

Briefing for the Public Petitions Committee

Petition Number: [PE01577](#)

Main Petitioner: Rachael Wallace

Subject: Adult Cerebral Palsy Services

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

Cerebral palsy

[Cerebral palsy](#) is the general term for a number of neurological conditions that affect movement and co-ordination. [Neurological conditions](#) are caused by problems in the brain and nervous system. Cerebral palsy is caused by a [problem](#) in the parts of the brain responsible for controlling muscles. The [condition](#) can occur if the brain develops abnormally or is damaged before, during or shortly after birth. It is estimated that [1 in 400 children](#) in the UK is affected by cerebral palsy. Cerebral palsy in adults is used to describe a variety of chronic movement disorders affecting body and muscle coordination, caused by damage to one or more areas of the brain that occurred around the time of birth or if the brain developed abnormally. There are no accurate figures available for the number of people with cerebral palsy in Scotland, but figures are emerging from the work of some research groups such as Bobath Scotland¹. The [estimates](#) are that approximately 15,000 adults have cerebral palsy in Scotland. People with cerebral palsy are now [living much longer](#) than they did in the past. In the past few people with cerebral palsy survived to adulthood, now 65% to 90% of children with cerebral palsy [survive](#) and have a normal life expectancy.

Symptoms of cerebral palsy

The [symptoms](#) of cerebral palsy normally become apparent during the first three years of a child's life. Cerebral palsy is a condition in which impairment or damage to the immature brain causes physical impairments to muscles and motor control. This leads to an [inability to control muscles, movements and posture](#). The [main symptoms](#) include muscle stiffness or floppiness, muscle weakness, random and uncontrolled body movements and balance

¹ Bobath Scotland is a Scottish charity which exists to improve the quality of life for people with cerebral palsy

and co-ordination problems. Many people with cerebral palsy also have a number of [associated problems](#), including repeated seizures or fits, drooling problems and swallowing difficulties. Some people with the condition may have communication and learning difficulties, although intelligence is often unaffected.

The symptoms of cerebral palsy [differ in severity from person to person](#). Some people will only have mild problems, while others will be severely disabled. The areas affected by cerebral palsy can also vary. Some cases only affect one side of the body, some affect primarily the legs and some affect both the arms and legs.

Ageing and cerebral palsy

Cerebral palsy is not a [progressive](#) condition in the sense that the original problem in the brain does not worsen with age, and life expectancy is usually unaffected. However, according to [Capability Scotland](#), many people, including some health professionals, think that because cerebral palsy is a “non-progressive disorder”, physical function will remain much the same throughout life i.e. it is regarded as a static condition. However [studies](#) by SCOPE² and Bobath Scotland would suggest otherwise. Research undertaken by the [University of Glasgow](#) on the experiences and perception of older people with cerebral palsy found that as people age their condition and the extent of their impairment changes. For example they could experience a change in what they can and cannot do.

As people get older their physical abilities decline (primary ageing). However, people with a physical impairment like cerebral palsy can experience the effects of [ageing earlier](#) as a consequence of their condition (secondary ageing).

The [physical and emotional strain](#) of living with a long-term condition such as cerebral palsy can put a great deal of stress on the body, which can cause further problems in later life. Many adults with cerebral palsy develop further [physical problems](#) (such as osteoarthritis) as a result of their condition, which can cause pain, fatigue and weakness. The daily challenges of living with cerebral palsy can be difficult to cope with emotionally, and adults with the condition are at an increased risk of developing [depression](#). However it varies from person to person with some people losing no more function than might be expected from the normal ageing process and others losing more function than expected.

The [research](#) by the University of Glasgow found that people, including health and social care staff, can be unprepared for the secondary effects of ageing with cerebral palsy and there is a general lack of knowledge about the process. For example Bobath Scotland and Capability Scotland believe that [some medical professionals are unaware](#) of the impact of cerebral palsy on ageing. However the [research](#) by the University of Glasgow found that some

² SCOPE is an English charity for disabled people

medical and health professionals did recognise that there were issues particular to adults with cerebral palsy. There seems to be a mixed picture of the knowledge and understanding, which health and social care professionals have with regards to ageing and cerebral palsy.

Treatments for cerebral palsy

There is no cure for cerebral palsy. However, there are numerous treatments available, which can treat many of its symptoms and help people with the condition to be as independent as possible. These [treatments](#) include physiotherapy, occupational therapy and medication to relieve muscle stiffness and spasms. In some cases, surgery may also be needed.

Services

[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 for children with cerebral palsy. As some health and social care professionals still regard cerebral palsy as a static condition [research](#) by Bobath Scotland and Capability Scotland found services often stop or are reduced when a person with cerebral palsy leaves school or reaches adulthood. This is because these professionals feel that the support or services are no longer required, but that person still has complex changeable needs and still has care requirements. For example as part of the [evaluation](#)³ of Bobath Scotland's Adult Therapy Pilot Project eight individuals taking part in the pilot project were recruited and interviewed for the evaluation. A number of these participants and their families highlighted that individuals with cerebral palsy:

[“ ‘dropped off’ the radar of mainstream services when they reached adulthood.”](#)

The majority of participants also reported an absence of support from mainstream health and social care providers in relation to new musculoskeletal problems. This was the view of a small number of people so it is not clear how representative this is of all adults with cerebral palsy in Scotland. However [research](#) by the University of Glasgow also found that there are very few health and social care support services available to people ageing with cerebral palsy and there are few services if any dedicated solely to their needs. The research also highlighted that it was “a bit like roulette” about the sort of services adults with cerebral palsy received. Other [anecdotal evidence](#) from people with cerebral palsy point to the fact there is no national clinical pathway or therapy for adults with cerebral palsy.

³ In 2012 Robertson Trust funding enabled Bobath Scotland to pilot an adult therapy service. Bobath Scotland and Capability Scotland individually commissioned the Strathclyde Centre for Disability Research at the University of Glasgow to undertake an evaluation of Bobath Scotland's Adult Therapy Pilot Project.

Some local authorities and health boards feel that there is no need for a separate pathway for adults with cerebral palsy and that the existing policy and provision is adequate for adults with cerebral palsy. This was based on [research](#) undertaken as part of the evaluation of Bobath Scotland's pilot adult therapy service. The research included interviews with a small number of health and social care practitioners (e.g. physiotherapists, local authority representatives and consultant adult neurologists across Scotland). This is similar to the response by the Scottish Government to the Parliamentary questions on adults with cerebral palsy, which are discussed in the section below. However in the [research](#) undertaken by the University of Glasgow some health professionals, i.e. rehabilitation consultants, recognised the need for specialist services focusing on the needs of people ageing with cerebral palsy. (Note that this was not the view of all the health and social care professionals interviewed).

Scottish Government Action

Scottish Government's current approach to services for adults with cerebral palsy is through general health and social care provision, which can be delivered by both health boards and/or local authorities. Access to care services for adults with cerebral palsy is based on an individual assessment of need. For example care services fall within core local authority social work service functions, which are generally supported by the Scottish Government. Physiotherapy services, which come under the remit of health boards, can also offer assessment and advice, which may be followed with treatment and/or equipment provision. The Scottish Government feels that it is for health boards to determine the level of service that they provide based on local priorities and need. The Scottish Government also feels that personalised and integrated services for adults who have cerebral palsy will be strengthened further with the implementation of the Social Care (Self-directed Support) (Scotland) Act 2013 and the Public Bodies (Joint Working) (Scotland) Act 2014. ([PQ S4O-04479](#), and was also discussed in Chamber, [Official Report, PQ S4W-23408](#)).

The Scottish Government also funds the [National Neurological Advisory Group \(NNAG\)](#), whose aim is to improve the patient journey from the point of referral into the service and to ensure that every patient with a neurological disorder such as cerebral palsy experiences a quality of care that gives confidence to the patient, clinician and carer. The NNAG is a collaborative group working with stakeholders to ensure better outcomes for people living with neurological conditions, throughout Scotland. The NNAG is currently looking at pathways across neurological conditions with a view to publishing a library of good practice pathways that can be adapted to meet the needs of individual boards. ([PQ S4W-23409](#)).

Scottish Parliament Action

The Scottish Parliament has not addressed this specific issue in the past. There have been some Parliamentary Questions on Bobath Scotland, (PQ [S4W-25951](#), PQ [S4M-09412](#), PQ [S4W-18114](#), PQ [S4M-04624](#)), but it has not specifically been on adults with cerebral palsy. The health committee has not done anything on this subject.

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16 October 2015

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