ones purpose if there's no longer any or little enjoyment.

What about the effects it has on my husband's health too, not only my rest is affected but his night is also disturbed. Who hears you when you cry, who comforts you in times of need, you wake each day (well if you've even had any sleep this is) on a chronic fatigue day when it's hard to even motivate yourself, you must try your utmost to carry on, await assistance to help with personal hygiene, dressing and that's before your mountain of medications.

Do the medications even work or just help lighten the pain, who knows, as it's very hard to get appointments with your GP let alone health professionals like the Pain Clinic - it's been over a year since I last saw them and who knows if I ever will again? Then you've to try provide information of why you need to see the doctor and it makes one feel you're not worth the paper they write on, they don't see the physical/mental pain, so surely there's nothing wrong! I feel I've to try make an appointment a month in advance and say I will definitely need this appointment on this specific date as this will be my symptoms but what you fail to realise is, this is my life, day in day out.

I can't be bothered eating, it's just too much hassle and effort. My life revolves around what my body will allow me to do, not what I'd like to do. Though I have dreams of what my diary could consist of, I don't know if I can commit to it until that given day. What will I feel like and how much can I push my pain threshold? Why can't other forms of treatment be more readily available on the NHS such as acupuncture, chiropractor, physiotherapy, hydrotherapy, massage therapy?

Why are appointments always in Aberdeen or further afield? Does no-one not see the pain caused by having to sit on that long journey to then be left waiting for our appointment and the thought of the long journey home. Then I need extra time, sometimes days to recuperate from the stress caused by the appointment.

Why do we have to prove ourselves and go through the stress of filling out form after form and attend stressful medical assessments which don't just affect your pain but mental and physical health too.

When your diagnosis is chronic long-term pain then we shouldn't be put through this added trauma because this is how one is affected by such things. I'm not wanting sympathy but a little respect, empathy and understanding of what one endures day in, day out. It's not a 'Bed of Rose's' that one chooses to endure. I'd swap my life in a heartbeat to live just a happier/healthier life for just one day, half a day. one minute, one second.

Would you care to swap with me? I'm guessing not - but all we ask is for that little bit of empathy to realise this is real – this is me!

My husband doesn't know from one day to the next, can he go out for just 1 hour, 1 enjoyable ride on his motorcycle? Can he risk leaving me?

Though he must do his checklist first.

- 1. Let her know where I'm going, roughly how long I'll be.
- 2. Is her Community Alarm Close to hand in case of emergency (of which we pay for every 3 months for that added reassurance when I'm not home)?
- 3. Is her mobile/landline close to hand?
- 4. Have I left a drink and meds close to hand?
- 5. Does she need help to use the bathroom before I leave?

The list goes on and on - can I or do I ever relax enough to enjoy my little break away from caring? It's down to me if things go wrong, I have no one else I can rely on, no friendship circle. our life revolves around the pain in one's life, the wife who I love dearly and wish I could heal, just for one moment, just for one day, but who sees this, who cares. my health suffers too. I'm the Carer when I'm needed though my wife doesn't want a babysitter - she wants to enjoy life with her husband. just that little moment, one special memory. But pain fractures our marriage.

I end the day having tried my hardest to keep what little independence I can. 'No, I'll do that!' I will do that!' 'I can do that!', but what about the days I've overdone things and the vicious cycle begins again. 'I can't do this!' 'Can you perhaps help with this!', - it's not easy to always accept one can no longer do or manage what I could do last week. my life goes by, second to second on what I can manage but perhaps can't always do.

I make meals on days I'm when I feel stronger, to cover at least 2 days and some to freeze and then I go without on days I'm not able to even leave my bed. 'can you help me wash, dress and get from A to B!

This is what my life consists of but by no means choose, but I'm a person too!

I don't want a label, but a little help along the way goes a long way in perhaps making life a little brighter, that little easier to wake each day with perhaps a different outlook on things. More professionals are needed to treat one and all. don't just leave me on the shelf assuming all is fine and cushy - I deserve a follow up appointment as expected and to be listened to - please!

My husband just says "It's like a never-ending story" – when will we be heard.

Despite requesting a follow-up appointment at the Aberdeen Pain Clinic some 18 months ago, I'm still waiting. I have spoken to Complaints about 2 months ago but there has still been no reply from them.

Once you've seen the consultant it feels like you're fobbed off, not believed and once you've had a few appointments you're then pushed to the back and forgotten about. This is how I feel and I think we need to be seen by people more used to chronic pain conditions who know who to refer one to. Right now, the NHS is a farce and one continues to suffer in silence as no one listens.

NC

I was thinking about the negative emotions that come with chronic pain and illness; 'anger and rage' being one. Then I thought how destructive that can be for me, but then I thought when these negative emotions are flipped - easier said than done - but I thought, anger has made me tenacious, resilient, perseverant. Then there are other emotions that are flipped so — Grief, I would say flipped, makes you more empathetic. I like to learn. I want to learn how to become as best as I can to handle this. So, I have written some emotions down and how we turn them to a positive. This is no Jeremy Kyle stuff here - just honest sharing. How do we transcend loss, pain, fear, surrender or trust?

I always see the negative as I think that's my default setting. I have never thought till today, you have become a great problem solver, more empathetic, more appreciate for friends, for the simple things I would take for granted - a warm bed, a roof over my head. I have never experienced the feeling of hope on a scale like I do today, and strength, because I think I'm weak. A friend said, "Darren, you have done quite well with this for 7 years". I don't see that as weak, that's strength. Sometimes, we are the last to see cause.

We are in the trenches, fighting to go from one day to the next. There is a major component to this illness and it's not just pain of the physical kind, its emotional; and all the feeling and emotions we cycle through on a daily basis. I suppose my ten cents worth is, if you need counselling to process those emotions - do it. I found a charity-based organisation in Glasgow and if it wasn't for them and donation-based counselling, my emotional barometer would be off the scale. And it still is at times - we are all human. I just realise this isn't all meds and shit. There is a mega emotional component to it.

DΗ

I have lived with fibromyalgia for about 15 years and have paid privately for treatment because the GPs just don't understand the illness. I work full time and take paracetamol and Ibuprofen when I can no longer cope with the pain. I also go for private therapies which have a huge financial implication of course.

E S

I work but it's getting more and more difficult. I am lucky that my company are so good. I think more education on chronic pain for employers would help them understand the difficulties we face. I also think there should be more support for families. It's bad enough us feeling cast aside but without our families it would be even worse. I think they need more help to look after us.

D P

I've had chronic widespread pain for over 9 years following failed back surgery. My life has changed enormously during that time. I loved my job in the NHS but ironically was dismissed because of ill health. I had to take time off frequently and understood the impact had on patients and staff. They must have been very frustrated with me as I have as myself!

I went frequently to my GP in the beginning, who increased the dose of medication to the maximum. I have now managed to reduce significantly the pain medication but this has only increased my daily pain levels and the fatigue is no better (I hoped that would improve). I am trying to use alternative approaches for controlling my pain. I use acupuncture, massage, pilates and see an osteopath. All these things are expensive and take up a lot of our finances. I wish these that things were made available on the NHS or discounted but understand the expense. I also use CBD drops which help but again are expensive. I wish trials would be hurried in this field so that it was available to everyone. I can understand why people are obtaining cannabis illegally to help them. I find the CBD without THC to be beneficial so it's not all about wanting to get high!

My days used to be divided into bad & good days. Now they are either bad or slightly better. I can't remember the last time I had a pain free day. The left-hand side of my body was left with nerve pain following my back surgery. I have pain in my shoulder, elbow, wrist, hand, hip, thigh, knee, ankle & foot. I used to love social occasions but no longer plan anything as have had to cancel too many times. I have lost many friends and my relationship with my daughters has suffered because of my inability to engage due to fatigue. My memory is awful, I often forget to take medication or take it then forget if I've taken it. I have many nights when I am unable to sleep due to pain or the opposite, especially if I've taken added medication where I can sleep for 10 hours and still need more.

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. He works hard and also worries about me constantly. I feel it is unfair that he has to miss out on things because I am unable. He prefers me not to cook anymore. Several times I have nearly set fire to the house, leaving pans in the heat or leaving the oven on. I feel a failure not being able to be a good wife.

I am often without the necessary energy to shower or dress. I get up late and have to wait until my body feels good enough to move. I consider it a better day if I'm up and dressed before 1.00pm. If I'm able to get out to have lunch or a coffee that's a blessing. I suffer with poor verbal communication now, often struggling to find the right words. I get very embarrassed talking to people who are strangers.

To the outside world I probably look fine. I don't expect people to understand how I can be ok one day but then confined to my bed or the couch the next. I wish there was greater education of invisible disabilities. I have to use a disabled badge and can see people looking at me with disgust. It's rare I actually even shop now; my husband has to do that also.

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.

I wish more hospital appointments could be local. I travel an hour to the nearest hospital, sometimes to have seen a consultant for no more than 10 minutes. This is exhausting and painful! My husband has to take time off to take me or using the bus can take 4 hours! I'm sure many appointments could now use telephone consultation or video link. The majority of appointments do not involve physical examination.

My initial appointment at the Pain Clinic was great, at a local hospital, long consultation, felt like I was really being listened to. Next two appointments were in Dundee, an hour away if lucky enough to go in car. All they wanted to do was reduce my medication. I felt hopeless and angry. That was 4 years ago, got discharged and haven't been back since.

There really is a shortage of trained staff in chronic pain field. The waiting times after referral are incredibly long, we need to be seen and helped much quicker. We long for someone to listen, believe and help us!! This is not all in our heads!!! I do appreciate the NHS is struggling but we really are a forgotten group of patients. M S

I struggle every day. Just to get washed and ready takes me 3 hours, sometimes I give up and think I am not putting myself through the hassle & pain. I also struggle greatly with constipation and also chronic psoriasis. I am on biologics and I get a jag in my stomach every 3 months, the side effects are horrific at times. I am on 30 tablets a day and have chronic fatigue and an under active thyroid. The list goes on and on. Sometimes I feel I would be better off in a home. I drop things all the time and I get irritable with myself and my stress levels go sky high. I am so grateful to this group as I am no longer alone. Nobody understands apart from people in this group who are disabled.

J M

I don't cope very well and the pain is very much coupled with depression. I have fibromyalgia (waiting on a hip knee scan as pain is different to fibro stuff). I take my pain meds upon waking, make a coffee, feed my dog and let him through up onto my bed where we both doze for an hour or so.

It's my dog that saved my life really, he keeps me going and I do my best to get him out every day. On bad days I drive my car to a field and let him out to burn off energy while I sit in the car. (Very bad days I use a dog walker).

I'm not sure what's worse or what came first following much life trauma, my mental health failed and pain and various fibromyalgia symptoms kicked in. I don't recognise myself anymore. I'm on my own and have totally isolated myself as a result anything that involves people on mass brings on panic attacks e.g. popping in to our Tesco's; walking straight in and straight out again! I tried to make an effort to do this daily but lately everything has gone to pot after I declared some inheritance money and wanting to support myself pay my rent etc for 18 months or so then when I went to claim rent again lost all my disability premiums and no choice but to claim universal credit.

I stopped universal credit and Moray Council Welfare Rights Department put in a mandatory reconsideration to get premiums reinstated by DWP. It's now two months on with no rent and hearing nothing. I have a little camper van I try and get away in. However, although I enjoy it, it's a struggle on my own and only manage a night or two with an hour's drive.

I comfort-buy utter crap normally when sleep does not come! I love clothes and used to love putting my face on and dressing for the occasion but don't go anywhere! I have a resistance issue (I can't remember what the medical name is) where antidepressants start to work but then tail off. Currently see Dr Brown or will be since she's returned from maternity leave. I have a Tempur mattress which gives me some relief along with my electric blanket. After 6pm pain down the neck shoulders and back burns and I can't cope unless I'm lying down as a result after I've been out with the dog and done the basics I take to my bed and have a living room I have sat in about ten times in 18 months!

ТВ

I have lived with chronic pain since I was young. It was just back pain back then, now it is fibromyalgia.

One of the hardest things about living with daily pain is that health professionals do damage when they don't mean to. What I mean by this is that they have reduced my pain med Codeine, without checking with me to see if a lowered dose is working for me, and when I have said I need it upped, they have ignored me and said I am too young to be on that dose of codeine.

I am currently waiting on paperwork to be filed by my social worker for carers, and this has been since January that I have been asking him to do this. I need carers because my chronic pain means I cannot shower myself, I cannot do daily chores as easily as I used to. I need carers because the simple things such as hoovering is impossible for me since they lowered my dose of pain medication following the guidelines on Opioid dispensing.

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 however was told it would be a pointless exercise. I've never been referred despite having chronic pain since I was 10 years old, I am now 22.

ΙK

I've worked for NHS Highland as nursing assistant since 2006 and subjected to a traumatic experience with management and HR due to unfair sickness absence policy that doesn't protect staff with disabilities.

I often forced myself to work through my excruciating pain in fear of unemployment. I was bullied by nursing colleagues and management as they tried to get rid of me. I was not supported when trialling treatment prescribed by Neurologist. Requiring time off due to a painful disability should not be classed as sickness. How can you expect disabled people to work when we're penalised? I was given 3 months dismissal notice due to my chronic migraine pain/fatigue resulting in suicidal thoughts as I'd lose my newly adapted home with no way to pay my mortgage.

Claiming PIP was another long traumatic saga and I don't have enough money in my pension fund to take early retirement due to ill health in my early 40 years of age. Luckily, I was redeployed to Procurement Department and flexitime has been helpful for remaining at work but is not without challenges. I have no energy for activities or cooking my own meals living alone and struggling daily to cope with PTSD.

I'm quoted in the government published bullying culture report. Diversity & Discrimination page 118 (25.32) Cultural and discrimination issues arise: "I'm left feeling victimised and discriminated by several NHS Raigmore staff for having a disability and doing my very best to remain in employment. I have never put anyone at risk as I know my own limitations and have friends that drive me home if required. The allegations are not a true reflection of my caring personality. NHS staff will pretend they care about you to obtain personal information then use it against you. It deeply upsets me that I have so many discrepancies and very sensitive information on my NHS personal file."

Please review NHS Capability Policy to support disabled employees.

RM

I suffer with several illnesses. Diabetes type 1, neuropathy (caused by the diabetes), arthritis, hearing loss, sciatica, asthma, Dupuytren's, depression and oedema to name some. These are for the rest of my life. They will not go away.

I have good days, where I can get up and do things like visit friends and maybe some crafts at home. Then come the bad days. Pain - so much pain that the meds don't work. Dark thoughts and feelings, having to eat (diabetes) when you really, really don't want to. Having to inject yourself 5 times a day. And also having to take a blood test at least once a day preferably 4. Lying in bed wondering what you did so bad in life that you ended up like this.

Then we fight, EVERY SINGLE TIME we FIGHT to claim a little help for ourselves. I have NEVER been given anything without a bloody assessment. The degrading, downright cruel, painful and ludicrous assessments. I go through them each and every time. Strangers seeing me for 1 hour of my life, then get to decide if I'm worthy of any help. And every single time I have had to appeal. Sometimes we just want to give up and crawl into a hole and die. But that never happens either.

Appointments are weeks to wait. And that's just to see the local doctor. Months for any specialists. I don't bother much now as it's always the same. They can only do what they have done so far. Try to help with the pain. Try to help the depression. I've learned now to just nod and say yep I'm fine to them. Even writing this I'm thinking "why bother. They won't care or listen" but still that little Spirit that's left in me says "try".

J R

I have had Rheumatoid Arthritis for nearly 20 years. I am in constant pain. For many years toxic people made me feel my life wasn't worth living. When I have to get help to lift a cup, some people thought I was faking it ... My current GP has spent 18 months getting me onto medication where I am in control and my body and mind can deal with what daily life throws at me.

My doc has diagnosed/ treated a lot of conditions which have arisen as side effects of RA/Osteoarthritis/worn joints/depression and so on ... My consultant team in ARI are invaluable and keeping me well informed and referring to me other teams as needed.

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. The amount of times I am pushed out of the way as I totter with two walking sticks grunting with each step and pain makes me cry. I don't want to be weak and helpless but I am. On my worst days I can't move, 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.

No medical procedures are done at the local Elgin Pain Clinic and they will not accommodate you if you cannot get to Aberdeen. Been waiting over a year if not 2 on being referred back to pain clinic. Doctors seem uninterested at times. If you cannot do their morning appointments then it's tough luck for you.

B W

LIVING WITH CHRONIC PAIN CHRIS BRIDGEFORD, AFFA SAIR FOUNDER

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 of the couch I was lounging on. A bolt of pain shot down by lower back and leg and my whole body went into paroxysms of pain. Little did I know then that the pain was still going on 41 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 nicknames 'Bamboo Spine'. After six months in hospital I returned home and began a life of constant neverending pain, depression and accusations. 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.

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 A.S., 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 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 and 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 9 units of blood and needing two operations the same day and a bowel resection. That same year my diagnoses had been changed to 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 had picked up Diabetes, had been living in constant states of anxiety and was also labelled with peripheral and cardio vascular 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 suspected of having 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 realised I wasn't as unique as I thought.

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 16 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. 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 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, even when it has been laundered with lashings of conditioner. 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 hurting 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.

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.

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 breakout 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 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' tell you to 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. My Asperger's tells me I won't know I've done too much till I've actually done too much as the level changes daily.

After a mid-day meal and pills (only 2 this time) you can do some web browsing, reading, or more TV watching, or practice meditation if your energy allows. The another a two-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 5 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! You've even resorted to just having a couple of pieces of toast or a microwaveable burger just because they take less energy to eat and prepare.

Three or four hours later, the pain has you so exasperated and exhausted it's time to go upstairs again. More pills -8 of them - and so into bed. 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:

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 will have any effect on it. It's 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, 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.

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 shouting, better you just keep your mouth shut and don't say anything to anyone.

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 40 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. Your new skill of meditation is helping more and more now and coupled with your Reiki training you can get peace for ten minutes to an hour.

Chris Bridgeford, Affa Sair, Founder

JASON LEITCH APOLOGY

Healthcare, Quality and Improvement Directorate

Professor Jason Leitch, National Clinical Director

T: 0131-244 1727 E: Jason.leitch@gov.scot

Mr Bridgeford 19 Knockomie Gardens Forres IV36 2TN

1 June 2018

Dear Mr Bridgeford

I am writing following the conclusion of the investigation by Ben Plouviez into the complaint you made on 21 February 2018 to the Permanent Secretary about the work of "the Strategic Planning and Clinical Priorities Department" in respect of the team's interaction with Affa Sair.

The Scottish Government Healthcare Quality and Improvement Directorate is committed to working with the health and care services and the public to provide safe, effective, person centred care. We particularly welcome and value the contribution that organisations such as Affa Sair bring to improving healthcare across Scotland. The voice of lived experience has a vital role to play at both national and local level to improve service delivery. Although the key issues of your complaint have not been upheld, I recognise that in this particular case the Scottish Government did not provide the level and quality of service that you both as an individual and as a representative of a third sector organisation should expect to receive. I want to apologise for those failures in service.

As you will see from the full report there were a number of reasons for this failure in service. That included the challenges of ministerial diaries, some administrative failings within Government and pressure of work on staff within the neurological and chronic pain team, including managing a period of staff vacancies. We recognised the need to strengthen the team through the appointment of a number of new and permanent members of staff in early 2017 but unfortunately it took until early 2018 for the team to be fully up and running. I am confident that moving forward we have the right resources in place to deliver a good quality service to everyone and to assure you that we are continuing to work to improve our communication and organisational processes as a result of your complaint.

I am sorry that we did not deliver the level and quality of service which you should expect from us and I very much hope that we can put this matter to one side and focus on how we can continue to work together to improve support and services for those affected by chronic pain. I would be happy to speak to you on the telephone if that would be helpful.

Yours sincerely

J. Alould

PROFESSOR JASON LEITCH National Clinical Lead

St Andrew's House, Regent Road, Edinburgh EH1 3DG

FOI RESPONSE 10th June 2019 (EXTRACT) REQUEST-575540-A743C099@WHATDOTHEYKNOW.COM

ANNEX D

What amount of grants/funding was given to each committee, body, or group in its lifetime and by whom?

The Scottish Government answered a Parliamentary Question (S5W - 01879) from Anas Sarwar on 7 September 2016 that provided information on this for NCPIG and the Ministerial Steering Group. https://www.parliament.scot/parliamentarybusiness/28877.aspx?SearchType=Advance&ReferenceNumbers=S5W-01880&ResultsPerPage=10

The NACCP and Short Life Working Group on Effective Prescribing for Chronic Pain and have not received grants or funding.

We cannot find any records to indicate that the NCPSG (2009-2014) received grants or funding.

ANNEX E

- Q. What policies/projects produced by the committees, bodies, or groups resulted in changes to chronic pain patients and what were the actual changes.
- A. We are unable to quantify changes to chronic pain patients, as there is currently no agreed routinely collected system for measuring baseline characteristics of people attending pain services, nor of subsequent outcomes. This important gap is being addressed by the current project developing a Core Minimum Dataset. Committee/ group members have contributed to the:
- establishment of the Scottish National Residential Pain Management Programme in Scotland (change: specialist intervention available in Scotland for the first time, three-week residential course for patients that require intensive support to manage their chronic pain);
- publication of the Scottish Intercollegiate Guideline Network (SIGN) guideline on chronic pain (136) (change: guideline for clinicians and booklets for patients on chronic pain);
- publication of the Scottish Government's Guideline on the Management of Children and Young People with Chronic Pain (change: guideline for clinicians that is also available to patients and their families);
- publication of the Scottish Government's Quality Prescribing Strategy for Chronic Pain (change: for patients this promotes better outcomes through focused reviews on analgesic prescribing for chronic pain);
- introduction of the Scottish Service Model for Chronic Pain level 1, universal information available to the population; level 2, support through community and primary care services; level 3, specialist pain/psychology clinics; level 4, tertiary specialist residential provision (change: pathways for chronic pain patients);
- service improvements undertaken by Service Improvement Groups (SIGs) /Managed Clinical Networks (MCNs) for Chronic Pain, such as pain clinics, developed in NHS Boards (2014-2016); and
- development of a minimum core dataset and quality performance indicators that is enabling measurement of clinical activity and outcomes (in three NHS Boards participating in the trial NHS Fife, NHS Lothian and NHS Tayside.

DIRECTORATE FOR HEALTH PERFORMANCE AND DELIVERY EMAIL

From: <Holly.Abercrombie@gov.scot>

Subject: Chronic Pain Primary Care Clinical Lead - Expressions of Interest

Date: 23 August 2019 at 11:34:30 BST

Dear Colleague,

Following the publication of the Scottish Access Collaborative Chronic Pain report and as indicated in the outline implementation plan, attached, we would like to invite expressions of interest for the role of Chronic Pain Clinical Lead to support the implementation and to take forward the findings from the report. It is anticipated that the Clinical Lead will:

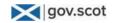
- have a Primary Care background with considerable knowledge and clinical experience of chronic pain
- will have a strong influence in guiding and supporting what needs to happen to progress the findings from the specialty workshop report and associated work-stream priorities across Scotland. Scottish Government Clinical Advisor
- work closely with the Scottish Government Lead Clinician for Chronic Pain
- will be able to commit to up to two sessions per week up to 31st March 2021
- SLA between Scottish Government and current employing organization
- A flexible working pattern can be agreed there may be times where little or no input is required or
 others when a whole day may be necessary for a particular event, but this can be planned well in
 advance so that it can be scheduled in to job plans as required.

If you're interested in undertaking this role, then please submit a short resume briefly describing your relevant skills and experience and why you're interested, to Holly Abercrombie (Holly.Abercrombie@gov.scot), Modern Outpatient Programme, Project Support Officer, by 31st August 2019.

Please share this e mail with colleagues who you think may have an interest.

Thank you Best wishes Carolyn

Carolyn Chalmers
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CDC Advises Against Misapplication of the Guideline for Prescribing Opioids for Chronic Pain Media Statement April 24, 2019

In a new commentary in the *New England Journal of Medicine (NEJM)*, authors of the 2016 *CDC Guideline for Prescribing Opioids for Chronic Pain* (Guideline) advise against misapplication of the Guideline that can risk patient health and safety.

CDC commends efforts by healthcare providers and systems, quality improvement organizations, payers, and states to improve opioid prescribing and reduce opioid misuse and overdose.

However, some policies and practices that cite the Guideline are inconsistent with, and go beyond, its recommendations. In the NEJM commentary, the authors outline examples of misapplication of the Guideline, and highlight advice from the Guideline that is sometimes overlooked but is critical for safe and effective implementation of the recommendations.

CDC is raising awareness about the following issues that could put patients at risk:

- Misapplication of recommendations to populations outside of the Guideline's scope. The Guideline is intended for primary care clinicians treating chronic pain for patients 18 and older. Examples of misapplication include applying the Guideline to patients in active cancer treatment, patients experiencing acute sickle cell crises, or patients experiencing post-surgical pain.
- Misapplication of the Guideline's dosage recommendation that results in hard limits or "cutting off" opioids. The Guideline states, "When opioids are started, clinicians should prescribe the lowest effective dosage. Clinicians should... avoid increasing dosage to ≥90 MME/day or carefully justify a decision to titrate dosage to ≥90 MME/day." The recommendation statement does not suggest discontinuation of opioids already prescribed at higher dosages.
- The Guideline does not support abrupt tapering or sudden discontinuation of opioids. These practices can result in severe opioid withdrawal symptoms including pain and psychological distress, and some patients might seek other sources of opioids. In addition, policies that mandate hard limits conflict with the Guideline's emphasis on individualized assessment of the benefits and risks of opioids given the specific circumstances and unique needs of each patient.
- Misapplication of the Guideline's dosage recommendation to patients receiving or starting medication-assisted treatment for opioid use disorder. The Guideline's recommendation about dosage applies to use of opioids in the management of chronic pain, not to the use of medication-assisted treatment for opioid use disorder. The Guideline strongly recommends offering medication-assisted treatment for patients with opioid use disorder.

The Guideline was developed to ensure that primary care clinicians work with their patients to consider all safe and effective treatment options for pain management. CDC encourages clinicians to continue to use their clinical judgment, base treatment on what they know about their patients, maximize use of safe and effective non-opioid treatments, and consider the use of opioids only if their benefits are likely to outweigh their risks.

The Guideline includes guidance on management of opioids in patients already receiving them long-term at high dosages, including advice to providers to:

- maximize non-opioid treatment
- empathetically review risks associated with continuing high-dose opioids
- collaborate with patients who agree to taper their dose

- if tapering, taper slowly enough to minimize withdrawal symptoms
- individualize the pace of tapering
- closely monitor and mitigate overdose risk for patients who continue to take high-dose opioids

Patients may encounter challenges with availability and reimbursement for non-opioid treatments, including nonpharmacologic therapies (e.g., physical therapy). Efforts to improve use of opioids will be more effective and successful over time as effective non-opioid treatments are more widely used and supported by payers.

CDC developed the Guideline to be practical and created clinical tools to help primary care providers help patients manage pain more effectively and safely, while mitigating the potential risks of prescription opioids when needed. CDC has also created specific resources on tapering, dosage, and appropriate application of the Guideline such as:

- Pocket Guide: Tapering Opioids for Chronic Pain is a quick-reference tool for when and how to taper and important considerations for safe and effective care.
- CDC Opioid Prescribing Guideline Mobile App is designed to help providers apply the recommendations of the Guideline in clinical practice. It features a morphine milligram equivalent (MME) calculator, summaries of key recommendations, motivational interviewing techniques, resources, and a glossary.
- Applying CDC's Guideline for Prescribing Opioids Series is an interactive, web-based training featuring 11 self-paced learning modules with case-based content, knowledge checks, and integrated resources to help providers gain a deeper understanding of the Guideline.

CDC continues to help inform and improve clinicians' ability to offer safer, more effective care based on the best available science. As part of that process, CDC is evaluating the adoption, use, and public health impact of the Guideline and its related resources.

###U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

CDC works 24/7 protecting America's health, safety and security. Whether disease start at home or abroad, are curable or preventable, chronic or acute, or from human activity or deliberate attack, CDC responds to America's most pressing health threats. CDC is headquartered in Atlanta and has experts located throughout the United States and the world.

Page last reviewed: June 5, 2019

Content source: Centers for Disease Control and Prevention