

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 am responding as someone who is/has lived with chronic pain for approximately the past 30 years. I gained significantly from navigating through part of Scotland's Pain Services in search of relief. However, found my north star through the provision of an Integrative model of care at the NHS Centre for Integrative Care, Glasgow.

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.

A centre of excellence in a single location is, by far, my preferred option. I feel this option would most appropriately fit the primary conditions if I were to require admission to a specialist residential chronic pain service in Scotland. This option has the potential to offer the respect of a service not only equal to Bath, but also a service that could offer an imaginative prospect to create and grow Scotland's own unique model. I feel that a residential chronic pain service housed in a centre of excellence in a single location is paramount to chronic pain patients' needs in Scotland today; with the necessary and vital combination of an Integrative approach and model of care.

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 can see that specific parts of other options in isolation may indeed offer potential benefits to chronic pain patients. However, I am concerned about the overall benefits that these options in themselves would have in the wider service provision of a specialist residential chronic pain service; especially as they are so far removed from my own preferred option i.e. 'a centre of excellence in a single location.' I am also concerned that the other options, in comparison, feel more impersonal, fragmented, varied and may lack the stable clinical base many patients would benefit from. (see below)

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.

I've had the privilege of being a patient- treated for chronic pain and interconnected complex chronic health challenges at the NHS Centre for Integrative Care, Glasgow. Undoubtedly, under this one roof, the camaraderie and support- which included meeting diverse groups of patients, as well as committed and compassionate clinicians and staff- helped me considerably beyond all expectations I had. I discovered and developed a deeper compassion and understanding for not only my own pain, suffering and health challenges, but equally for others. From this integrative model of care, I was able to grow in confidence, acceptance, knowledge and resilience during my incredible patient journey.

The purpose built Healing Space and Gardens at the NHS Centre for Integrative Care offered insurmountable benefits. I feel passionately that this format is pivotal if Scotland is going to have her own specialist residential chronic pain service. I found the Healing Spaces and beautiful Gardens key to my learning and development e.g. reducing stress, reducing pain, enhancing wellbeing, offering a quiet reflective space after treatments/ consultations etc. It allowed me, just to be... and altogether take in the therapeutic benefits that such an environment facilitates in the mind and body.

I believe it is generally widely accepted that Healing Spaces reduce the stress response- leading to enhancements in health and pain management. Dr Esther Sternberg MD, Immunologist & Director at the Arizona Center for Integrative Medicine at the University of Arizona in Tucson has done extensive research into Healing Spaces.

Below is a link to the 'On Being Radio Show/Podcast' *The Science of Healing Places*. The host Krista Tippett interviews Dr Sternberg on her research. I welcome you, at the very least if you can, to listen to the first 10 minutes.

<http://www.onbeing.org/program/science-healing-places/4856/audio?embed=1>

At the NHS Centre for Integrative Care I found a place that could help, care, nurture, support, and guide me through the torturous physical pain and psychological distress that originated from the effects of an adolescent spinal-disease. I was given the space, time and tools required to help build the foundations of acceptance I needed. I was inspired to learn, develop and put into practise an inside-out approach; taking personal responsibility where possible, absorbing and trialling self-care, self-management and pain-management tools; ultimately learning skills that would enable me to better manage my pain and health condition. Thereby giving me as a patient, every possible opportunity to be an active participant in my care, rather than being only a passive recipient of services. If it were not for Integrative Medicine- I wouldn't be currently capable, or have the ability, to manage my living experience of pain and an evolving health condition.

While learning to manage my long-term health condition and pain, I had the help and benefit from a multidisciplinary Integrative team of expert Consultants, Doctors, Physiotherapists, Nurses, Holistic Therapists etc. Throughout my time as a patient, I always felt safe to explore my developing boundaries in an environment that was non-judgemental, compassionate, caring, holistic and patient-centred. In addition, I was encouraged, and indeed inspired, to learn and study wellness as a student of my own health.

Through my experience of Integrative care as a pathway through chronic pain and better health, I had the opportunity to participate in the following:

- Deeply insightful and transformative integrative consultations with the Consultant Physician and House Doctors.
- Heartening hands-on physiotherapy, from the most inspiring Physiotherapists I have ever had the privilege to meet; providing me with a therapeutic consultation for the body- which had been long deprived of any real authentic listening or a genuine caring and healing touch.
- A dedicated Nursing team who compassionately cared for me, while respecting and encouraging my autonomy.
- A Holistic therapist offering a wealth of open-hearted support, advice, intuition, and respite from my pain.
- A Healing Space & Garden to reflect, heal and gently exercise and walk in.
- A safe and welcoming place to meet fellow patients, talk, share and learn from each other.
- Mindful Movement stretching exercises.

- Vital Nutritional information/ education.
- Mindfulness Based Cognitive Therapy (MBCT)
- Wellness Enhancement learning Programme (TheWEL)
- Psychoneuroimmunology (PNI). The joining up of the psychological processes, the nervous system, and the immune system of the human body, and how it all interacts. My Consultant would call this 'sewing the head back on the body.'
- Psychosocial. Just to be aware of how our psychological state and social environment interact with our health and pain.
- Neuroplasticity. How the brains neural pathways were once thought to be rigid, but are in fact malleable. Meaning we have some potential to change our behaviour, thought processes, reduce stress, anxiety, depression, pain using e.g. MBCT, Mindfulness exercises and other Self-Directed exercises.

Before my journey through Integrative care, I could not possibly conceive of how I could ever continue to cope with and live through the relentless cycle of pain. However, through my experience of Integrative care and learning, it quickly became my life-line. It's encouraging and satisfying on so many levels to learn, practise, and grow in confidence and experience change.

Albert Einstein once said, 'Knowledge is experience, everything else is just information.' I consider myself grateful beyond any words, to have been gifted with the most incredibly inspiring and trusted information. What we then do with that information is what is important?

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.

During my initial care at the NHS Centre for Integrative Care, it was both vital and necessary to have had the benefit of a nurse run residential in-patient unit. Otherwise, I wouldn't have had the ability to fully participate in, or take full advantage of my care programme. Equally, I feel it would be beneficial and fundamental for patients to have this kind of facility available in a specialist residential chronic pain service.

The logistics of travel and preparing for travel meant I wouldn't have had the energy or stamina required to go home after treatment at the end of each day, only to return the following day. Therefore the NHS Centre for Integrative Care in-patient residential accommodation was a blessing. This meant only one journey in and one journey home during an inpatient stay.

The facility had close access to the train station and also parking, which was directly outside the building. Again, I feel these would be essential requirements for any patient wishing to travel to a specialist residential chronic pain service.

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)

- Physiotherapy
- Integrative consultations
- Healing space – e.g. residential environment/ garden
- Nutritional information/ education
- Mindfulness Based Cognitive Therapy (MBCT)
- Self-management classes/ programmes such as TheWEL & MBCT i.e. Wellness Enhancement Learning/ Mindfulness Based Cognitive Therapy

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.

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

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.

As previously mentioned in Question 1 – ‘I gained significantly from navigating through part of Scotland’s Pain Services. However, found my north star through an Integrative approach and model of care.’

While attending the Pain Clinic at Glasgow’s Royal Infirmary, I began the colossal rationalizing and restructuring of my psychotropic and pain medication- periodically checking-in with the Consultant Anaesthetist. During this time, I was also attending the NHS Centre for Integrative Care, where I was able to dive into the care and resources that I previously mention in Question 4 – all needed for this challenge.

In managing the major restructuring of my medication, as part of the bigger picture in self-managing my pain, health condition and subsequent depression- I had significant and timely assistance from my Consultant Anaesthetist. This included information on interactions of medication.

As much as it’s virtually impossible to single out any one modality of care that I received. At one particular decisive life-changing stage, while withdrawing from anti-depressant medication (which I’d taken for 14years) and then Pethidine medication (which I’d taken for 4years) – I learned Mindfulness Based Cognitive Therapy (MBCT) and Mindfulness techniques. These modalities turned out to be crucial during this time, and indeed remain so.

During my journey through pain, learning self-care, self-management and pain-management techniques and tools at the NHS Centre for Integrative Care, I was also able to vastly reduce my dependence on NHS services- to the point that my GP is now my sole port-of-call.

This brings me to what I briefly mention in Question 3 – ‘I can see that specific parts of other options in isolation may indeed in themselves offer potential benefits to chronic pain patients.’ I feel it would be extremely beneficial to have available access to ‘skilled chronic pain clinicians’ using e.g. remote ways/ technology etc. to ascertain information and possible assistance- rather than having to re-enter the system as a new referral.

I feel this could be extremely helpful for many pain patients who are self-managing and/or have evolving health conditions; where sensitivities and demands etc. in the whole body can develop through prolonged use of pain medications, and need advice. If I remember correctly Susan Archibald the petitioner who initiated this debate called on the Scottish Parliament to urge the Scottish Government to 'transfer more of the management for chronic pain into primary care.' I signed Susan's petition and feel this could be of tremendous benefit to chronic pain patients.

I hope that in some part, my own experiences as a patient journeying through pain, can be constructive in helping to develop a specialist residential chronic pain service in Scotland. I absolutely believe that there is a realistic and comprehensible vision that a fruitful relationship between Scotland's Pain Services and an Integrative Model of Care, could in fact achieve and deliver the best possible service model and outcome for Scotland's chronic pain patients. I feel this is the time, a golden opportunity, we should not miss out on?