

**PE1577/F**

Petitioner Letter of 19 September 2016

**Re: Petition PE1577 – Adult Cerebral Palsy Services**

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

During this meeting with the minister I stressed that a NHS clinical pathway is needed for adult's with Cerebral Palsy. Currently, there is not a clinical pathway and an adult with cerebral palsy has to navigate a piecemeal system to access services. There is no dedicated health professional that specialises in cerebral palsy in adulthood in the NHS. There is no coordinated clinical pathway as there is with other neurological conditions. I have to coordinate my own care and support.

The medical profession does not recognise cerebral palsy as a complex chronic condition. Although the brain damage caused a birth does not progress, adults with cerebral palsy deteriorate over time because of secondary ageing. It is not a static condition and adults can see a marked deterioration in their mobility and health as they age with cerebral palsy.

I suffer from pain caused by severe spasms and muscle stiffness and I take powerful medication to try and control my pain. When I was a child I received specialist physio therapy and hydro therapy to manage my condition. As an adult I have found that there are no specialist physios working in the management of cerebral palsy in adults on the NHS. Any benefits from therapies received as a child have been wasted through lack of provision.

Maintenance physio therapy is essential in managing adult cerebral palsy and can minimise pain and discomfort whilst maintaining an adult's mobility and function. However, the therapists must have a specialist knowledge of cerebral palsy. This is essential because therapists without this knowledge can do more harm than good. It is important to establish a pathway that provides specialist support from occupational therapists, speech and language therapists , orthotics and orthopaedics. The pathway should also include input from clinicians that can manage muscle tone, pain and spasticity.

I am concerned that the Scottish Government has been solely focusing on the Bobath Pilot Scheme that they provided funding of thirty thousand pounds. Firstly, this level of funding is a drop in the ocean when it comes to combating this problem. Secondly, whilst Bobath do fantastic work, they are a small private charity and are not part of the NHS. I am petitioning for a national clinical pathway for adults with Cerebral Palsy on the NHS. I am also concerned that the Scottish Government has only consulted with Bobath Scotland on this issue and not conducted a wider consultation with NHS Professionals and other agencies.

As of yet I have had no further letters from the Scottish Government or from the clinical priorities team. Although, I know that parliament has been in recess and there was a Scottish Parliament election in May. However, there is still a lot of progress to

be made. I would like to meet with the new minister for health to discuss the way forward. Furthermore, I would like to meet with the clinical priorities team in order to progress the issues raised in the petition. I would like the committee to assist me in any way they can to improve the lives of fifteen thousand people living with cerebral palsy in Scotland.

Yours sincerely,

Rachael Wallace