

PE01577/I

Petitioner Letter of 9 March 2017

I have had a meeting with the Clinical Priorities Team on the 30th of January 2017. We discussed my experiences of the problems I and many others with cerebral palsy face when trying to access support and care on the NHS. I also discussed the issue of establishing a clinical pathway for adults with cerebral palsy so that each health board in Scotland can provide continuity of care and specialists that have expert knowledge of cerebral palsy in adulthood.

The feedback from the Clinical Priorities team was positive and there is work being done at a local level through the Bobath Scotland Pilot scheme and other neurological condition frameworks and national neurological committees.

It is good to see that work is being done however I still have concerns.

In the meeting, it was discussed that it may take 10 years to develop a clinical pathway and framework for adults with cerebral palsy. This is too long.

I am concerned that cerebral palsy may be merged into a framework /pathway with other neurological conditions. This concerns me because cerebral palsy is a complex condition which is unique and while it shares similarities with other neurological conditions, cerebral palsy requires its own specialist physio's and consultants. This is evident from the fact that cerebral palsy does not fit into any current neurological framework or adult service.

In addition, it was discussed whether the lack of adult services for cerebral palsy was a local health board issue rather than a national issue. I have presented submissions in the past that prove that this is a national issue that affects approximately 15,000 people in Scotland living with cerebral palsy. There has also been evidence submitted by Bobath Scotland and Capability Scotland that supports this argument.

On Tuesday the 7th of March 2017, I met with Aileen Campbell, Minister for Public Health and Sport. The meeting was positive and I felt Ms Campbell listened and was interested to hear what I had to say. We discussed my personal experiences and how we could move forward on this issue.

The main points from this meeting was that:

1. There is a lack of specialist staff such as physio's for adults with cerebral palsy. The minister stated that she would need to look at workforce planning.
2. There is no continuity of care for adults with cerebral palsy and there needs to be leadership at a national level and local health board level to solve this.
3. There is a problem with the way self directed support guidance is interpreted at a local level. Local Authorities will not let SDS be used to pay for specialist physio or treatment. The minister confirmed that SDS could be used for this purpose and is going to look into this matter. This would not solve the problems raised in the petition but it is a tool that could be used to help.

4. We discussed raising the profile of cerebral palsy within the medical profession so that clinicians understand that cerebral palsy is a chronic lifelong condition that needs specialist support.
5. I said that I would be very happy to work with the minister and her team in order to solve the problems raised in my petition. The minister agreed that she would be happy to work with me. The minister stated that some areas such as workforce planning will take time, however, the solutions to the problems raised in my petition had to be implemented in a time frame that was agreeable with me.

Although this was a successful meeting there are no firm commitments in writing or on public record about what action the minister will take. I am asking the Public Petition's Committee to ensure that this happens and clarify the next steps with the minister in order to move forward.

Yours sincerely,
Rachael Wallace