Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or <u>whh-tr.whitthealthPALS@nhs.net</u>

If you need a large print, audio or translated copy of this leaflet please contact us on 020 7288 3182. We will try our best to meet your needs.

Twitter.com/WhitHealth Facebook.com/WhittingtonHealth

Whittington Health NHS Trust Magdala Avenue London N19 5NF Phone: 020 7272 3070 www.whittington.nhs.uk

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Cerebral Palsy Integrated Pathway (CPIP)

A patient's guide





What is CPIP?

CPIP is a programme which provides regular follow-up assessment for children with (or suspected to have) Cerebral Palsy. It looks at changes in joints and muscles to aid early detection of emerging problems that need treatment.

The programme includes clinical examinations and hip X-rays at regular points in childhood.

What is Cerebral Palsy?

Cerebral Palsy is the name for a group of physical disorders that affect movement and co-ordination. It is caused by brain injury or dysfunction occurring before birth or in the first two years of life. The impact on a person's functional abilities is individualised and can range from mild to severe disability.

Although the brain injury itself does not get any worse, over time problems can often develop with joints. Often certain muscles will have increased tone (spasticity) while other muscles may be weakened. This can interfere with the development of motor skills. Spasticity can lead to pain, and over time, shortening of muscles and tendons. If joint movement is restricted, and soft tissue tightens around joints, they can become permanently stiff (known as a contracture).

Who is CPIP important for and why does it happen?

All children with Cerebral Palsy should be under the CPIP programme. The results allow therapists to analyse joint movement range and muscle length, and how this influences a child's motor skills. Therapists can then work with children and their families on formulating treatment plans based on individualised goals.

Notes

What can I do if I have more questions?

Please ask your physiotherapist if you have any questions. If they can't answer your question they will be able to contact the right team member and get back to you.

Useful links:

https://www.nhs.uk/conditions/cerebral-palsy/

https://www.cerebralpalsy.org.uk/

In addition, the clinical exam, alongside the hip X-ray, highlights risk factors and signs of hip displacement (see below). The therapist will also check posture, spinal alignment and may want to observe walking if appropriate.

Sometimes an assessment will be completed on a child without a diagnosis of Cerebral Palsy. This may be because the child is at risk of Cerebral Palsy or because the therapist wants to complete an assessment that gives an overview of joint range of movement and muscle length. Your physiotherapist will discuss this with you.

What is hip displacement and dislocation?

Children with Cerebral Palsy or a delay in attaining motor milestones are at risk of hip displacement, which can lead to full dislocation. When children are late to stand this can lead to the hip joint not developing as it should. When the muscles surrounding the hip joint are tight or stiff this can pull the joint out of place. If muscles and soft tissue are lax then this can also compromise the alignment of the hip joint.

When does CPIP start and how often will my child need a clinical examination and X-ray?

Your child will join the CPIP programme when they are diagnosed with Cerebral Palsy, or a diagnosis is likely. We aim to complete the initial assessment before the age of 2, and then the frequency of examinations is:

- 6 monthly for children aged between 2-6 years
- Annually for children over 6 years
- More frequently if there are particular signs or risks identified

How often your child requires a hip X-ray depends on their motor skills and the detection of early warning signs from the clinical exam.

How is the clinical examination done?

Your child will be booked for an appointment with two members of the physiotherapy team. During the appointment your child will mainly lie on a plinth and have measurements taken of joint range of movement and muscle length. It is important that the measurements are done using a plinth to ensure they are taken accurately. They will then be observed in sitting and standing (if appropriate) to record spinal alignment, posture and walking.



How can I interpret the results of the clinical examination?

After a clinical examination the physiotherapist will send out a report and a copy of the results to you, your child's GP and medical team if they have an open referral. The report and results are saved in your child's electronic records which allows for comparisons to be made with previous CPIP assessments.

CPIP uses a traffic light system:

The Traffic Light System – adapted from CPUP



Red

indicates what we regard as a normal or almost normal value.

value should prompt a review of the child's management strategy.

value may require referral to orthopaedic department for assessment.

If all the scores are green then there are no concerns and the physiotherapy management of your child's condition will stay the same.

If a new amber or red value is seen then this provides us with an early warning of a potential problem. The physiotherapist will look at these values alongside the overall picture of the assessment and work with you to change the management plan. This will likely include an exercise programme to stretch and strengthen muscles, and a postural management plan. We can also advise on suitable sports and physical activities. When children enjoy the physical activity they will be more likely to participate and will learn self-management skills for the future. The physiotherapist may also refer to and seek advice from paediatric and orthopaedic doctors to consider medical and/or surgical management strategies.

How are the X-rays done?

Hip X-rays are generally completed at the Whittington but may be done at different hospital. X-rays will be interpreted and reported on by a radiologist. If any hip displacement is identified a measurement of the amount of displacement will be recorded. This finding will likely change the physiotherapy and medical management of your child's condition. This will be discussed with you.