



PUBLIC PETITION NO.

PE01577

Name of petitioner

Rachael Wallace

Petition title

Adult Cerebral Palsy Services

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to develop and provide funding for a clinical pathway and services for adults with cerebral palsy.

Action taken to resolve issues of concern before submitting the petition

I have been in contact with Murdo Fraser MSP and he has written to the Scottish Government on my behalf. Mr Fraser has requested a meeting with the Minister for Sport, Health Improvement and Mental Health. A meeting has not as yet been arranged. In addition, Mr Fraser has submitted 2 written parliamentary questions. The responses I received from the Minister on the issues of providing a clinical pathway and services was inaccurate and unsatisfactory.

In addition, Mr Fraser has asked a question in the Chamber at general questions on the 18th of June 2015 - To ask the Scottish Government what action it is taking to improve care services for adults with cerebral palsy. (S4O-04479). The Minister's reply was inadequate.

Furthermore, I run an online support group called "Living Positively with Cerebral Palsy". This allows people with cerebral palsy to share their experiences of living with cerebral palsy. The message from my website is that there is not a national clinical pathway or therapy for adults with cerebral palsy.

Also, I have been working closely with Bobath Scotland to raise awareness of cerebral palsy and lobby for a clinical pathway and therapy services for adults.

Petition background information

Cerebral Palsy is not a local Health board issue - it is a national issue. According to figures from Bobath Scotland, approximately 15,000 adults have Cerebral Palsy (CP) in Scotland. Paediatric services are well established with input from multidisciplinary teams such as specialist physiotherapy, occupational therapy, speech and language therapy, orthotics, neurology and regular orthopaedic reviews. When a person with CP leaves school all these services stop, however that person still has complex needs CP is not a static condition, all the beneficial therapies they received as a child are to maintain health, mobility and quality of life.

As an adult with CP, I have to pay for private physiotherapy from a paediatric physiotherapist as there are no adult Allied Healthcare Professionals who are trained to work with adults with Cerebral Palsy in the NHS. There is no coordinated clinical pathway which results in the patient having to self manage their own condition. You are relying on the good will of health professionals, who on top of their own workload, are willing to take an interest in someone with Cerebral Palsy. Medication that I was put on in my teens was not reviewed until my early twenties by a brain injury specialist who was eventually found via several emails to Neurology by paediatric services.

Cerebral Palsy does not fit into the National Neurological Advisory Group as there is not a clinical pathway, as there is with MS, Parkinsons and Epilepsy. Therefore adults with CP are unable to access high quality healthcare services that are safe, effective and put the patient at the centre of their care.

Although CP is not considered to be a progressive condition, studies by SCOPE (Cerebral Palsy and Ageing) and Bobath Scotland would suggest otherwise. Evidence from the SCOPE website:

<http://www.scope.org.uk/Support/Parents-and-Carers/Landing/Cerebral-palsy/Ageing>

Common problems reported by people with CP as they get older:

- Increased pain and discomfort especially in the joints resulting in less flexibility.
- Increased spasms
- Increased contractures (shortening of muscles especially in limbs which can result in limbs remaining in a fixed position).
- Digestive difficulties
- Emergence or increase in incontinence
- Fatigue – many individuals with CP use 3 to 5 times the amount of energy that non-disabled people use when they move and walk.
- Weight gain or loss
- Many adults with CP will experience post-impairment syndrome – a combination of pain, fatigue and weakness to muscles and bone deformities often caused by repetitive motion.

Sometimes the effects of ageing can be heightened due to inadequate rehabilitation following surgery or even the constant use of equipment. For example, poor wheelchair seating and support can affect posture causing pain, discomfort and sometimes loss of function in limbs.

Cerebral palsy in adulthood should receive the same status as other neurological conditions such as MS. An adult with CP should receive regular care and physiotherapy from a multidiscipline team of Allied Health Professionals who specialise in cerebral palsy. It would be essential to create a clear clinical pathway for adults that GP's can refer to. In the future, I would like to see a specialist consultant albeit a doctor, physiotherapist or neurological specialist who is the key person who coordinates therapies and care for adults with cerebral palsy. I would like to see this be rolled out across all health boards across Scotland.

Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/adultcerebralpalsyservices>

Related information for petition

Do you wish your petition to be hosted on the Parliament's website to collect signatures online?

NO

How many signatures have you collected so far?

1

Closing date for collecting signatures online

N/A

Comments to stimulate online discussion