

DRAFT MINUTES CPG ON CHRONIC PAIN MEETING NOVEMBER 18, 2015

Attendance: MSPs. Alex Neil, Cabinet Secretary for Social Justice; Bill Kidd, John Finnie, CPG convener, Jim Hume, Lib. Dem Health spokesperson, Dr Richard Simpson, Labour shadow Minister for Public Services, Michael McMahon, Labour shadow Minister for Community.

Attendance: 6 MSPs, 38 Non MSPs (see list at end)

The meeting was chaired by co convener Bill Kidd MSP, who welcomed everyone.

ALEX NEIL, CABINET SECRETARY FOR SOCIAL JUSTICE ON OPPOSING CRUELTY TO BENEFITS CLAIMANTS

Alex's main message was that he was fighting to change the culture of how benefits claimants are treated when Scotland eventually gains control over some – not all – benefits. That won't be till at least 2017.

He was well aware that cuts imposed by the DWP were destroying lives “very often for the most petty reasons. I want change to ensure that, in Scotland, people are treated with dignity and respect”

. The cabinet secretary stressed that Westminster was limiting the amount of benefits Scotland would handle to a small proportion of the overall benefits work. Also, his Government still hadn't been told how much money they'd have. But he was determined to end some of the worst excesses of the current DWP. He would end annual assessments of people with conditions which don't change. Many did not need annual assessments. Patients at the meeting told him of their humiliation and upset at poor assessments.

“To bring some people in for assessment every year I think is cruel.” He pledged that the Scottish Government would end the notorious “84 day rule” through which parents of disabled children who were in hospital for long spells lost key benefits, including carers' benefits. Alex called this rule by the UK Government “an absolute disgrace” pointing out that some of these children suffered chronic pain as well as other conditions. “To punish parents who have many expenses visiting their sick children daily by taking away their money is inhumane and must end”

Mr. Neil was thanked for answering many questions and staying beyond his diary time to talk informally. He was also applauded for his support for the CPG's long campaign for the first Scottish residential service, which he steered through and gained when he was Health Secretary.

WAITING TIMES AT CHRONIC PAIN CLINICS.

There was anger when the meeting learned that the Scottish Government, which had promised a year ago to produce waiting lists at clinics for November 2015, would not release the figures. Elizabeth (Liz) Porterfield, head, Strategic Planning/Clinical Priorities, said the figures were collated by ISD but some boards had used different methods and there was a Codes problem.

Dr Richard Simpson MSP who is investigating “hidden waiting lists” said the figures could have been issued with caveats– there was no need to withhold all the information. Prof Martijn Steultjens of Glasgow Caledonian University said there were people on the Cross Party Group who could judge the data. It was very

unfortunate that it had been decided not to publish or show what they had of the data to the group. John Lawrence asked if in the case of a civil action, the Government would have to produce such data, saying “You’d have to get these figures for a court but not for us”

Liz agreed but said she still thought the figures were not helpful in present form..

Kathleen Powderly said “This is serious. There are people desperate for help, some are suicidal with pain- someone had three times tried to commit suicide yet some can’t get their act together and inform us just how many are on waiting lists and for how long.” Susan Archibald, a member of the Ministerial Steering Group confirmed that this Group, chaired by the public health minister Maureen Watt, had agreed not to release the figures in their present form. DG Elder said she believed Ms Porterfield was only conveying the withholding but should not be regarded as having made the decision.

MSPs Simpson and Hume said the Group would now be forced to use FOI to try to discover the waiting lists sent by boards to ISD in Edinburgh. The CPG unanimously requested the voluntary secretary write to all 14 Boards to request under legislation.
Action: DG Elder

PETITION OVER FUTURE OF THE CIC – CENTRE FOR INTEGRATIVE CARE
CPG member Catherine Hughes reported that there would be another hearing soon by the Public Petitions Committee on her petition to try to protect the hospital. The Government and Greater Glasgow Health Board continued to write to patients and MSPs assuring them not only that they didn’t intend to close the CIC but they also averred that no change in delivery of service was planned. Catherine reported that health secretary Shona Robison was now arranging to meet her in early December. Catherine said she had waited a year for this meeting on Dec 9. (Update note: Ms Robison cancelled the evening before the meeting, time was halved and Ms Watt substituted)

TWO SUB GROUPS ON BENEFITS & ON CAM AND THE FUTURE OF THE CENTRE FOR INTEGRATIVE CARE

The meeting heard from Claire Schiavone, pain patient and from Kathleen Powderly, a Grampian health professional. They had led on forming these two new sub groups, with input from DG Elder. They had worked over the last five months to research and recruit organisations and interested individuals.

They were applauded for all their voluntary work and the meeting concluded that these two groups were viable and should continue. Claire said she had personal experience of losing her home through benefits cutbacks after a wrong assessment Kathleen pointed out that those boards opposing the CIC and CAM mostly had shown little or no progress with their conventional services, depriving patients of one type of service without improving the other.

NEW RESIDENTIAL CHRONIC PAIN SERVICE AT GARTNAVEL, GLASGOW

Liz Porterfield reported that 46 people had been recommended “from the Borders to Shetland” By the end of October, 14 were assessed as ready for the programme in

Glasgow and nine of the 14 assessed took part. A second group was due to start in January 2016. There is a planned accommodation change from a hotel near Gartnavel to serviced facilities also nearby.

LETTER TO PARTY LEADERS ON 2016 ELECTION MANIFESTOS

The Group agreed that the secretary should write to the leaders of all five political parties at Holyrood requesting they consider shortages in chronic pain services for inclusion in their manifestos. Action: DG Elder

PATIENT ACTION GROUP'S MORAY CAMPAIGN

“Affa Sair”, a group of patient activists, have fought Grampian health board's closure of their local pain service at Elgin since it shut four years ago. This forced pain sufferers to make 150-mile return journeys to Aberdeen in all weathers. The patients won a promise that the Elgin service would re-open in December 2015. The board let them down on that but, after more campaigning and support from local MSP Richard Lochhead, the promised re-opening is for early February 2016.

MINUTES: Minutes of our May 20 meeting were approved unanimously.

ATTENDANCE: MSPs 6:

Alex Neil, Bill Kidd, John Finnie, Jim Hume, Richard Simpson, Michael McMahon.

Non MSPs: 38. Nicola McEvoy, Claire Schiavone, Janice Connelly, Dr Fiona McLeod, Sheila Inglis, Kathleen Powderly, John Thomson, Liz Porterfield, Linda Mawson, Susan Archibald, Arlene Byrne, Geraldine McGuigan, Fiona Robinson, Pete McCarron, Catherine Hughes, Anne Hughes, Margaret Wyllie, Dorothy-Grace Elder, Laura Clark, John Lawrence, Gaby Stewart, George Welsh, Fiona Frances Adam, Prof. Martijn Steultjens, Elizabeth Murphy, Samuel Glass, Martha Heaney, Irene Logan, Patricia Donnachie, Margaret McLucas, Dr Moira McGuigan, Dr Joanna McParland, Diane Goodwin, Maureen McAllister, Julie Wilkes, Susan Scott, Christine Peace, Lloyd Mawson.

Organisations represented: Arthritis Care, Ehlers-Danlos Support org., Lothian Backcare, College of Occupational Therapists, Council for Natural Healthcare, Scottish Government, Archibald Foundation, Glasgow University, Glasgow Caledonian University, Fibromyalgia Friends Scotland, CIC hospital,

Apologies: Jackie Baillie, Mairi O'Keefe, Kathleen Grieve, Prof Tim Eden, Prof J McEwen, Lord Foulkes, Michael Grieve, Heather Wallace.