

## Cross-party Group on Chronic Pain – Meeting of 25<sup>th</sup> June 2014

Submitted at the meeting to ask for inclusion on the CPG's working plan. Co-convenor and chair for the meeting suggested that the issues could be discussed on the next meeting of the group.

### ISSUE 1

We (on the CPG) have been focusing greatly on some of the GRIPS recommendations and the specialist chronic pain centre but I'm becoming increasingly aware of how benefits assessments have been affecting chronic pain patients and of how there isn't much support for them to defend their cases (and, where there is, it is fragmented – the level of support depending basically on luck). Those extra burdens plus inherent issues related to their conditions eg difficulty of movement, difficulty thinking clearly/'foggy brain', make chronic pain patients easy target.

It seems that medical doctors used to make assessments (or at least some of them) lack any knowledge about chronic pain and how it affects patients (their main stance being if the cause for the pain can't be identified or cannot be seen, then there is no reason for receipt of benefits and/or the patient is lying – despite pain consultants, GPs and physiotherapists reports supporting the patients' cases).

Issues seem to arise at different points in the benefits assessment:

When chronic pain patients are called for benefits assessment, there doesn't seem to be any source of advice they can count on. I've been told that Citizen's Advice sometimes give the wrong information or don't know what advice to give as is the case with one of the patients I'm currently helping.

I have been told that, during assessment, interviews can be confrontational and the interviewee is not allowed to have someone else for support with them apart from their solicitor or someone medically trained.

Chronic pain patients are having to represent themselves in the appeal process, having to resort to study benefits regulations and clinical/medical aspects of their or hire a solicitor at great expense even though some solicitors have no experience in benefits regulation and are of little more use than self-representation.

One of the patient's pain consultant told her that he is seeing more and more chronic pain patients having issues with benefits.

Very briefly, as examples paint a clearer picture, here are two different experiences of patients regarding benefits assessment:

1. I've also been contacted by a chronic pain patient in South Lanarkshire who is the carer to one of her autistic children. Sometimes she is immobile and depends on friends and her children for daily living. Her benefit was cut but, after fighting for 8 months, she managed to have her benefit re-instated. She shouldn't have been put into that situation in the first place – she told me that it took a big toll on her.
2. The mother of a 10-year-old girl diagnosed with 'Severe Chronic Pain contacted me about her experience. It's better if I just copy you what she told me (edited – bolds are mine):

*"I have a ten year old daughter who has been having serious health problems for 3 years now. She was diagnosed with severe chronic pain syndrome and can only mobilise using her crutches or her wheelchair - despite this, her DLA (mobility component) was not renewed last year. She was previously awarded this benefit and when her claim came to be renewed, they only awarded the Higher rate Care Component. When I queried this, they stated that as she was now 10, she should be able to cope with her disability! Our GP was horrified but unsurprised by this view and stated that more patients every week are coming to the surgery regarding this".*

On further enquiring she said that

*"With regards to Taylor's treatment [her daughter], we had had very little help or advice". . . .  
"When the Consultant told me that her diagnosis was Severe Chronic Pain Syndrome, I asked her what happened next and was told we had to just live with it. There has been no follow up and I have even requested a second opinion from Yorkhill as I can't bear to see Taylor being in so much pain and not be able to offer her any hope that it will get better."*

*"The officer I spoke to at DWP when the claim was initially refused told me that Chronic Pain Syndrome is not recognised as a disability for the purposes of Disability Living Allowance so I am not hopeful that the appeal will succeed. It is very upsetting and it also means that Taylor's Blue Badge was not renewed and she has to walk some distance with her crutches (she hates her wheelchair) when attending appointments etc"*

This mother is representing herself at the appeal and is in the process of studying medical books and talking to chronic pain and benefits experts to defend her daughter's case.

---

## ISSUE 2

The other issue is one which I have touched on a couple of times during the life of this CPG. It is the patients' equal right to access evidence-based drug-free interventions including the use of some forms of CAM for the management of chronic pain within the NHS and the promotion of research on those fields.

Given that 80% of all chronic pain is musculoskeletal-related\* and that existing evidence points to non-pharmacological interventions (including CAM) as the most effective ways to manage MSK-related chronic pain, it makes sense to make use of those interventions.

In practical terms, if CAM therapists can take some of the appropriate chronic pain cases – especially within the community – this would free up more physiotherapists and psychologists to take care of patients that required their specialised input.

I've been advocating for some years the use of CBT-trained psychotherapists for cases where a psychologist isn't essential (it is the use of CBT that has shown to be effective – some psychologists are not trained in CBT) and the use of massage where physiotherapy is not readily available (a proposal that makes even more sense now that SIGN (as well as NICE) has listed massage as one of the most effective interventions for some types of chronic pain).

There is also the health inequality issue that the SIGN guideline on chronic pain has highlighted. Currently only patients who can afford to pay for the CAM treatments recommended by SIGN are able to use them – unless they are lucky enough to be referred to a handful of chronic pain centres that offer similar therapies (assuming that they can be seen straight away).

The main issue preventing CAM pain management in the NHS as it stands seems to be regulation and referral pathway. Neither of those are overly complicated to implement. As you probably know, the Department of Health in Whitehall has created and funded the Complementary and Natural Healthcare Council (CNHC) to regulate CAM throughout the UK but Nicola Sturgeon had refused to recognise them as regulators in Scotland when she was the Health Secretary. There are many therapists in Scotland already registered with the CNHC.

There are, of course, many issues – none insurmountable – which could be resolved through the input of our CPG. As we all know, chronic pain is multi-faceted. The social health aspect is as important as the physical and mental health. Those three aspects are closely interlinked.

From Paulo Quadros (Intlife)

\* Developing a National Model for Chronic Pain Services in Scotland (Societal Impact of Pain Symposium), Scottish Government, 5 May 2010