

Response to consultation paper re chronic pain residential unit

QUESTION 1 As per form

QUESTION 2

Option 1 is my preferred option as I think it is realistic that there will be limited funds available and would rather see one centre of excellence with all facilities than smaller centres which may be lacking in certain provisions. As long as the centre is situated centrally with motorway/rail links it should be accessible to all who need it.

QUESTION 3 Don't disagree with any options. Anything is better than nothing as at present.

QUESTION 4 no comment

QUESTION 5 Upfront travel costs may be a barrier to some people.

QUESTION 6 As per form

QUESTION 7 As per form

QUESTION 8 As per form

QUESTION 9 N/A

QUESTION 10 N/A

QUESTION 11 As I sufferer of CRPS who has experienced first hand the lack of knowledge and understanding of the condition by medical profession in general and by some in particular, (Earlier this year I was told by a Consultant Hand Surgeon "Don't worry you only get crps for 2 years so you've only a couple of months to go" . As she is a medic carrying out 'routine' surgery for carpal tunnel syndrome after which many patients acquire crps, in my opinion, she should have the knowledge to be able to look out for and diagnose the condition) I consider it is imperative that any proposed unit needs to be staffed with the specialist knowledge to deal with and treat patients with this condition as there is little available to us elsewhere in Scotland. I have been in touch with many people who have been to Bath and cannot recommend Professor Candy McCabe and her staff highly enough

for the help and assistance they were given there and some have even gone on to say that if it were not for the team at Bath they might not even be here today. At present sufferers in Scotland are passed from pillar to post between orthopaedics, rheumatology, physio, pain management and more often than not just treated in primary care as our GPs don't have a "one stop shop" to send us to. I was diagnosed very early (the week after coming out of plaster) and on paper had the best chance of recovery/remission but there was no proper treatment plan in place for my GP to follow and I have just been learning about the condition as I go along from other sufferers through a support group on a social networking site. As far as I am aware, other chronic pain sufferers have support through different hospital departments, national charities etc but we appear to be the forgotten few, albeit the condition is not nearly as rare as is sometimes reported.

It is also important that we have some "named person" contact in times of crisis. At present sufferers of crps are scared to contact NHS 24 or attend their local A and E at such times as they are inevitably met with the question "You've got what?" and then have to proceed to explain why blood pressure cuffs shouldn't be placed on affected limbs or needles inserted in particular areas etc. This all causes additional stress to the patients at the time and an appropriate advice line would be a godsend where patients and carers could find out when emergency treatment for pain or infection are necessary and given under the proper conditions for them.

As, hopefully, in future more and more people will be properly diagnosed with CRPS through education and awareness they should have access to a facility where the condition can be explained to them and educated in what they might do to help themselves to lessen disfunction etc. Also, some people after years of such pain and medications ceasing to have effect, do at times require respite care in a unit where they can be re-assessed and at the same time have proper rest under supervision of properly trained staff.

I only found out about "the Min" after I joined a support group and communicated with other former patients and its only since this Petition and consultation came about that I realised that my GP and probably many others were not aware of its existence or the fact that patients from Scotland could be referred. A centre of excellence in Scotland as well as helping sufferers will also help to raise awareness of the condition of CRPS among the medical profession in general.