



Information for parents

CPUP – A preventive follow-up programme for children with cerebral palsy or suspected cerebral palsy.

Cerebral Palsy (CP) is the term used for the physical disorder caused by brain injury or dysfunction occurring before the age of two. There are many different causes of cerebral palsy and the degree of functional impairment varies in each child from nearly normal function, to pronounced functional impairment.

Children with cerebral palsy often have increased tone (spasticity) in certain muscles while other muscles may be weakened. There is often an imbalance between muscles that stretch and bend around the joint. This can lead to the shortening of muscles ie muscle contractures. In some children, the imbalance in the hip joint can lead to pulling of the head of the thigh bone out of its position in the hip joint leading to hip dislocation. Imbalance in the back, can lead to a crooked spine or scoliosis. Today, there are many different treatment methods to decrease spasticity and to prevent contractures and hip dislocation. However, it is very important that preventive measures are taken at an early stage in order to achieve the best possible effect.

For several years, the Orthopaedic Departments and the Habilitation Centres for Children and Youths in Sweden have collaborated on a collective follow-up programme for children with Cerebral Palsy or suspected Cerebral Palsy. In 2005, the programme was designated a National Quality Registry by The National Board of Health and Welfare, and now the entire country is participating in the CPUP programme.

The purpose of CPUP is to ensure that children, with risk of developing significant contractures or hip dislocation are detected early and receive treatment as early as possible. The goal is that no child should be affected by severe contractures or hip dislocation and that every child should achieve the best function possible.

The follow-up within CPUP involves the child's physiotherapist and occupational therapist, who will make an assessment of the child's muscle tone, joint motion ability and function twice a year until the child is aged six. After that, an annual assessment is made until the child reaches adulthood. Current treatment is also noted. Functions affecting the child's motor ability are also assessed by a paediatrician after the age of four, which is when a CP diagnosis usually can be established or dismissed.

The child's hip and spine are also regularly examined radiographically. The frequency of radiographic examination is determined by the orthopaedic surgeon making an assessment of the current and previous radiographs and the physiotherapist's report. The general recommendation is that a radiographic examination of the hips is taken annually from the age of two and a spinal radiograph is taken on older children and youths developing clinical scoliosis.

Following the instigation of The CPUP Programme, the number of hip dislocations has significantly decreased. Significantly fewer children have developed contractures and scoliosis through participation in the programme. There has also been a decrease in the number of orthopaedic operations performed on contractures and the co-operation between the different specialists involved in the care of children with cerebral palsy has improved.

All the information from the CPUP assessments is stored in a database. The child's habilitation team and doctor are able to get a CPUP report, showing the child's development over time and give warning signals for need for intervention. This is fundamental in order to initiate the right treatment at the right time for each individual child.

The database adheres to the Secrecy Act Regulations of The National Board of Health & Welfare and also to the regulations of The Swedish Data Inspection Board. This means that a single child will never be identified when experiences from this follow-up programme are compiled into general reports. By studying and carrying out research on the information available in the CPUP database, we can improve our knowledge regarding changes over time in different types of cerebral palsy. Moreover the different treatments can be compared as to how they affect final outcome.

Participation in CPUP is entirely on a voluntary basis and can, at any time, be discontinued.

For more information regarding CPUP please see www.cpunp.se
More information on National Quality Registry please see www.kvalitetsregister.se

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