



Information for parents

CPUP – Preventive follow-up programme for children with cerebral palsy or similar symptoms

Cerebral palsy (CP) is the collective name for motor impairments caused by brain injury or dysfunction occurring prior to the age of two years. There are many different causes of CP and the degree of functional impairment varies. There are children with almost normal function and children with severe functional impairment.

Children with cerebral palsy often exhibit increased tone (spasticity) in certain muscles, while other muscles can be weak. Lack of balance between flexor muscles, which bend joints in arms and legs, and extensors, which stretch them, can lead to a shortening of muscles, which in turn causes stiffness of the joints (contractures). In some children, the imbalance in the hip joint can cause dislocation of the hip. Unbalanced muscles in the back can cause sideways curvature of the spine (scoliosis). There are currently several different methods of treatments that reduce spasticity and prevent contractures and hip displacement, but it is crucial to start this treatment early on.

For several years, the Orthopaedic Departments and the Habilitation Centers for Children and Youths in Sweden have been cooperating in a joint follow-up programme for children with cerebral palsy or similar symptoms, known as CPUP. In addition, beginning 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 intent and purpose of CPUP

The CPUP follow-up programme is intended to ensure that children who risk developing contracture or dislocation of the hip are identified and receive treatment at an early stage. The goal of CPUP is to ensure that no child should suffer from severe contractures or hip displacement, and that every child should achieve the highest possible functioning level he or she is capable of.

How does the monitoring work?

CPUP monitoring works by the person's rehabilitation team examining and reporting motor ability and function on a regular basis according to a programme adapted to the age and motor ability of each person. In cases of impaired motor ability, monitoring is offered early on, often before the child has even been diagnosed with CP. At four years of age, a paediatrician determines whether or not a child has CP, or whether there are other functional impairments and illnesses. The physiotherapist, the occupational therapist and the speech and language therapist examine and monitor motor ability, hand function, communication, the ability to eat and swallow and ongoing treatment once or twice a year until the age of six. After this, the examinations generally take place every year or every other year, with sometime less frequency once adulthood has been reached.

At the initiative of the Swedish National Association for Disabled Children and Young People (RBU) and CP Norden (Federation of CP Associations in the Nordic Countries), psychological assessments and reporting of cognitive functions are included in CPUP, and are recommended before the start of school and at about 12 years of age.

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 recommen-

dition 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.

CPUP prevents exacerbation and improves treatment

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.

The CPUP programme enables a child's rehabilitation team and treating physicians to follow that child's individual development and identify any warning signals for need for intervention. This is fundamental in order to initiate the right treatment at the right time for each individual child.

All children are welcome to take part in the CPUP programme, and also are entitled to end their participation at any time.

Unless expressly requested otherwise, all information regarding the treatment, functional ability and results of radiographic examinations of each child in CPUP are recorded and kept in a National Quality Register. Gathering all the information about children with cerebral palsy in a National Quality Register database increases the chances of improving and safeguarding the quality of treatment as large quantities of data can be compiled and evaluated. The information compiled also contributes to new knowledge on how best to treat the problems related to cerebral palsy, thanks to a comprehensive view of treatment methods throughout the country. This knowledge is used to improve the care and treatment of children with cerebral palsy.

Registering the information in the Quality Register database makes it easier for the treatment team to monitor the development and treatment of each child. In addition, if a child moves to another care provider, the treatment can be monitored by simply transferring the information to the new team, provided no request to stop registration is made in conjunction with the move.

The database for the National Quality Register is subject to the confidentiality provisions of the Healthcare System, and the rules of the Swedish Data Protection Authority. This means that individual children will not be able to be identified when the information has been compiled in general reports.

Every person has the right to prevent his or her information from being registered in the National Quality Register but this will not affect their treatment monitoring according to the CPUP programme. You also have the right to have your information removed from the register (see annexed pages).

You can find additional information about CPUP on the annexed pages at on the CPUP website, www.CPUP.se

You can find additional information about the National Quality Register at www.kvalitetsregister.se

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Additional information about the CPUP National Quality Register

Processing of information in CPUP

The handling of personal data as part of CPUP is governed by the General Data Protection Regulation (GDPR) and Chapter 6 of the Patient Data Act (PDL). The information in the CPUP Quality Register may be used only to improve and safeguard the quality of treatments of problems related to cerebral palsy, produce statistics and for healthcare research. After a secrecy determination, this information can be released to a party who will be using this information for any of these three purposes. When data are compiled, no national registration number or names are included. In other words, the presentation of data is anonymous. If information is allowed to be released from CPUP, this can be done electronically. You can contact a data protection officer with any questions you may have about your rights.

If you do not wish to participate in CPUP, no information about you will be entered in the register.

The central data controller responsible for the handling of information about you and is compiled for CPUP is the Regional Executive Committee for Region Skåne.

The data protection officer at Region Skåne can be reached at the following address: **Data protection officer**, Region Skåne, 291 89 Kristianstad. Telephone: 044-309 30 00. E-post: region@skane.se

The register depository officer is Gunnar Hägglund, Orthopaedic Department, Skåne University Hospital, 221 85 Lund:E-post: gunnar.hagglund@med.lu.se

Confidentiality

Personal information is protected by the healthcare confidentiality provisions of the Public Access and Secrecy Act. This means, as a general rule, that information may be released from the CPUP Register only if it is clear that neither the person in question nor any person in a close relationship with him or her would suffer from the release of that information.

Security

Each person's information in the CPUP Register is protected from access by unauthorized persons. There are special requirements relating to security, that mean, for example, that only a person who has a need for that information for the improvement and quality assurance of the care and treatment may access the information, that a check should be made that no unauthorized person may access the information, that the information must be protected by encryption, and that any log-in that allows access to the information may only be done in a secure manner.

Access

County Council employees who report to CPUP have direct access to the information they reported to the CPUP register. No other care provider has direct access to this information. As the person responsible for the register, the register depository officer can access the information.

Sorting out information

Pursuant to a decision of the archive authority of Region Skåne, the information will be saved, for the present, for historical, statistical and scientific purposes.

Your rights

- Participation is voluntary. You are entitled to refuse to have information about you entered in the Quality Register.

- You are entitled, at any time whatsoever, to have information about you deleted from the Quality Register.
- You are entitled to find out what information about you is contained in the Quality Register, and in that case, to obtain a copy of this information, known as an abstract of a register entry, free of charge. You are also entitled to receive the information in electronic form.
- You are entitled to have any incorrect information about you corrected. You are entitled to have any incomplete information supplemented.
- Under certain circumstances, you are entitled to request that the processing of information about you be restricted. This applies to periods during which other objections are being considered. A restriction means that the Quality Register is not allowed to do anything with the information about you other than to continue to keep it on file.
- You are entitled to obtain information as to which healthcare units have had access to information about you and when. This is called a log abstract.
- You are entitled to receive damages if information about you is handled in violation of the General Data Protection Regulation or the Patient Data Act.
- You are entitled to submit a complaint to the Integrity Protection Authority, which is the supervisory authority for this area.

If you want additional information about the CPUP, please contact:

Register depository officer Gunnar Hägglund

CPUP

Remissgatan 4, Wigerthuset

221 85 Lund

If you wish to obtain a register abstract, please send your request in writing to:

Register depository officer Gunnar Hägglund

CPUP

Remissgatan 4, Wigerthuset

221 85 Lund

Indicate the name of the register and the healthcare unit where the information was gathered.
The application must be signed personally by the child's custodian.

If you wish to have your child's information deleted, please contact:

Register depository officer Gunnar Hägglund

CPUP

Remissgatan 4, Wigerthuset

221 85 Lund

Indicate the name of the register and the healthcare unit where the information was gathered.
The application must be signed personally by the child's custodian.

If you wish to obtain information regarding who has accessed your child's information, please send your request to:

Register depository officer Gunnar Hägglund

CPUP

Remissgatan 4, Wigerthuset

221 85 Lund

Indicate the name of the register and the healthcare unit where the information was gathered.
The application must be signed personally.

Information om CPUP – National monitoring programme for persons with cerebral palsy (CP)

As an adult with CP, you run the risk of pain and greater difficulty in moving around as you get older. This can be the result of increasing weakness, hip problems (e.g. hip displacement), stiff joints (contractures) or increasing curvature of the spine (scoliosis). The earlier we discover an exacerbation, the easier it is to prevent it from getting worse. That's the reason we are now offering you, as an adult, the opportunity to take part in the CPUP monitoring programme.

The intent and purpose of CPUP

The CPUP monitoring programme is intended to ensure that persons who risk developing contracture or dislocation of the hip are identified and receive treatment at an early stage. The goal is to ensure that no one should suffer stiffness, pain or hip displacement and that every person should achieve the highest possible functioning level he or she is capable of.

How does the monitoring work?

For the past several years, all the children and adolescents in Sweden who have cerebral palsy have been offered regularly scheduled monitoring as part of the CRUP programme. This programme is now also being offered to adults with cerebral palsy. In general, monitoring of adults are not needed as often as in one's youth. You have the right to terminate your participation at any time whatsoever.

The mobility of the various joints of the body is measured by a physiotherapist or occupational therapist at the examination. Your muscle tension, flexibility and function are assessed. You will be asked questions about your everyday functioning, whether you experience pain, fatigue or other difficulties. The treatment you are receiving will be described. The results of these tests will be compared to previous examinations in order to see whether anything has changed. A determination will be made as to whether your treatment needs to be changed in order to improve your flexibility or to prevent exacerbation.

Those persons who are at risk of developing scoliosis or hip displacement are given an x-ray examination. The orthopaedist, after having read the information from the examination and viewing previous x-ray images, decides whether an x-ray examination is needed.

CPUP prevents exacerbation and improves care and treatment

Hip dislocations have been prevented in almost all the children and adolescents who have participated in the monitoring programme. Significantly fewer persons have developed contractures and scoliosis. There has consequently been a reduced number of contracture operations.

Unless expressly requested otherwise, all information regarding the treatment, functional ability and x-ray results of each person participating in the CPUP are recorded and kept in a National Quality Register. Gathering all the information about persons with cerebral palsy in a National Quality Register database increases the chances of improving and safeguarding the quality of treatment as large quantities of data can be compiled and evaluated. The information that has been compiled also contributes to new knowledge on how best to treat the problems related to cerebral palsy, thanks to a comprehensive view of treatment methods throughout the country. This knowledge is used to improve the care and treatment of persons with cerebral palsy. The more people who take part in CPUP, the more reliable the results will be.

Registering the information in the Quality Register database makes it easier for the treatment team to monitor the development and treatment of each person. In addition, if a person moves to another care provider, the treatment can be monitored by simply transferring the information to the new team, provided no request to stop registration is made in conjunction with the move.

The database for the National Quality Register is subject to the confidentiality provisions of the Healthcare System, and the rules of the Swedish Data Protection Authority. This means that individuals will not be able to be identified when the information has been compiled in general reports.

Every person has the right to stop his or her information from being registered in the National Quality Register with this affecting their treatment monitoring according to the CPUP programme. You also have the right to have your information removed from the register (see annexed pages).

What benefits do you derive from CPUP?

You receive preventive monitoring of your ability to move, in order to preserve this ability as well as possible, instead of seeking help after the exacerbation has already taken place. At the latter point, it is often much more difficult to do anything about it. The monitoring is a preventive examination. It is similar to going for regular dental examination where small cavities are discovered and treated long before the need for a root filling or the extraction of a tooth is required.

You can find additional information about CPUP on the annexed pages at on the CPUP website, www.CPUP.se

You can find additional information about the National Quality Register at www.kvalitetsregister.se