

**PE1577/E**

Petitioner Letter of 2 March 2016

Dear Mr McMahon,

**Response to the Mr Hepburn's Letter dated the 2nd of March 2016.**

I met with Mr Hepburn with Murdo Fraser MSP on the 1st of March 2016 to discuss my petition.

During the discussion I informed Mr Hepburn that I would like the Scottish Government to fund a NHS clinical pathway for adults with Cerebral Palsy. I emphasised that the pilot project run by Bobath Scotland was a little part of the overall care and support of an adult with cerebral palsy needs.

Maintenance physio is paramount for adults with cerebral palsy and the Bobath method of physio is well respected. Bobath Scotland do fantastic work which I have benefited from in the past, however Bobath Scotland is a small charity and my petition is calling for a NHS clinical path way for adults with cerebral palsy. This pathway has to include input from neurology , orthopedics , speech therapy , orthotics, pain management clinicians, physio and occupational therapy. There are other services that may need to be included to be tailored to an individual's needs. It is important that there is a key clinician that coordinates an adults' care and the specialists must have a sound knowledge of cerebral palsy along with the clinicians I've listed. Physios that specialise in cerebral palsy do not exist on the NHS and the wider medical profession need to be educated on cerebral palsy in adulthood. It is a chronic long term condition that deteriorates over time and the medical profession and other agencies need to have a good understanding of this. I discussed the issue of self-management with Mr Hepburn and expressed concern there was that no specialist support available to help me with this.

I am concerned that so far Mr Hepburn appears to have only consulted Bobath Scotland about the issue of adult cerebral palsy services. I would like Mr Hepburn to consult NHS professionals and paediatric services and Capability Scotland about the transition (or lack of it) to adult services. Most of the clinicians I have discussed this with said that there is a huge gap in services for adults with the condition and there is a need for an NHS clinical pathway.

I would like Mr Hepburn to inform me of what an alternative model of care is, as this is unclear from his letter. I stressed that this was a national issue and a NHS clinical pathway needs to be rolled out throughout Scotland in order to avoid a postcode lottery. As I understand the Scottish Government is implementing self-directed support and integrated health and social care boards throughout local authorities in Scotland. Mr Hepburn said that this will have a role to play in providing support for adults with cerebral palsy. I said that I have tried to access self-directed support to fund the specialist physio I need. However, I was denied access to this because it did not fit the criteria for social care. From my perspective SDS does not seem to be working on the ground. At the moment it does not seem to give adult's with cerebral palsy the support they need in order to live an active and health life.

I would like to work with the Strategic Planning and Clinical Priorities team in order to build a national NHS clinical pathway for adults with cerebral palsy. There is still a vast amount of work to be done to achieve this and I still have unanswered questions from Mr Hepburn to resolve. I would like to ask the Committee to take this into consideration and ask that the Committee include my petition in the legacy paper.

Yours sincerely,

Rachael Wallace