

Cross-party Group on Chronic Pain - meeting of Feb 2012

In February 2002 a web page provided by the Parliament for a debate on chronic pain (instigated by Dorothy-Grace Elder) received more than 130,000 hits from the public and history was made. (The highest previous response on any issue had been 3,000 hits on nurses' pay).

This was the first of such debate in Britain and possibly in the world putting the issue of chronic pain in the political agenda. Apart from the website hits, letters were received not only from Scotland and the UK but also from Syria, Egypt, Canada, USA, all over Europe and Australia from a variety of people ranging from pain sufferers in those countries, Prince Charles and sailors at an American warship at sea, drawing attention to worldwide sailors having a higher rate of pain injury problems than most other jobs. A family in New South Wales in Oz wrote to say that they'd set alarms so that they could listen to the live debate online due to the 11 hour time difference.

The chronic pain campaign was proudly put on the Parliament's video of "The first 1,000 days of the new Parliament", featuring one of the two original pain patients, Anne Murray, who, with her neighbour John Thomson had met Dorothy-Grace regarding the campaign.

The Group and the campaign seem to have lost their momentum. In 2001 Steve Gilbert, one of the then leading chronic pain campaigners, submitted a document to the Scottish Parliament and the Public Petitions Committee urging the Scottish Parliament "to act urgently to redress this [underfunding] situation". In that document Steve described the "gruelling journeys for people in pain" to receive treatment in different areas in Scotland and patients from Aberdeen being "sent to a residential programme in England". He stated then that "it has been impossible to persuade many Health Boards to fund services adequately."

Eleven years later, people are still needing to travel far for treatment not only around Scotland but also England, the *urgent* action to redress the underfunding situation has still not taken place and Steve is still trying to persuade Health Boards.

There have been some progress on mechanisms to enhance access to pain management and MCNs, from what I know that is happening around the world, are potential world leaders in this area – this despite receiving one of the lowest levels of funding in health care.

There are a few things I think would help our Group to return to the vibrancy and effectiveness of eleven years ago but some things would need to be put into place for this to happen.

1. **Cross-party Groups Regulation:** It would be good if all members could understand the scope of Cross-party Groups including what we can and cannot do. This would avoid efforts being directed at actions which fall outside Cross-party Groups remit and would help to focus on what we are able to do as a Group.

The current Regulations published in 1999 do not seem to have all the answers and I know that work on refining them has been an on-going exercise. From what I read, Jackie Baillie has a lot of experience with this.

2. **Communication/information sharing:** The work of the Group has changed from involving hundreds of people from the UK and abroad to the work of a handful of people. Not diminishing the value of the work done by those few people, there should be wider consultation on decisions more transparency and more communication.

This seems to be a major source of frustration amongst Group members and a source of division. Instead of working together for the sole benefit of patients as we should, we now have a 'them and us' situation growing within the Group – one faction working with the Government and the other against. In order to remedy this situation, I think that we need to establish communication mechanisms and increase transparency.

Although I'm not discussing details on this document, we could make use of social media to involve the public again and discuss different issues amongst ourselves without having to wait for the next meeting. For instance, I've had mutually beneficial discussions with members of the American Pain Society through LinkedIn and with researchers through Facebook. (The members participating of the American Pain Society discussion didn't know about the 'DoloTest' presented to our Group at the last meeting and now they do and are investigating it).

I also think that we should be able to communicate with each other through email so that we could ask for information or feedback directly from Group members who would be able to share them, exchange ideas and so on. Regardless of what the regulations are, I feel that, if people choose to be members of a public body, they should expect to be counted, contactable (and accountable).

It would be great for the sake of transparency as well as dissemination of information, if everything done by Group members working on behalf of the Group could be published (even if in 'Twitter form' which includes just over 100 words so this shouldn't take a lot of time).

Even a webpage could be set up for the Group, if this is allowed. Other Group members may have many more ideas.

3. **Collaboration:** As well as sharing ideas on line, it would help the Group to find solutions to the different chronic pain issues if we communicated with organisations around the world and learned from them (and they could learn from Scotland in turn). For instance the Department of Veteran Affairs in the US have well developed mechanisms to treat pain and provide pain management and evaluation. Organisations in Canada and New Zealand have developed integrative solutions to pain management within their national health services that could be adapted and replicated here. In Glasgow, some organisations have developed mechanisms to provided individual health support within the community as well as assessment tools (I was part of the original one).
4. **Actioning of Group decisions:** To maximize effectiveness, we need to be clear what decisions/actions must go through the convenors before being implemented and which can be actioned directly by the Group's secretary. This would avoid unnecessary delays such as the one for the motion voted at our last meeting regarding funding, etc. I also think that further support for the Group's secretary should be welcome.
5. **Publicity:** We should have more access to and interaction with newspapers, TV and radio to publicise the work of the Group and chronic pain issues. To avoid miscommunication and cross-purpose, the Group should be able to decide and approve any media statements. Perhaps a 'press officer' should be appointed.
6. **People in pain need help now:** Through our work, we must be able to address some chronic pain issues quickly by whatever means available. By this I mean that whenever possible, while we work on long-term issues, we should support *any* tools or mechanisms that may either reduce pain or make pain management more easily accessible to patients. I think that the hundreds of people who originally supported our campaign and especially the patients who were instrumental in the formation of the Group would and have the right to expect that.

There is enough expertise in this Group for ideas on how this could be achieved, which would be brought about through discussions and shared experiences. There is also work being done on health management through Social Enterprises Networks across Scotland. Interacting and collaborating with other organisations may prove fruitful (see item 3 above).

In this respect, I can only speak from my own skills and experience. I was invited to become a founder member of this Group because of my expertise in non-pharmacological chronic pain interventions. Yet, very little – if nothing – has been done to explore those alternatives (in or outside the Group) even though guidances and reports published through time accept that alternatives to mainstream interventions have a place as chronic pain management tools.

There is plenty of good (RCT) evidence showing that alternative, drug-free interventions work, are safer and have less negative side effects than pharmacological ones. One such example is

NICE's guidelines on the treatment of non-specific lower back pain. This has been already known since 2008 when QIS responded to an enquiry from NHS Highlands. Nevertheless patients have had to wait and now wait even longer while SIGN re-assesses the guidelines. When/if SIGN agrees with NICE and other organisations around the world, patients will still not have access to the recommended non-pharmacological interventions as there is no referral pathway, no register of non-pharmacological therapists and no intention to create one as the CNHC in England/Wales.

Mainstream chronic pain management (ie chronic pain management provided by the NHS) for *all* types of pain consists of *mainly* three tools: drugs, psychological intervention and physiotherapy/TENS. There are many more effective tools in many areas (plant-based, nutritional, physical etc). 'Drug-free' interventions have shown most effectiveness in musculoskeletal conditions. As those types of chronic pain account for about 80% of all chronic pain, if we could deal with them quickly through non-pharmacological means, a large percentage of around 800,000 people would be fairly quickly helped.

I think that this is a discussion that should be encouraged in the Group both at our meetings and discussion groups outside meeting times.

For more on this issue for anyone who is interested, including all my documents and correspondence with the Scottish and British Government please refer to www.bit.ly/IntlifeNHS1

7. For some reason we seem to have skipped the McEwen Report and jumped straight into the GRIPS. Although the GRIPS Report reiterates some recommendations in the McEwen Report, the latter includes recommendations not addressed by the GRIPS. We should keep the McEwen report on sight and support all its recommendations. We should also promote implementation of the Best Practice Statement ~ February 2006 'Management of chronic pain in adults'.

I have deliberately not included any research references as this would take up too much space on this document as well as being irrelevant at his stage. I am able to provide good quality research references to anyone interested.

There is little value in blaming the Scottish Government (past and present) for their inability to deal with the chronic pain issue. To my knowledge, all other governments in the world have the same difficulty. Their equivalent of reports such as the McEwen and GRIPS cover the same issues and issue roughly the same recommendations. The way forward would be for the Government to recognise that they do not have much idea of what to do about this issue (rather than issuing politically defensive statements and replies to questions) and, as soon as this is recognised, we could all move on together.

I would hope that members would seek clarification before reacting to any statements they might disagree or take exception to in this document.

Finally, I urge you to read the following letter sent to me in 2009 (I have others) before you decide that we need to have a few more meetings and reports before something can be done for chronic pain sufferers.

I decided to leave it exactly as the sender wrote (names deleted). Unfortunately this is not unusual!

"i have a left shoulder pain from a fall for which i have had 3 surgery,s on, i also suffer chronic sciatica, and i am on morphine for acute chronic pain,

i also have recently had my bladder removed for acute chronic infections sadly i still have infections in my only kidney [my left kidney was removed due to stones and chronic infections] i am literally at my wit's end.

i have already been told by the surgeon i met in x x x x that he would be willing to fit me with a pain pump if i can find someone who would be willing to do the refills, my pain doctor is x x x x x x x x x x it is he who i am under, he trained the doctor in x x x x whose name is x x x x x x x x who is willing to do this surgery for this pump, he also told me i will do whatever it takes to help you to get this pump, put bluntly i have been let down again and again by this doctor [x x x x x] it is also he who has recommended me for this pump yet he does a complete u turn, and now I'm back to square one!

i have tried everything there is to help myself, i used to be so independent and had a full and active social life, although i am now going out and about i can't deny i sometimes i think why bother?

i have been on M.S.T 100mg 3 x Day and i take oral morph 20 x 25ml every 4 hours [it's supposed to be for breakthrough pain] i cannot go a single day without the morphine or the sleeping pills and of course the other meds for my kidney, i am literally at the end of the line, i no longer trust any doctor and i can't tell you how many shrinks i have seen with reference to this living nightmare!

i have a surgeon who is willing to give me this hope [and yes i am aware that this pump may not work] but surely i should be given the chance? i now feel very very let down by these doctors and if i am honest i don't know what else i can do? i have thought about killing myself but if i did that they would all turn and say "told you so it was in her head!" [.] “

i have spent money i could ill afford to try to stop this living nightmare, for what empty promises, i am literally at my wits end. my marriage of "23yrs has now ended because my husband could no longer cope with me being ill all the time, i can't go any lower than i am now [.] i really cannot believe how badly i have been let down, even my parents say they cannot understand why these doctors can't help me, personally i think they can help me they just hope I'll leave them alone [i have written countless letters again to them but no avail] i am so desperate i would do anything just for someone to actually help me, what else can i do?

is it going to take me another 3+yrs to get me some help? because i honestly feel i am at the end of the line, now, i simply cannot go any further down than i am now, [.]

I apologise for being so miserable i haven't slept much which again is due to this mess i call life , this pain is never ending as I'm sure you know i just want the chance to be given a chance, do i ask to much?