

PE1577/Q

Petitioner submission of 2 September 2019

Thank you for reconsidering my petition. Since it was last considered I have been on Health Improvement Scotland's Neurological Standards Development Committee. I found this a positive experience and it enabled me to work with clinicians to update the 2009 Neurological Standards. This also enabled me to raise awareness of Cerebral Palsy and contribute to the standards which influence neurological care in Scotland. However, these standards govern the standard of care for all neurological conditions and the standards are not mandatory or enforceable. The standards are aspirational and demonstrate best practice. I am not sure how far these standards will go to help adults with Cerebral Palsy. The standards are a good starting point for highlighting issues that people with neurological conditions face but does not solve the problems raised in my petition.

Unfortunately, in May 2019, while I was an inpatient in Ninewells hospital, I sustained two fractures to my ankle. This was due to poor maintenance and equipment failure. The official investigation highlighted failing on the part of NHS Tayside. I am bringing this to your attention because it highlights the issues raised in my petition. Firstly, the orthopaedic consultants at Ninewells had no understanding of Cerebral Palsy and said I would be able to be discharged within a few days when I was bedbound and needed 24-hour care and pain relief. Secondly, there was no clear pathway to a rehabilitation bed within Tayside due to my age and my condition. I received inadequate physio from a physio therapist who specialised in medicine and had no experience of working with adults with cerebral palsy. This slowed down my rehabilitation and it was only when I desperately contacted my own orthopaedic surgeon and asked him to take over my care that the situation improved. I was transferred to Perth Royal Infirmary and the care I received there was excellent. I received intensive rehabilitation from a multi- disciplinary team and over the week I was there they helped me to build my confidence and made sure I was safe to go home. If it had not been for my surgeon, then I would not have received the care I did. This situation highlights that there is a lack of understanding of cerebral palsy amongst clinicians within the NHS. There is no clear pathway to access physio therapy and other specialist services needed by adults with cerebral palsy.

I am due to meet with representatives from the Scottish Government to discuss these issues. However, there has not be any action on the part of the Scottish Government when it comes to providing NHS services for adults with cerebral palsy. They have not resolved any of the issues that I have raised in this petition and have not given me what I am calling for. I ask the petitions committee for their support and help to move this forward.