

Information for parents

What is 'CPIP'?

CPIP is a follow-up programme for children with **cerebral palsy or suspected cerebral palsy**, allowing early detection of changes in muscles and joints with the option of earlier treatment for your child. This may help prevent problems developing in the future.

What is 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. Spasticity is a condition in which muscles stiffen or tighten, preventing normal fluid movement.

This can interfere with children's ability to move and to learn to walk. Spasticity can also cause pain, and, over time, shortening of muscles and tendons. When joints do not move normally they become permanently stiff because the soft tissues tighten around them (known as a contracture).

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 curved spine or scoliosis. There are many different treatment methods to decrease spasticity and to prevent contractures and hip dislocation.

These may include exercise or stretching and positioning programmes from your physiotherapist, the use of splints during the day or at night or drug treatments to reduce the tightness in muscles.

This does not describe all the treatments available.

It is very important that the right treatments are available at an early stage to help prevent problems developing in order to achieve the best possible outcome.

What is the purpose of CPIP?

The purpose of CPIP is to ensure that children with risk of developing contractures or hip dislocation are detected early to enable timely intervention can be made by medical professionals.

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.

What happens during CPIP?

Research has shown that x-rays of the hip taken at the right time can help us to spot this problem earlier – and take steps to reduce the chance of it getting worse.

The follow-up within CPIP involves the child's physiotherapist 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. These assessments help the physiotherapist decide how often your child needs to be seen for treatment and what treatment options are best for your child. Regular assessment and early treatment combine to improve outcomes.

X-rays

Children with CP should have an x-ray at 2 years of age. If your child is mildly affected you can expect one further x-ray at 6 years of age. For those more severely affected there will be annual x-rays until age 8 years of age and then every other year.

This is because there is a greater risk of dislocation in more severe cases. All children will be invited for a final x-ray at age 16.

How successful is CPIP?

Children treated under a similar programme in Sweden experienced significantly fewer hip dislocations. Significantly fewer children from this group developed contractures and scoliosis through participation in the programme.

There was also a decrease in the number of major orthopaedic operations performed for hip dislocation and the cooperation between the different specialists involved in the care of children with cerebral palsy improved.

Participation data

All the information from the CPIP assessments is stored in a secure NHS database. We can learn from experiences across Scotland to improve care in the future.

The child's community paediatric team and doctor are able to get a CPIPS report, showing the child's development over time. This report also highlights warning signals showing when there is a need for intervention.

This is fundamental in order to initiate the right treatment at the right time for each individual child.

Only anonymised information (that cannot be traced to you or your family) will be used in research.

This means that a single child will never be identified when experiences from this follow-up programme are compiled into general reports.

By carrying out research on the information available in the CPIPS database, we can improve our knowledge regarding changes over time in different types of cerebral palsy.

The different treatments can be compared as to how they affect final outcome.

Further information

For more information regarding CIPPS, please contact the Children's Therapy Team on: 01302 642636.

Patient Advice & Liaison Service (PALS)

The team are available to help with any concerns, complaints or questions you may have about your experience at the Trust. Their office is in the Main Foyer (Gate 4) of Doncaster Royal Infirmary. Contact can be made either in person, by telephone or email.

The contact details are:

Telephone: 01302 642764 or 0800 028 8059. **Email:** dbth.pals.dbh@nhs.net

