

Consultation response: the provision of specialist residential chronic pain services in Scotland

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

- a) an individual who experiences chronic pain
- b) a family member or carer of someone who experiences chronic pain
- c) a health professional
- d) an organisation representing people who experience chronic pain
- e) other stakeholder (please tell us in the comments box below)

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location *← If patient transport supplied this would also be ok - but not if had to go by public transport*
- Option 2 – a service delivered by local chronic pain clinicians (supported by other clinical advisors in another part of the country) *although heavily travel would be a problem.*
- Option 3 – a service delivered in different locations (by a team of chronic pain specialists – an outreach or roving service)

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

Due to how debilitating travelling would be, it would mean resting for days or taking lots more medication which would then impair my thinking so would it difficult to take part + probably feel nauseous with extra painkillers. My only worry with option 2 however is that presently the pain clinicians doesn't feel he can offer me anything as I am intolerant to medications and so he has discharged me after only seeing me twice. I therefore wouldn't get referred to the services you speak of. I think it would be important for the local clinicians to learn from specialists what biological methods of treating pain are not the be all and end of all. One size (treatment) doesn't fit all. I would hope for more complimentary therapies to be offered + self management skills.

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Question 3: Are there any of the options you disagree with? (If No, move straight to Question 4.)

If yes, please tell us which one(s) in the comments box, and why?

I have concerns about Option 1 - where would it be? Would patient transport be provided? as i couldn't mentally, rationally or physically cope with public transport to somewhere i don't know, or to faraway distances. My cognitive ability is compromised when pain levels, fatigue set in. I would worry about there being no local follow on support if treatment was faraway. I feel local clinicians need to be retrained & brought up to speed with alternative ways of addressing pain - not just medication. If patient transport was supplied then the stress would be taken out of travelling for distance so would just be the bodily effects to deal with.

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

Bringing in more complimentary, non medication means of addressing pain - not just CBT though - more things like acupuncture, mindfulness training, hypno therapy, bowen technique, osteopath or chiropractor, aromatherapy, massage, tai chi instruction (for health version not mainstream version). The physio therapists, doctors, clinicians need to be made aware of the different types of pain there are such as fibromyalgia, chronic fatigue etc as they seem to say theres nothing they can do for you - its not like arthritis or such where you can get injections etc. Being told to go away there is nothing to help you leads to selfharming. Teaching people how to cope with self harm would be good too as the doctors + even mental health people i've met, don't want to know.

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Please list as many as you wish in the comments box below and include any others that are important to you.

① Upfront travel costs.

② Wouldnt be able to cope with planning journey by public transport, would be stressing about missing connections etc. ~~etc~~ Would be stressing about getting there on time - generally the whole process would be stressful. Panicking about not being able to carry luggage by myself etc. Panicking about falling asleep due to medication on the bus/train and going beyond your stop etc. Would need to be patient transport car, where someone else picks you up from your door and is responsible for getting you there on time.

③ People with anxiety, depression etc might exacerbate their levels of stress being away from home, family (pets - maybe have noone to take care of them for 2-4 weeks at a time).

④ GP's and local pain clinicians discounting that you are eligible due to the type of illness you have or the fact that you cannot tolerate medication ie fibromyalgia - doesnt respond well to usual treatments and involves so many other systems of the body - that a lot of the current people i deal with - discharge me from their care - pain clinic, physiotherapy - saying theres nothing we can do for you - GP shrugs shoulders & fee - so would they even refer me?

⑤ The sheer exacerbation of the pain + exhaustion that would be the end result of travelling any distance to the place would mean recovery time would be few days before able to do any testing, assessment.

⑥ Back to anxiety levels - for those of us who havnt slept away from home in over 20yrs then there would be anxiety round not being able to sleep or not liking the food offered, at meals etc. Would there be allowances made to provide medication for this purpose?

⑦ Would you be able to take hotwater bottles etc - i have to use one throughout the day to ease pain.

⑧ Would you have to wait long time for there to be enough people to run the treatment course - if it was Option 2?

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

(choose as many as apply)

- A chronic pain assessment
- Supported one-to-one sessions to teach coping skills
- Group sessions
- Residential accommodation
- Opportunity for immediate carer/support provider to accompany patient
- Peer support
- Tailored exercise programme - ie chronic fatigue & fibromyalgia sufferers are made worse by exercise classes, so would need to be gentle movement class.
- Medication assessment
- Other (please tell us in the comments box below)

Hydro-pool sessions

Complimentary therapy treatments - holistic approach such as acupuncture, nutritionists, allergy testing for foods substances that might be causing or exacerbating the pain. Alexander technique, Tai Chi for long term pain sufferers - not the standard type of martial art Tai Chi. Qigong, Hypnotherapy, Herbal or Homeopathic prescribing. Prescribing of natural health supplements ie Melatonin - for sleep, 5HTP - for mood, pain, fatigue, sleep. Cannabis medicinal - for pain. Different psychological services than ^{type} are available now - CBT doesn't work for everyone - but maybe a more pain specific. Look at how to improve our ways of coping mentally + emotionally. Self harm support - none addressing this just now in GP or mental health. Mindfulness training + follow on groups. Relaxation training. Creative expression to act as a distraction to pain. Counselling on the fact that there is no cure - so how to get to grips with accepting this is what your life is now and how best to self manage it.

It is hoped the local healthcare professionals would be brought up to speed on how to deal with long term chronic pain patients - as they only seem geared to acute pain treatments + people who can tolerate medication - anybody over with is turned away - this being physiotherapists, pain clinicians, GPs, Mental Health Team.

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Yes No Don't Know *Not really sure why that would still be required? as hopefully a newer more closer service would be more effective as can learn from errors of other centres.*

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yes (please answer Question 9)

No (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

N/A never been offered.
Don't believe I would ever get chance to get referred or offered a place as my GP didn't think it even worthwhile referring me to local pain control clinician at the hospital due to me being unable to tolerate side effects of medication - I am on the bare minimum of pain relief just now that no way meets my requirements for pain relief but my GP doesn't want to offer stronger medication or medication for sleep as it may result in me getting addicted, even although it is well documented in my notes that I do not abuse medication. After arguing to get a referral to pain clinic - I was then only seen for 2 appts then discharged, saying they could offer me nothing. So what now? Some with Mental Health team as I can't tolerate anti-depressants. My GP has even said not to bother taking up the Chronic Pain service offered by Pharmacy as she reckons it would lead to overprescribing! So it is doubtful I would get referred w/ my conditions - fibromyalgia + chronic fatigue / post viral fatigue are not Level 4 conditions.

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

Sorry for the state of the writing but it pains me to write, apologies too if my answers are not always relating to the question asked as I can go off on a tangent and not realise I'm not covering the question asked.
There definitely needs to be continuity of support locally, and any intensive 2-4 week programme has been done - cause if the local healthcare aren't going to be up to speed - you will default back to how you were, without ongoing support. So local training is required, especially for physiotherapists - who only seem willing to treat acute pain cases.
There needs to be acknowledgement that not everyone can tolerate medication but that doesn't mean they should have the door shut on them. GPs need to back up patients, when it comes to completing benefit forms - you have to pay for a supporting letter - just now and even then it nowhere tells the true extent of how your daily life is affected by pain - as they only see you for 8 mins at a visit. They don't realise the struggle and so may report that you can cope ok with day to day activities - which ends up resulting in you losing your benefit. It is bad enough lighting the welfare system on your own without a GP hinting you maybe able to work!

(End of questions. If you require more space to write answers, you may submit as many additional pages as you wish. If doing so, please clearly state the question numbers that your answers relate to.)