

PE1577/H

Petitioner Letter of 2 December 2016

I would like to reiterate that my petition is calling for a clinical pathway for adults with cerebral palsy on the NHS. This would include support from a multi discipline team of Allied Healthcare Professionals such as physio therapists that specialise in cerebral palsy in adulthood. It would also include support from orthotics , orthopaedics consultants and neurologists. As it stands I have to navigate myself through a piecemeal system to find appropriate support. Furthermore, I pay privately to see a paediatric physio to help me manage the effects of cerebral palsy and secondary aging. There is no specialist services provided on the NHS for adults with cerebral Palsy. On a daily basis I have to cope with chronic pain from muscle spasms and take multiple medications to control my pain.

I was very disappointed with the Scottish Governments response dated the 11th of November 2016. The Bobath Pilot Project is only covering one local authority and health board area. It is not Scotland wide. Bobath Scotland are a private charity and are not part of the NHS. Whilst they have specialist knowledge of cerebral palsy, one small charity alone cannot solve the gap in NHS services for adults with cerebral palsy. This is why it is important to consult a wide range of medical professionals and stakeholders and not just one charity who only specialises in one part of the treatment of cerebral palsy. I would have thought that an obvious step to take would be to consult with the wide range of paediatric NHS experts and adults who have Cerebral Palsy as to the best transition and provision for a person with CP. The Scottish Government takes a very narrow view on the treatment and care of adults with cerebral palsy. Furthermore, the Scottish Government makes no commitment to create a clinical pathway and provide specialist services for adults with cerebral palsy. I feel that no progress has been made by the Scottish Government and they are giving the same responses to my petition every time I make a submission . The key questions from my last submission have not been answered.

I have emailed both the Clinical Priorities Team and the Minister for Health and Sport to request a meeting to discuss the important issues raised in my petition. I await their replies.