

DRAFT MINUTES
CROSS PARTY GROUP on CHRONIC PAIN, MEETING
NOVEMBER 12, 2014

John Wilson MSP chaired.

Members welcomed a review by the Standards Committee, which highlighted our Chronic Pain CPG for achievements in campaigning for patients. Out of 89 Cross Party Groups, ours was one of ten mentioned for achievements.

The review highlighted the CPG's successful campaign to create Scotland's first residential centre for chronic pain patients, which had been accepted by the Cabinet Secretary for Health, Alex Neil, the public health minister Michael Matheson and unanimously by all Parties. The Scottish Government has had a house in the grounds of Gartnavel renovated for the Centre, sparing future patients travelling to Bath in Somerset.

UPDATE: SCOTLAND'S FIRST RESIDENTIAL SERVICE

Dr Mike Winter, Medical Director of the National Services Division, which commissions projects, reported on creating the service at the Gartnavel Hospital complex, Glasgow. He confirmed that the new centre would open in January 2015 and that its first site at Gartnavel would be temporary, in a house in the grounds which was being renovated for the purpose. Eventually, possibly in 2017, the centre would be moved to permanent premises at Gartnavel.

Dr Winter said it would first open for assessment, then treatment for suitable patients from all over Scotland and a nearby hotel almost next to the Hospital was earmarked for accommodation. (Residential means patients are not in wards but in the more sociable atmosphere of a hotel or other accommodation, paid for by the NHS). Dr Winter took questions - two points were raised by CPG members:

*Dr Winter reported that the leadership of the centre had not been selected to date (Nov 12)

*Job advertisements had not been placed so far, with the centre opening in January.

HELP FOR ME SUFFERERS

Alex Fergusson MSP spoke of the need for ME and Chronic Fatigue Syndrome patients suffering chronic pain to be part of the CPG's work, especially as the separate ME Group had folded. Mr.

Fergusson, a long-term campaigner for ME, was assured that the Group represented all with chronic pain. He also asked Dr Winter if the new residential service would have special help for these patients, as happened at the Welsh residential service. Dr Winter said there would be no specific service. (Policy is to aid all with chronic pain, whatever the diagnosed condition.)

CHANGE TO STEERING GROUP

CPG member Prof. Martijn Steultjens, professor of musculoskeletal health at Glasgow Caledonian University, reported to the Group on meetings initiated by Scottish Government health ministers. They had invited members of the Group to give their views on what more can be done to improve services. Members invited included the co chairs – Jackie Baillie MSP attended. Others who gave their time were Prof Steultjens, Prof Tim Eden (chronic pain patient and cancer specialist) and DG Elder, voluntary secretary. Prof Steultjens reported that a priority should be cutting waiting lists at day clinics, tackling boards on understaffing and issuing regular figures on waiting lists, shortages and any improvements. The current Steering Group, set up in 2009, had grown in number to over fifty members (by February 2014) but had not tackled day clinics where it was felt priority attention was needed. No sub group set up by the Steering Group concentrated on the day clinics, nor was there a sign that the 14 Service Improvement Groups round Scotland would do so, although all their plans were still not disclosed. Prof Steultjens said ministers assured the CPG that cutting waiting lists at day clinics remained a Government priority.

The Government has now decided to appoint a new Steering Group which will take charge and be chaired by the Public Health Minister. Professor Steultjens said this will be a small group to achieve action. Members welcomed this, it being pointed out that a Minister led group will be answerable to Parliament and should also end the lack of transparency at present. The present Steering Group is to be re named the National Chronic Pain Improvement Group and will report to the Ministerial Group.

SERIOUS DELAYS IN TREATING LANARKSHIRE PAIN PATIENTS

Three pain patients addressed the CPG over delays of between two weeks and 14 weeks on receiving Lignocaine infusions, which they need every six weeks. Otherwise, they returned to

“unbearable” pain levels threatening their jobs and family responsibilities.

Several members commented that this was an example of lack of action on Pain clinic shortages. The CPG would not have known about this, had the patients not contacted the CPG directly after trying every other avenue for many months.

The three explained that only Lignocaine infusions had “changed their lives completely” and made them free from pain but only if the infusions were given on time. All three are women, aged early 30s to mid 40s, were trying to remain in jobs and avoid lengthy absences or being hospitalised.

Delays of weeks, quickly returned them to consuming pain and fear of job loss. One described her pain level as “like having a red hot poker thrust into my kidneys every few minutes”

These patients blamed serious staff shortages in Lanarkshire clinics. They said it had taken good work by the Lanarkshire pain team to discover the right treatment but now this was under threat through delay, despite the pain team trying everything possible to get them appointments.

A fourth Lanarkshire patient made the same case by letter. The CPG expressed shock at the situation and promised to pursue. Ms Liz Porterfield, the new Government representative to the CPG, promised she would investigate and compile the letters sent by these named patients. She said such problems would not normally show up in statistics. **ACTION:** Liz Porterfield (completed in November)

ACTION: The Conveners and Professors Steultjens and Eden and the hon. secretary to write to the Public Health Minister about the patients’ urgent requests.(ACTION: November/December, continuing)

MS Porterfield, who is head of Strategic Planning /Clinical Priorities, also assured the CPG that reports on waiting lists and other problems would now be made on a quarterly basis. She was thanked for her helpful attitude and several members hoped this would lead to a better relationship with the Clinical Priorities division, which had been criticised in past years.

CAM ALTERNATIVE TREATMENTS FOR PAIN

The meeting agreed to requests from members that complementary treatments on the NHS should be a future subject for the Group’s agenda. Paulo Quadros proposed that the CPG support chronic pain patients' equal rights to access through the

NHS, if they wish. This should at least involve the Complementary and Alternative Therapies (CAM) recommended by the SIGN guidelines on CP management and related findings in the GRIPS Reports. He also wished the Group updated on the implementation of the SIGN guidelines issued in Dec 2012. Paulo's personal experience was that few GPs were aware of this or of the chronic pain website established about a year ago. It was also agreed that the effects of benefits cuts to chronic pain sufferers should be on a future agenda. Members will produce key points of information for both topics, at separate meetings.

RETIRING CO CONVENERS

Jackie Baillie and John Wilson were ending their terms of CPG office. They were applauded for their years of service to the Group and members welcomed news that they will remain members. Jackie Baillie was thanked specifically for her many years of questions to Parliament, and her unfailing support for the CPG and patients every time extra help was needed and John particularly for his support at the Public Petitions committee.

NEW CO CONVENERS

The meeting elected Bill Kidd MSP, John Finnie MSP, Neil Findlay MSP as new co conveners and welcomed them.

MINUTES

The draft minutes of the meeting of June 25, 2014 were approved unanimously.

These will be posted on the Cross Party Group Parliamentary site.
Acton: DG Elder

ATTENDANCE:

MSPs

John Wilson MSP, chaired this meeting.

Jackie Baillie MSP

Bill Kidd MSP

John Finnie MSP

Alex Fergusson MSP

Fiona McLeod MSP (briefly)

NON MSP MEMBERS

Prof. Martijn Steultjens

Prof Tim Eden

Dr Mike Winter

Elizabeth Porterfield

Susan Archibald

Fiona Robinson

Geraldine McGuigan

Arlene Byrne

Paulo Quadros

Anne Murray

Dorothy-Grace Elder

George Welsh

Frank Mawson

John Thomson

Mike Kerr

Joan Kerr

Mairi O'Keefe

Phil Atkinson

Laura Clark

Gabrielle Stewart

Dr Pat Roche

Prof Nick Allcock

Dr Heather Cameron

Claire Schiavone

Sonia Cottom

David Falconer

Kathleen Powderly

Pete McCarron

Susannah Ramsay

Catherine Hughes

Dr Helen Jackson

Christine Martin

Anne Simpson