

## Consultation response

**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)

I suffer from Spinal Bifida and CRPS I am also a member of the Cross Party Committee!

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

- Option 1 – a centre of excellence in a single location
- Option 2 – a service delivered by local chronic pain clinicians (supported by other clinical advisors in another part of the country)
- 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.

I attended the centre down in Bath in April/May 2013 and I thank god I did every day as it has changed my life for the best. The centre does not only treat you for your pain but also your mental pain, as only a pain patient can understand what its like and that's no disrespect to any other patient. Before I attended Bath I was really struggling with both aspects and for the first time in my life I wanted my life to end. Now after my treatment I can see the future I wanted before things took a turn for the worse, without Bath help I may not have had a future. One of the things the governments must look at is the medication given to pain patients, as it won't help a % in fact it will cause more problems, plus you can over anaesthetised! I thank Bath and the doctors everyday and the patients in Scotland can also feel this that's why its so important the government agree to one residential centre it can change so many peoples lives! The one thing I must say as part of the Cross Party Committee since joining I thought everyone was in this together. I was so wrong it's plain to see that certain individuals and organisation have there own agenda and the patient is being forgotten. I have just joined over the last few months, as I wanted to do something and

not just sit and do nothing and I would not have been able to do this without Bath.. Please note the patient must come first not a doctor or charities!.

**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?**

Comments (box expands with text input - there is no word limit)

**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.**

Comments (box expands with text input - there is no word limit)

**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.**

As I alluded to earlier we have to look at the medication given to pain patients. One of the tablets I was on was tramadol and was taking a very high amount of 400gm a day or eight tablets. Since I stopped taking them I have felt no difference and my pain!. As our Doctor told us a patient like myself the pain is so high these tablets can only touch the pain might give a small realise but over all it was best to come off them. I have seen up teen pain doctors and the first thing they do is give you more and more pain tablets this culture has to stop. There also has to be more education given to Doctors as I have seen Doctors who didn't know what CRPS was and guess what they decided to give me more tablets. My eyes have opened up since Bath and Scotland eyes must open up and give us the centre we want and by god need!

**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                            | X |
| Supported one to one sessions to teach coping skills | X |
| Group sessions                                       | X |
| Residential accommodation                            | X |

- Opportunity for immediate carer/support provider to accompany patient X
- Peer support X
- Tailored exercise programme X
- Medication assessment X
- Other (please tell us in the comments box below)

There has to be support for the partner or families of patients as I have saw with my owe eyes how it has affected my wife. Down in Bath they had a family day but it was only a day in my opinion this is not long enough, and seeing someone go through a condition is sometimes worse than suffering from it! Imagine seeing your loved one in bed tears running down his face screaming and you can't do anything it really does have lasting affects. My wife is still working on coming to terms with the reality that I will be suffering with this condition the rest of my days, as that's the reality there is no cure. That's the one thing you are asked and you are told early and it's repeated through out the four weeks I was there it's harsh but you need to hear this. I can know focus and put all my energy into fighting daily as I learnt my body works three times as hard as an able body person.

**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

**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.**

I think what I have written above says it all without Bath I may not have been here. I have also been able to go out for dinner with my wife as you lose the time together and go out with my friends for a drink only lemonade for me now though! And in August I was given the chance to follow my football team overseas which was great. I have lived my life while fighting pain I have some good days still mainly bad days but I can handle things better. The best way I can sum up Bath and that' it's a boot camp with love

as they really do care for you and you will make friends for the rest of your days. They also keep in touch with you when you leave and are only a phone call or email away for advice. Open your eye Scotland needs this centre.

**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?**

Comments (box expands with text input - there is no word limit)

**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.**

The only other thing I have to say is I had to pay out of my own pocket for each trip to and from and in total it cost circa of 1000 pounds. This needs looking at as this will be the main reason why patients have not taken the opportunity either a fund bank needs put in place to help each patient or all monies need paid out prior!