MINUTES OF CPG ON CHRONIC PAIN MEETING JUNE 20, 2017 (Approved at meeting on October 4, 2017)

MSPs present: Elaine Smith (chairing), Anas Sarwar, Rona Mackay, Alex Neil, Jackie Baillie, Jackson Carlaw.


Elaine Smith MSP chaired and thanked all for coming. She extended a warm welcome to speakers Dr Rachel Atherton, clinical lead at the Scottish National Residential Pain Management Programme (SNRPMP) and Patrick Hughes, a patient who had recently completed his 3-week course.

Dr Atherton thanked the CPG for years of campaigning to create Scotland’s first residential service. Present at the meeting were MSPs who had led the Parliament into unanimous support – Alex Neil, the former Cabinet Secretary for Health, who made the key decision, Jackie Baillie MSP, then Labour's shadow health secretary and the Conservatives’ Jackson Carlaw MSP - former CPG conveners who remain strong supporters. Creating the residential service was a key aim of the CPG which was started by Dorothy-Grace Elder, who was thanked for campaigning for it since 2001. A residential programme is for those who need more intensive input and coping strategies, psychological and physical. Before the CPG’s campaign, such patients were sent to Bath in Somerset, an 800 miles to over 1,000 miles round trip ordeal from Scotland for people in severe pain, journeys usually made twice.

The crucial vote was in Parliament in May, 2013 in a debate proposed by Mr Neil and strongly supported by Ms Baillie and Mr Carlaw leading their Parties’ support. A public consultation followed, aided by the CPG. The Scottish Government now provides annual funding of £700,000 for the residential service. Health Boards are not charged for their patients being sent, unlike the previous arrangement with Bath.

Dr Atherton said that the first patient was assessed in January 2015, road shows followed for months to inform patients and
health staff. During 2015, a complete team was established at Allander House, in the grounds of Gartnavel Hospital. The first group of patients started in November 2015. The staff cover psychology, physiotherapy, occupational therapy, nursing, medical. By June 2017 there had been 185 referrals, 143 patients assessed and six groups of 42 patients had completed Phase 1. (Group members commented that only 14 patients had been sent to Bath in the last known year, 2012.)

Patients were from all over Scotland – Shetland, Orkney, the Western Isles, the North East, Thurso area, Argyll and Borders as well as populous areas. Only secondary care (pain clinic) clinicians could recommend, not GPs.

The service is also for those in geographic areas unable to travel to, or realistically access, a local day clinic. In the third week, families and friends are invited to the group to understand what has been learned. There is a three-month review after patients return home and a six-month review.

The programme is not intended for an inpatient level of care - groups are housed in modern flats in Glasgow, have evenings free and weekends off. That’s part of the help. Most share activities, arranging meals, socialising with each other, visiting attractions together. Some have had years of “isolation” because of their pain.

Messages from patients about the course: “It was a breath of fresh air that has changed me forever”
“It changes the way you think and helps improve your life. I loved every minute”
“I’d score it 15 out of 10”

Patrick Hughes, who graduated from the service recently, said he started the course as a person who had lost hope. Injured in a car accident, he had suffered chronic pain for four years and felt isolated. “I didn’t want to leave the house; I lost my job, didn’t meet my friends and felt a burden on my loved ones.” He discovered people in his group had similar thoughts and found great empathy from fellow patients as well as from staff.

“At first on the course, nine people were thinking they might go home. But we found that ‘the power of the group’ should never be understated. We kept each other going.
It changed my life. I left looking at life in a completely different way.” From never wanting to go out, meet people or risk walking any distance, Mr Hughes had this recent experience: “Recently, my wife and I walked the dog for two miles. I haven’t done that in two years. I still have pain but have learned to cope and I am optimistic about the future. Even with pain, I can have a proper life and a full life. The Group are all still friends and in contact. The other day, I got 73 messages.”

Rachel and Patrick were applauded by the CPG and MSPs commented that Patrick’s story showed that the long struggle to create the Centre had been worthwhile. Lasting group support was not geographically possible for most from Scotland who had gone to Bath.

SHORTAGES AT DAY CLINICS AND WAITING TIMES FACTS REMOVED.

The secretary reported that the group’s detailed complaint over objections to Chronic Pain Waiting Times facts being removed from the Summaries by the Information Services Department, ISD, had gone to the UK statistics regulator on April 28. The regulator’s office said there were delays due to the June general election purdah period An illuminating email trail was sent under a Freedom of Information application by the CPG secretary, showing disturbing behind scenes actions which resulted in cuts to facts about what are bad waiting times. The Scottish health statistics body, ISD has a £26 million NHS budget and 616 staff. They gave no explanation for fact removal.

All concerns of CPG members were raised with the UK regulator over severe information cuts: including why treatment time had been removed from the summary, the downgrading of pain psychology clinics information, which is wiped out except for one bullet point. Members protested that psychology work was vital, often coping with depression and suicide prevention. Missing information led to bad waiting times appearing a bit better.

Members also wanted pain clinic return patients counted. They were, according to many patients, waiting much longer for renewed help. But only new patients were being counted and this did not show the whole pressure on short-staffed clinics. At the June 20 meeting, Lanarkshire Return patients cited severe delays - one
return patient requiring regular injections said that dates being offered were now for summer 2018.
At previous meetings, it was pointed out that Lanarkshire pain clinics still had only two consultants and had lost three nurses in an area with particularly high prevalence of chronic pain.
Long waiting times were also raised about Glasgow, Ayrshire and Arran, the Western Isles and Grampian. The meeting made it clear that substantial delays were not the fault of the clinics, the excellence of their work being applauded. The regular complaints were of short staffing and short resourcing.

NEW CHRONIC PAIN ADVISORY COMMITTEE

The meeting decided to object over the remit and composition of the new committee. This would be the fourth publicly financed committee. The other three had failed to improve pain services, in the CPG’s experience. Members pointed out that the new group contained six out of ten people who’d been on previous failed groups. While they were glad that Susan Archibald had been appointed, there was an absence of campaigning outspoken charities and severe shortage of patient representatives. There’s no sign of open recruitment.

Rona Mackay MSP proposed, and the meeting backed, that the Advisory Committee conducts an urgent update of the staffing situation in NHS Scotland chronic pain clinics.
Action: MSP co convener Elaine Smith to write to the deputy chief medical officer & the health secretary.

NHS Code of Conduct: are its worthy words heeded?
This concerns the CPG’s complaint to the chief executive of NHS Scotland, Paul Gray, over NHS Dumfries & Galloway refusing to send waiting time information, for which they were found in breach of FOI legislation on two counts. The CPG concern was over what the Information Commissioner could not tackle but was up to the NHS Code of Conduct to deal with - the links between this Board and Government and ISD officials. Some 27 NHS staff had their time wasted over attempts to thwart the CPG’s FOI when it reached Dumfries & Galloway. All other Boards sent figures. Co convener Miles Briggs MSP submitted the CPG’s complaint under the NHS Code of Conduct in December 2016. On April 4, 2017 Mr
Gray replied, apologising for over three months delay because he wished to “be thorough”. He wrote that only one person had been questioned – the CEO at NHS Dumfries & Galloway, who had claimed that his Board did not hold the information, which the Commissioner later proved they did. As the Group had specifically objected to the CEO’s actions throughout, no one found this a thorough investigation and there was no sign that the Code had been used. Accordingly, Mr Briggs objected and requested information under FOI over the state of Mr Gray’s “investigation”. On June 1, Mr Gray replied, inviting Mr Briggs to a meeting with him. There is still no mention of the Code.

Update: Centre for Integrative Care beds closure
Catherine Hughes reported that, despite strong public and Parliamentary protests, Glasgow’s health board closed the inpatient ward at the CIC in April. This means that the CIC, after decades of taking inpatients from many parts of Scotland, could no longer help them. It will continue for outpatients only. The Scottish Health Council (SHC) had recommended that closing the hospital’s beds was only a “minor change”, not “major change” as the public had protested. MSP Anas Sarwar had informed the CPG earlier that was what Parliament also voted for, supporting his motion. “The SHC, which is claimed to be the patient voice, was useless for us” said Ms Hughes. She had queued for two years to see the Health Secretary personally but was suddenly summoned to Edinburgh to meet Ms Robison only the day before the Board decided the ward closure. Ms Hughes said: “The Health Secretary said at the start of the meeting that she was not going to change her mind from what the SHC had recommended. Seeing a few patients was only a token exercise” Ms Hughes added that the hospital had been subjected to systematic staff cuts for years. In 2010, there were 22 nurses, now there are only two or three. The CPG and patients had been informed by the Scottish Government that creating a new building next to the CIC was being considered for a permanent home for the Residential Service. It did not happen. Now, the Residential service looks like moving in but not confirmed. The Govt also proposed a Parliament function to promote the CIC, which did not happen.

Ms Hughes stressed that the CIC was built in 1999 entirely by public subscription funds at a cost of £2.7 million. So how could the
NHS could get away with removing beds and downgrading a hospital to a clinic? This was worrying for the public donating to any hospital in Scotland. Ms Hughes and other patients had uncovered documents and sought legal action as public bodies had not helped. “But patients can’t afford the law” she said.

Lightburn Hospital closure.
The CPG regretted deeply the loss of facilities for long term conditions at a time of increasing need – with beds closed at the CIC and the same health board now confirming they would close Lightburn Hospital, which also aids long term conditions.

MSP Ivan McKee, Glasgow Provan, apologised he could not attend on June 20 but sent an email updating on continuing resistance to GGCHB’s decision to close Lightburn Hospital. Mr McKee said:

“I am continuing to press the Cabinet Secretary to reverse that decision, based on the reasons put forward by Nicola Sturgeon in 2011.” A motion calling for reversal of the closure decision, which he had signed, was now before Parliament.

Motion S5M-06194: Pauline McNeill, Glasgow, Scottish Labour, Date Lodged: 20/06/2017
Overturn the Decision to Close Lightburn Hospital

Attendance:
MSPs: Elaine Smith (chairing), Rona Mackay, Anas Sarwar, Alex Neil, Jackie Baillie, Jackson Carlaw, Six MSPs.

Non MSPs: Dr Joyce Davidson, Emma Carson, Liz Barrie, Catherine Hughes, Anne Hughes, Fiona Robinson, Mairi O'Keefe, Martha Heaney, Kathleen Powderly, Dr Andrew Pearson, John Thomson, Susan Archibald, Peter McCarron, Dr Rachel Atherton, Patrick Hughes, Rosalind McMillan, Katrina Bissett, Dr Jacqueline Mardon, Carol Fairley, George Welsh, Maria Doyle, Samantha Byrne, Alex McKinley, Elga Graves, Maureen McGinn, Ming Chen, Dr Malcolm MacLean, Dr David Craig, Dr Anna Graham, Linda Mawson, Hazel Young, J. Katharine Kilgour, Dorothy-Grace Elder (voluntary secretary) 33 non MSPs. 39 attending in total.
Organisations: Arthritis Care, Fibromyalgia Friends Scotland, Lanarkshire Lignocaine Patient Group, Centre for Integrative Care, Leuchie House Respite Centre for long term conditions.