

CPG ON CHRONIC PAIN. MINUTES OF MEETING JUNE 20, 2018.

Welcome from co-convenor Rona Mackay MSP, chairing. Attendees included members from Aberdeenshire, Fife, Dunoon, Glasgow, Edinburgh, Lanarkshire, Renfrew, Ayrshire, Borders. (Attendance: 44, including 4 MSPs)

Minutes of meeting of March 14, 2018 approved.

Today's meeting had received an appeal from Affa Sair, the volunteer pain group in Moray and Grampian, for support with a complaint they made about the civil service and how their case was handled. The meeting agreed unanimously to support Affa Sair particularly if they decide to take their complaint further. Affa Sair now has 410 members.

DISCUSSION: HOW MUCH MONEY WILL BOARDS GIVE TO CHRONIC PAIN OUT OF £51 MILLION EXTRA?

ISD revealed that 19 NEW chronic pain patients in Scotland died on the waiting lists to see a specialist in one recent quarter. Return patients aren't counted yet – but their waits are even longer and our group has been notified of suicide attempts due to the waits which can be 18 months and more past treatment time. But, when health boards are given extra amounts of taxpayer money to aid waiting times for all conditions, chronic pain was ignored by most.

Our CPG discovered that Health Boards are giving only about £333,000 to their pain clinics out of £51.6 million extra from the Scottish Government - meant specifically to tackle waiting times. (Barnett money) But boards are allowed to decide which services benefit.

Most ignored chronic pain or gave only tiny proportions of their huge "bonus" That's despite chronic pain having some of Scotland's worst waiting times.

CPG co convenor Miles Briggs MSP and Douglas Pattullo, his office manager, contacted the CEOs of all 14 Boards.

*Only six out of 14 boards gave anything to ease chronic pain waiting times.

Amounts were small compared to the extra millions apportioned to Boards.

NHS Greater Glasgow allocated just £142,000 out of their extra £12.5m.

NHS Lothian just £75,000 out of £7.37m,

NHS Grampian £35,000 out of £4.9m, (Grampian waits are worst at 42 weeks average)

NHS Dumfries & Galloway gave £22,000 out of £1.49m.

NHS Ayrshire & Arran allocated £15,000 out of £3.7m.

NHS Lanarkshire gave £44,000 out of the £6.5 million they received.

Boards will share another £50 million in 2018. So will chronic pain be short changed again?

The meeting discussed why chronic pain was so badly treated. Some believed it was lack of action from the Govt Advisory Committee, which seemed to be the same

as its three defunct predecessors and lack of interest from ministers since Alex Neil, a known supporter of pain patients, ceased to be health secretary. Other possibilities were that no Scottish based charity tackled waiting times and clinic staffing full on, only the CPG in Scotland. Action on Pain, based in England, backed us and are a feisty charity for patients.

Dr Macaskill and others stressed that this appeared a major human rights issue when, in a democracy like Scotland, people could not get relief from severe pain in time. The group had previously tried on human rights and would try again. Action: CPG to pursue on human rights.

Return patients ignored.

That return patients not being counted harms pain services overall is shown clearly in responses by boards to the CPG. The six boards out of 14 which see all new patients within 18 weeks used this as a reason for NOT spending anything of the extra fortune on chronic pain. That ignores their many return patients and harms both new patients and returns, treated by the same small staffs.

Follow the money: Who is watching where the money is spent? The secretary said no-one had said they were monitoring this £101.6 million fortune. But Audit Scotland had told her they are now looking at this and querying the wording of Government letters, some of which may allow boards to divert the waiting times money to other issues.

Secretiveness again: Getting boards to answer the simple question on public money: “How much will your board give to chronic pain services?” proved very difficult. The meeting thanked MSP Miles Briggs, his office manager Douglas Pattullo and the CPG secretary Dg Elder for over three months of perseverance. It took from March 27 to late summer to get info from some boards, some had to be queried repeatedly on non-transparent replies. NHS Lanarkshire was so obscure in its communications it had to be asked four times to clarify points but still found difficulty with openness. Fife was least open. NHS Fife did not reply to five approaches including phone calls.

Tayside replied at first that the Scottish Government hadn’t yet told them how much money they would get. But the CPG informed Tayside that Govt had told boards on May 12, 2017 and this was now a year later in 2018. NHS Tayside then apologised for a “misunderstanding”. They were not giving any of their extra money (almost £4million) to ease waits for pain patients. See The Sunday Post article by Marion Scott (a separate attachment to the email).

FIRST WAITING TIMES REVEALED ON SOME RETURN PATIENTS

ISD have revealed the first waiting times on return patients. The meeting welcomed this work warmly. It has taken years of battling by this cross party group to try to ensure that return patients are no longer “invisible”. New patients at NHS pain clinics are counted but become “returns” immediately after a first visit, no longer counted and the full pressure on short staffed clinics unknown.

ISD discovered that Scottish pain clinics saw 974 “first return” patients in a nine-month period. This indicates up to 1,200 first returns annually are added to the

workload in pain clinics. Beyond that, thousands more return over the years, ISD is still working on that.

The meeting thanked ISD for beginning to prise open facts long undeclared, and look forward to more information they aim to produce this Autumn.

SUICIDE RISK CAUSED BY EXCESSIVE WAITING TIMES

The meeting discussed the continuing lack of helpful response on suicide risk, detailed bravely by a Lanarkshire patient member at our March meeting, following suicide attempts when waiting times stretched to over 18 months when the patient should have received repeat treatment in six months. The patient was again present and said that she now felt forced to use private medicine to prevent reaching a suicidal state of agony again. The actual treatment, by NHS Lanarkshire pain specialists, was excellent but the huge delays harmed all the work. She could not afford private treatment at £2,050 plus a £300 consultation fee, did not approve of going private on principle but felt 'Because of my husband and children, I had to protect my life from being driven to another suicide attempt'.

MESH INJURED WOMEN

Jackson Carlaw MSP stressed that the aim remained that there be "no whitewash" on mesh implants as the previous report had been. In Parliament on June 20 he and other MSPs paid tribute to Michele McDougall, a very "brave soul" who had recently died of cancer. She had been unable to gain chemotherapy because of the debilitating consequences of faulty mesh devices implanted in her groin and abdomen years earlier.

The Health Secretary Shona Robison promised there would be debate time when the latest Report by Professor Britton is published, date unknown at present. Mr Carlaw

mentioned the combined work of Alex Neil, (SNP) Neil Findlay (Labour) and himself (Conservative) to say: "Every Party realises there is something seriously wrong". Mr Findlay had reminded people that 101 MSPs (out of 129) had called for there to be no more whitewash on mesh.

All MSPs at the CPG meeting agreed that the courage of Mesh survivors in forming their global campaign from Scotland was the key breakthrough. One survivor present said she would have killed herself had she not discovered the Scottish Mesh Survivors campaign.

Journalist Marion Scott said women were still not getting the truth. "Some in the NHS don't seem to have learned anything. We get reports of women being told "It's not mesh, it's tape so it's ok. Tape is mesh"

CHRONIC PAIN AND PHYSIOTHERAPY:

Physiotherapists Emma Mair and Dan Thompson of NHS Ayrshire & Arran were thanked warmly for giving an illuminating talk on how physiotherapy could help many.

They pointed out how attitudes had changed and there was tailoring to specific needs of individuals and finding out what they most wanted. One patient sought to be able to work in her garden again and that was an inspiring goal.

Pain Concern. A member asked the meeting if anyone had heard of the difficulties of the charity Pain Concern, which had now decided not to close its office in Edinburgh. The charity has received public money over the years. The Companies House register showed that four directors had resigned, including the chair Heather Wallace, who resigned in January 2018 but still represented patients on government related projects. The charity's supporters had said they hadn't been told why there had been resignations when they contacted Pain Concern. It was explained that the CPG does not hear from Pain Concern and has no links with them at all and that people can only direct their queries to the charity.

ATTENDANCE:

MSPs: Rona Mackay (Chairing), Elaine Smith, Tom Mason. Jackson Carlaw.

Non MSPs: Karen Neil, Claire Daisley, Nancy Honeyball, Lorna Farrell, Lis Watson, Marilyn Weir, Marion Scott (all Mesh Survivors Group), Mary Craig, Anne Murray, Emma Mair, Dan Thompson, (NHS Ayrshire&Arran), Peter McCarron, John Thomson, Liz Barrie, Donald MacAskill, Scottish Care, Dr David J Weeks, Dorothy-Grace Elder (Voluntary Secretary), M. Dornan, Paulo Quadros, Malcolm Maclean, Thyroid Patient Advocacy, Ming Robertson, Anne Marie Diamond, Dr Jacqueline Mardon, Margaret Smith, Queen Margaret University, Sharon Turnbull, Alison McColl, both Fibromyalgia FFU-Scotland, Marion Butchart, Linda Mawson, Frank Mawson, Graeme Houston, C. Cumming, GDA, Beverley Dick, Laura Clark, Arthritis Care, Carol Brown, Frances Boyle, Fibromyalgia Friends, Scotland; George Welsh, Catherine Hughes, Anne Hughes, Latoya Francis, Twimukye Mushava, The Poverty Alliance.

44 total.