

## 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
- 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 HAVE EXPERIENCED THE BENEFITS OF SET UPS SIMILAR TO A CENTRE OF EXCELLENCE & NOW BELIEVE THIS TYPE OF MODEL OFFERS, LONG-TERM, THE BEST SERVICE FOR PATIENTS. SPECIFICALLY, BASED ON MY OWN EXPERIENCES (HEART & VASCULAR SURGERY AT THE GOLDEN JUBILEE HOSPITAL, SCOTLAND'S SPECIALIST HEART & LUNG CENTRE; & FATIGUE MANAGEMENT COURSE AT GLASGOW HOMEOPATHIC HOSPITAL): SEEMS TO ATTRACT 'TOP PEOPLE' I.E. CONSULTANTS, ETC; PROMOTES THE FURTHERING OF SPECIALIST KNOWLEDGE & BEST PRACTICE IN RELATION TO A HEALTH CONDITION/ISSUES; ALLOWS FOR TREATMENT/INTERVENTIONS TO BE DELIVERED IN A VERY FOCUSED MANNER. HOWEVER THIS MUST BE 'BACKED UP' BY ADEQUATE LOCAL PAIN SERVICES.

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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?**

[Empty comment box for Question 3]

**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.**

[Empty comment box for Question 4]

**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.**

BASED ON MY OWN EXPERIENCE - I WAS ORIGINALLY DIAGNOSED WITH M.E. / CFS BUT NOW WITH ATYPICAL SYSTEMIC LUPUS, BOTH OF WHICH INVOLVE NOT ONLY CHRONIC PAIN BUT ALSO SIGNIFICANT, OFTEN DISABLING FATIGUE; NERVOUS SYSTEM SYMPTOMS; ETC:

- TRAVEL, WHERE CHRONIC PAIN IS A FEATURE OF A WIDER CONDITION E.G. M.E. / LUPUS, TRAVELLING ANY DISTANCE CAN BE EXTREMELY DIFFICULT. THE PATIENT MAY BE ENTIRELY RELIANT ON SOMEONE TO DRIVE THEM - IF SOMEONE IS AVAILABLE. TRAVELLING BY PUBLIC TRANSPORT MAY BE BEYOND SUCH A PATIENT'S CAPABILITIES, EVEN IF ACCOMPANIED. THEREFORE, AVAILABILITY OF A CAR & DRIVER; COST OF PETROL; LENGTH OF JOURNEY, WILL ALL BE FACTORS DETERMINING WHETHER A PATIENT IS ABLE TO ATTEND. IN SOME CASES OF SEVERE M.E. OR LUPUS, A PATIENT MAY REQUIRE EXPERT HELP WITH CHRONIC PAIN BUT SIMPLY BE TOO ILL TO TRAVEL & ATTEND A RESIDENTIAL COURSE.
- COST. SOME PATIENTS WILL BE TRYING TO EXIST ON ESA ALONE & WILL NOT BE ABLE TO AFFORD TRAVEL COSTS, UNLESS THESE ARE REIMBURSED. SOME MAY NOT BE ABLE TO FIND THE MONEY 'UP FRONT' & WAIT FOR REIMBURSEMENT.
- PRESUMABLY ACCOMMODATION WILL BE F.O.C.?
- FOR PATIENTS WITH CONDITIONS THAT ALSO INVOLVE SEVERE FATIGUE, A RESIDENTIAL SERVICE MAY BE TOO INTENSE & DETRIMENTAL TO THEIR OVERALL HEALTH - UNLESS SUCH A SERVICE IS ABLE TO TAILOR ITSELF TO PARTICULAR CONDITIONS & PERMUTATIONS THEREOF. AGAIN, SEVERELY AFFECTED PATIENTS ARE LIKELY TO REQUIRE THE MOST 'BESPOKE' SERVICE IN ORDER TO NOT ONLY ATTEND, BUT FEEL CONFIDENT TO, IN THE FIRST PLACE.

**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 †
- Medication assessment
- Other (please tell us in the comments box below)

† FOR PATIENTS WITH M.E./CFS & LUPUS, ANY EXERCISE PROGRAMME WOULD NEED TO BE <sup>FULLY</sup> CONSENSUAL & TAKE INTO ACCOUNT THE SPECIFIC NATURE OF THESE CONDITIONS I.E. EXERCISE, DONE WRONGLY, CAN BE QUITE HARMFUL - THIS IS, IN CASE OF ME., COVERED IN SG'S AUGUST 2010 BEST PRACTICE STATEMENT (SCOTLAND) ON M.E./CFS.

THAT IS, AS PER OTHER COMMENTS, THE APPROACH TO CHRONIC PAIN NEEDS TO BE TAILORED (RATHER THAN GENERIC) TO PARTICULAR CONDITIONS, WHERE APPROPRIATE.

I BELIEVE THIS IS MOST LIKELY TO OCCUR UNDER A CENTRE OF EXCELLENCE MODEL.

**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.**

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?

[Empty response box for Question 10]

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.

LOCAL CHRONIC PAIN SERVICE PROVISION WILL CONTINUE TO BE REQUIRED, EVEN IF A CENTRE OF EXCELLENCE IS ESTABLISHED. FOR SOME PATIENTS, THIS WILL BE ~~THE~~ <sup>THE</sup> SOLE, MANAGEABLE AVENUE FOR TREATMENT / SUPPORT, & IT WOULD BE HIGHLY UNJUST IF THE MOST UNWELL WERE TO BE NEGLECTED - FUNDING FOR LOCAL PROVISION NEEDS TO BE PROTECTED.

(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.)