

Scottish Parliament Cross Party Group on Chronic Pain.

MINUTES of the CPG's online meeting on May 11, 2020.

Welcome by this meeting's chair, Miles Briggs MSP, shadow health secretary.
Minutes of October 9, 2019 approved.

This meeting called for urgent reform of what was termed the "undemocratic and secretive" way chronic pain moves have been run for years. This was brought to a head due to increased suffering over the suspension of clinics giving infusion and injection treatments. There was no patient consultation on alternatives and patients felt "abandoned" when lockdown hit.

Christopher Bridgeford, chair of the patient-run charity Affa Sair said "Statements that the NHS is open as usual are simply not true in the case of those with chronic pain who rely on infusions and injections. These were withdrawn with no effective alternative." Chris, whose group has over 550 members, added that infusion patients have been subjected to deplorable levels of suffering and it seems no one is in charge. Did the Scottish Govt now officially regard chronic pain relief as "non-essential"?

Patients going to England because treatments stopped in Scotland.

The meeting heard first-hand that some were in such pain that they had to go a private clinic in England, paying £860 - £960 first time, about £650 subsequently.

A patient present who was driven to England, Fiona, described the two-way journey as being "Total agony. It took around ten hours return, lying in agony in the back of the car" The NHS treatments denied are lignocaine infusions and some injections, the "only treatments which really work" say certain patients. Some injections contain steroids – not suitable if the patient later contracts Covid-19. But steroids can be removed in some cases. Lignocaine infusions, which do not carry this risk, were what Fiona and another patient needed. While anaesthetists were on Covid-19 duties, did that mean all of them and their teams weren't allowed to help with chronic pain? Pain nurses often dealt with infusions.

Fiona explained: "I was in a terrible state when my NHS usual treatment ran out on April 1. My Lanarkshire clinic, relied on for years, was closed. Yet the NHS offered to take me into hospital for morphine and sedation. Would lying sedated in hospital for a time not be more risk to me, staff and others than a couple of hours in a day clinic for an infusion? I know our excellent clinicians did not want our suffering to happen"

This had been a policy decision imposed on clinics.

Nan, also at the meeting, spoke as the mother of an adult patient who has twice had to be driven to England for private treatment. Her son had devastating chronic nerve pain managed by Lignocaine for years until shutdown, with no alternative. He has children at home, and couldn't risk pain extremes and falls, and his wife is an "essential worker".

The family managed to get the money but the mother asked: "What about all the others who cannot pay?" She agreed with Paulo Quadros that re-opening in Scotland was essential. Her son needs treatment every five weeks or so.

Several others present, dependent on infusions, were women trying to remain in work.

Nan urged that these infusions need to be restored urgently in NHS Scotland.

Dentists are allowed to do basics such as relieving agony through extraction during lockdown, using lignocaine/lidocaine

Chris thought that the stoppage enforced by managers could cause doctors to breach their Hippocratic oath of "Do no harm"

Infusion treatments allowed for other conditions, not chronic pain.

Lynn, a former nurse, pointed out that some other infusions -not under the chronic pain heading -had continued over lockdown. She still got NHS biologic treatment by infusion. This revelation led to renewed questions on lack of protection for the interests of chronic pain patients. Lynn's overall view was: "Lockdown has shown that there are two types of services.

The first is set up to meet the needs of officials and managers with a 'command and control' approach. The second has no patient perspective, is not uniform and promotes self management, a subtle form of 'patient blaming'"

The voluntary secretary, DG Elder, warned that there was fear that, if officials got away with stopping injections and infusions for months, despite the suffering that caused patients, then some may try to stop this help permanently. This will save money instead of replacing short staffing, but excuses are likely to promote pain management! Cutting injections and infusions is being done in parts of NHS England and some in Scotland have already pointed to copying England.

Patients had already told about these services being stopped at the New Victoria in Glasgow last summer, and the CPG has complained. One fibromyalgia sufferer, Irene, had 15 years of successful treatment stopped. She contacted the CPG, saying she was offered "self-management" courses instead. She told doctors she had already trained in these – but, whatever their use, they were no substitute for "the only pain relief which works for me". One excuse is that infusions and injections don't last long enough. But the patient commented: "If some get six weeks relief and others get months, who judges what is of worth but the patient?" Health boards could see there was no sign of Govt bodies interested in chronic pain so felt free to do what they wanted.

What is the truth about all pain staff being diverted?

Liz pointed out that the suicide risk and attempts were well known over long delays in normal times due to short staffing. The Government and Boards were taking a bigger risk now during excessive waits by not re-opening clinics to protect lives.

Liz said anaesthetists usually worked part time in chronic pain. "But now it is implied they are working full time on Covid-19 duties while there are few operations being done. But there is still no time to help pain patients.

What is the truth throughout Scotland? Have all pain clinic anaesthetists and all pain nurses and teams been working full time on Covid-19 everywhere?

Can we get a breakdown?" Can no-one be spared to help patients?

Several asked if empty parts of hospitals and the Louisa Jordan in Glasgow could be used as central points for chronic pain treatments for Scotland. No one wants journeys but with patients feeling forced to go as far as England, surely NHS Scotland could help? Or are Government and Boards stopping them?

What is needed

There was extensive discussion on the need for Scotland to have an energetic, modern, transparent body dealing with progress and policy which is pro patient in outlook.

Patients believed 11 years of lack of progress by 4 Government appointed bodies dealing with chronic pain policy, currently the National Advisory Committee on Chronic Pain, (NACCP) had been the major problem for clinic staff and patients.

A new, pro patient, pro staff organisation was needed.

Marion said that “this secret committee is not fit for purpose” Chris said specialist pain clinics were being run down but they had also not shown progress on GP services.

A **motion** by Chris Bridgeford seconded by Marion Scott stated:

That the Scottish Government disbands their current advisory body, the National Advisory Committee on Chronic Pain, as it has consistently failed to improve services and aid patients and staff long before the Covid-19 emergency, which has left patients without proper help and that the Government ensures that no future health bodies meet in private and bar attendance by the public and media, undemocratic practices out of step with modern Scotland. They should start afresh with new people rather than those who’ve been involved for up to 11 years and ensure that 50% of advisors have lived experience of chronic pain.”

Fiona said that any appointments should be restricted to a few years “to prevent fixed views and allow new ideas to breathe”

Chronic pain policy and moves are dealt with totally behind scenes

at private meetings of a Govt committee, not a Scottish Parliament committee.

Ten out of 15 members are Board or Scottish Government managers and officials. Patient representatives are confined to four charities who get Government funds.

The Alliance provides Govt money to the other three – Pain Concern £90,206; Pain Association £28,128 last year; Versus Arthritis has £369,563 for a five-year project (source: Alliance website) The Alliance gets Govt support for its offices and around 40 staff, plus Govt gives it £4 million to pass to various organisations.

A recent Govt proposal to put just two independent patients on this committee, and create a separate arms-length panel of patients without voting power, were not viewed as being able to make substantial change in a set up still dominated by officials.

Other patient comments:

Faith injured her back while working as a nurse and has had chronic pain for 8 years. She had regular injections to manage her pain and was now at university rebuilding her life. The stoppage of her injections was devastating, leaving her with “no effective alternative – just isolation and online ‘support’ proved ineffective.”

Fiona Manclark from Moray said mental health issues caused by chronic pain for adults and children must be taken seriously, especially over long delayed help. She had waited 18 months to attend an NHS pain clinic but found that it was more of a group meeting like Alcoholics Anonymous rather than direct help.

Several patients were angered at constant promotion of “self-management” without practical help.

The NACCP claimed to support a cutdown on drugs and medicalisation”

Yet they did not involve any NHS experts in alternative methods.

Kathleen and Catherine asked why, while conventional clinics were not being helped, there was also a mindset which didn't seek alternative help to replace opiates and drugs with unwanted side effects. There were NHS trained experts at the Centre for Integrative Care who may help provide reduced waiting times and a more sustainable form of long-term care. Why weren't they involved? The CIC was thanked for contacting all its chronic pain patients by phone.

Rona Mackay MSP and Monica Lennon MSP agreed that chronic pain problems in Scotland had become magnified through lack of management and the issues would need to be pulled together in different areas.

Tom Mason MSP said that the present crisis must be used as an opportunity for a new beginning for chronic pain treatment, removing the lack of past help. A letter should be sent soon to each health board with clear policies for each as a starting point.

Motion agreed:

Chris Bridgeford proposed "Pain relieving infusions and injections should be resumed forthwith to relieve the intolerable pain suffered by those patients reliant on these types of treatment. By not allowing treatments to go ahead, advisors and government can do considerable harm to patients. Many will be despairing, some to the point of suicidal thoughts/attempts due to the agony suffered without the type of help that works for them"

Thanks to Alexander Cowan for hosting the CPG's 1st online meeting.

ATTENDANCE May 11 online meeting

MSPs

Miles Briggs, chairing, Rona Mackay, Tom Mason, Monica Lennon, Brian Whittle. five

NON MSPs

Fiona Robinson, Arlene Byrne, Geraldine McGuigan, Chris Bridgeford, chair, Affa Sair charity, Kathleen Powderly, Marion Scott, Lynn Laidlaw,

Faith Ougham, Dr Jackie Mardon, Rona Agnew, Steve Kent, Christine Macdonald, Sheila Morrison, Liz Barrie, Irene Loudon, Carrick Welsh, Bathma1, ?? Dr Kirsty Proctor, Catherine Hughes,

Hazel of Fibromyalgia Action UK, Anne Hughes, Linda Mawson, Paulo Quadros, Mike Grant, Affa Sair, Amber Welsh, Lauren Bennie, C Headspeath?, Fiona Manclark, Senga Grant, Christine?, Nan Black,

Sheila Morrison, George Welsh, Alex Cowan, Dorothy-Grace Elder, Bailie Soryia Siddique, 36 41 in total – note: online causes problems for identifying some names. Let

dg.elder@ntlworld.com know.