Shropshire Community Health NHS
NHS Trust

Policies, Procedures, Guidelines and Protocols

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2	V2 13/02/2018	Review and update to include NICE Guideline NG 62 Jan 2017
3	V3 08/02/2022	Reviewed with no further changes -in line with current guidance
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Contents

1 Introduction

The Surveillance of Cerebral Palsy in Europe (SCPE) is a network of Cerebral Palsy (CP) surveys and registers which was formed in 14 centres in 8 countries across Europe, aiming towards the standardisation of a definition of CP, inclusion and exclusion criteria and classification and description of children suffering from the condition[1].

2 Purpose

In January 2017, NICE published a comprehensive guideline on diagnosing, assessing and managing Cerebral Palsy in children and young people up to the age of 25 years[2]. This guideline aims to incorporate the recommendations so that care given locally meets the national standards.

3 Definitions

Key abbreviations and definitions are listed as below.

3.1 National and International Associations:

Cerebral Palsy Integrated Pathway (CPIP): UK pathway for hip surveillance to prevent hipdislocation. Pathway allows patient to have regular, standardised physical and radiologicalassessments which allows the early identification of hip displacement and timely intervention.

National Institute for Health and Care Excellence (NICE): National health body that overseesup to date guidance, policies, procedures and publications on all health-related topics.

Royal College of Paediatric and Child Health (RCPCH): National college that oversees education and training of all Paediatric doctors, providing evidence-based guidelines andpolices and leading service planning and delivery for the well-being of all infants, children,and young people.

Surveillance of Cerebral Palsy in Europe (SCPE): European association to develop bestpractice in monitoring trends in cerebral palsy, and to disseminate knowledge to health professionals, policy makers, patients, and families, to provide information for resource planning and raise standards of care for patients with cerebral palsy.

3.2 Medical definitions:

Ataxic: loss of coordination of the muscles, especially of the extremities.

Cerebral infarction: an area of necrotic tissue in the brain resulting from a blockage ornarrowing in the arteries supplying blood and oxygen to the brain.

Cerebral Palsy (CP): A term used to describe a group of permanent disorders of the development of movement and posture, causing activity limitation, resulting from non-progressive disturbances (structural abnormalities) that occurred in the developing fetal or infant brain.

Computed Tomography (CT): scan using x-rays to see internal details of organs and bones

Dyskinetic: abnormal, uncontrollable, involuntary movements.

Dystonia: abnormal muscle tone resulting on muscular spasm and abnormal posture

Functional Mobility Scale (FMS): Tool for quantifying mobility according to the need for assistive devices in different environmental settings. This can be used for assessment at a point in time or for assessing change over a period.

Gross Motor Function Classification System (GMFCS): A five level classification system that describes the gross motor function of children and young people with cerebral palsy based on their self-initiated movement.

Hypotonia: decreased muscle tone leading to floppiness

Magnetic Resonance imaging (MRI): scan using magnetic imaging to see internal details oforgans and bones

Spasticity: increased, involuntary, velocity-dependent muscle tone that causes resistance tomovement

4 Duties

4.1 Chief Executive

Should ensure that all clinical staff working with children and young people have access to this guideline. Should ensure that appropriate training and updates are provided to all relevant staff groups. Should ensure that staff have access to appropriate equipment that complies with safety and maintenance requirements.

4.2 Managers

Managers should ensure that staff are aware of and have access to policy guidelines. Staff training needs should be highlighted and addressed. Appropriate education, supervision and mechanisms are in place to ensure good practice

4.3 All clinicians working with children and young people

To be aware of the guideline and follow appropriately.

5 Cerebral Palsy Management Guideline

5.1 Diagnosis

5.1.1 Risk factors and Causes:

Risk factors for CP are divided into antenatal, perinatal, and postnatal categories. Please see Appendix 1 for further information. For a full list of causes, please refer to NICE guideline[2] (Section 1.2). NICE have also advised for a local enhanced clinical and developmental follow- up programme for children who have any of the risk factors listed in Appendix 1. Follow up of “at risk” infants, such as those born prematurely, is done by Neonatal Team at Shrewsbury & Telford Hospital (SATH). However, some patients under routine postnatal surveillance by midwifery (later on health visiting services) and primary care practitioners. Both health visiting and primary care practitioners can refer to Community Care services and NICE have an associated guideline for the developmental

follow up care of preterm infants (definition less than 37 weeks' gestation) that Communityclinicians may refer to for these patients[3].

5.1.2 Presentation:

This can include the following:

- delayed motor milestones: not sitting by 8 months (corrected for gestational age), not walking by 18 months (corrected for gestational age)
- asymmetric movement patterns: early asymmetry of hand function (hand preference) before 1 year (corrected for gestational)
- abnormalities of muscle tone including hypotonia, spasticity or dystonia
- other presentations including:
    - unusual fidgety movements or other abnormalities of movement
    - feeding difficulties (for example reflux or aspiration)
    - unexplained irritability and/or seizures

Red flags to consider for alternative diagnoses other than CP:

- if clinical signs and symptoms do not match with the diagnosis of CP
- if none of the above risk factors are present
- if there is a family history of a progressive neurological disorder
- regression of already attained abilities
- development of unexpected focal neurological signs
- MRI findings that are suggestive of a progressive neurological disorder or not in keeping with the clinical signs and symptoms of cerebral palsy

5.1.3 Investigations

Clinician should offer an MRI to investigate the cause in a child or young person with suspected or known cerebral palsy if the diagnosis is not clear from the history, their developmental progress, findings on clinical examination and results of cranial ultrasound examinations. Locally this can be arranged through our Radiology department of Princess Royal Telford Hospital.

When deciding the best age to perform an MRI scan for a child with cerebral palsy, NICE[2] advise to take account of the following:

- subtle neuro-anatomical changes that could explain the aetiology of cerebral palsy may not be apparent until 2 years of age.
- the presence of any red flags for a progressive neurological disorder
- that general anaesthesia or sedation needed for young children having MRI
- the views of the child or young person and their parents or carers

It is important to counsel parents about the reasons behind performing an MRI scan. Parents should be aware that an MRI will not accurately establish the timing of a hypoxic–ischemic brain injury in a child with cerebral palsy and that sometimes it is not always possible to identify the cause.

When considering blood tests and other investigations, this is not covered in the current NICE guideline. Metabolic and Genetic studies can be performed depending on the clinical presentation.

Patients with Hemiplegic CP have a high incidence of cerebral infarction. In 2017, the RCPCH have recently released guidelines in the overall diagnosis, investigation,

management and rehabilitation for Stroke in Children[4] that clinicians can refer to for further guidance. Clinicians can consider liaising with local Consultant Paediatrician with Hematology Interest (currently based at Princess Royal Hospital Telford) for advice regarding thrombophilia screening.

5.1.4 Classification

Patterns of motor disorder are subdivided into spastic, dyskinetic (including dystonic) and ataxic forms depending on the area of brain that is involved. The distribution of the motor disorder (hemiplegia, diplegia, quadriplegia) can also be used tosub specify.

Both NICE[3] and CPIP[5] use GMFCS[6] to assess and classify level of function. CPIP also use FMS[7] to assess needs for assistive devices.

5.1.5 Prognosis

Please refer to the NICE guideline[2] (Section 1.7) for information to give to parents and carers on prognosis for walking, speech and language and life expectancy in patients with cerebral palsy.

Further information from literature provides evidence that although there were deaths throughout the childhood and teenage years, most children with bilateral cerebralpalsy are likely to survive to adulthood, especially if they do not have major functional impairment at 2 years[8].

5.2 Multidisciplinary Care and Support

5.2.1 Information

Children and young people with cerebral palsy and their parents or carers have a significant role in decision-making and care planning. Parents and carers should be provided with clear, timely and up-to-date information to on the following topics:

- diagnosis, aetiology, prognosis
- expected developmental progress, comorbidities
- information regarding local integrated multidisciplinary team
- availability of specialist equipment to meet care needs
- resources available and access to financial, respite, social care and other services/support for children and young people and their parents, carers, and siblings
- educational placement (including specialist preschool and early years settings)
- transition

This can be facilitated by various professionals within the multidisciplinary team during consultations. Written information can be distributed with copies of letters and reports to patients and families. Up to date information can be accessed through NICE[2] and local community paediatric services website. Please see NICE guideline[2] (Section 1.6) for alternative forms of communicating information.

5.2.2 Multidisciplinary Team

To facilitate early diagnosis and intervention patients should be referred to a child development service for an urgent multidisciplinary assessment. Locally, children can access a multidisciplinary team which includes:

- paediatrics (acute and community)
- community child nurses

- physiotherapy
- occupational therapy
- speech and language therapy
- dietetics
- psychology (currently accessible for children who are open on the Community Child
- Nurse service)
- local authority for educational support

Ongoing communication between the multidisciplinary team and primary care is important and all information should be shared with relevant members of the team as well as the patient, parents, or carers. This can be done by copying letters/reports to parents/patient, primary care practitioner and members of team involved in the patient's care. The information and support should focus as much on the functional abilities of the child or young person with cerebral palsy as any functional impairment (please refer to GMFCS[6] and FMS[7] as used by CPIP[4]).

Children and young people should have access to other services within their local (via acute services if provided) or regional network (via tertiary centres) as appropriate, including:

- paediatric Neurodisability, neurology, neurorehabilitation, respiratory,gastroenterology and surgical specialist care
- orthopaedics
- orthotics and rehabilitation services
- social care
- visual and hearing specialist services
- teaching support for preschool and school-age children, including portage (home teaching services for preschool children).

Referrals to both local and tertiary services can be done by any member of the local multidisciplinary team.

5.2.3 Support Groups and services

It is important to inform children and young people along with parents and carers about local services and support/advocacy groups and how to access them. Clinicians should discuss access to local services, extracurricular and activities, promotion of inclusion and participation engagement with school. Locally for further information please contact the current Lead Consultant for Neuro-disability or refer families to Family Information Service (Shropshire) or Family Connect (Telford) or NHS choices website.

When appropriate, young people with cerebral palsy may access via their local GP services or school nursing service, further information about menstruation, fertility and contraception, sex, sexuality, and parenting.

Clinicians can suggest the benefits of using the "patient pathway" to children or young people and their parents or carers[2]. Parents or carers should be encouraged to develop and maintain a personal folder in their preferred format containing relevant information that can be shared with their extended family and friends and used in health, social care, educational and transition settings. This discussion should be documented as part of the consultation. For information to include see NICE guideline[2] (Section1.6)

5.3 Medication

For guidance on the safe and effective use of medicines, current NICE guidance[2] is to refer to the NICE guideline on medicines optimisation[9]. Locally clinicians can liaise with acute paediatric pharmacists for further information. For guidance on managing problems with movement and posture in children and young people with cerebral palsy, see the NICE guideline on Spasticity in under 19s[10]

5.4 Management of associated health issues

5.4.1 Eating, drinking and swallowing difficulties

Locally refer to specialist Speech and Language Therapy for initial feeding assessment.

Refer to local acute paediatrician with interest in gastrostomy (currently base at Princess Royal Hospital Telford) for further management if required.

Refer to local tertiary hospitals to ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access to specialist assessment, including advice from other services such as paediatric surgery and respiratory paediatrics.

For further advice about assessment and management please see NICE guideline[2] (Section 1.8)

5.4.2 Speech, language, and communication

Discuss with children and young people and their parents or carers about communication difficulties that can be associated with cerebral palsy, please refer to NICE guideline[2] (Section 1.9). For assessment and further support, please refer to local Speech and Language Therapy services via the Early Links Group at Shrewsbury and First Steps at Telford.

5.4.3 Optimising nutritional status

Regularly review the nutritional status of children and young people with cerebral palsy, including height and weight with plotting on growth chart. Refer to local dietician if any concerns. Please refer to NICE guideline on nutrition support for adults for enteral feeding for over 18's[11]

5.4.4 Managing Saliva control

Please refer to NICE guideline on management of saliva control[12]

5.4.5 Low bone mineral density

Please refer to local Low bone mineral density guideline (Fracture risk management in vulnerable children Sept 2020 Dr Short[13]).

5.4.6 Pain, discomfort, and distress

Pain is common in people with cerebral palsy, especially those with more severe motor impairment[2]. This should be explained to patients, parents, and familiar carers along with the importance of recognising the signs and addressing the cause. Clinicians should also remember that usual causes of pain, discomfort and distress that affect children and young people also occur in those with cerebral palsy. It is important to assess pain in children and young people with cerebral palsy at every contact. If a reversible causes of pain, discomfort and distress is identified in children and young people with cerebral palsy,treat the cause as appropriate. Further information and guidance is available in NICE guideline[2] (Section 1.13) but clinicians should also consider referral to local acute paediatricians if needed.

If there is no identifiable cause, consider a trial of simple analgesia for mild to moderate pain with monitoring of the duration, pattern, and severity of symptoms[2]. If a trial of analgesiais unsuccessful, clinicians should consider referring the child or young person to a specialistpain multidisciplinary team for further management. Locally this would be Children's Community Nursing Team based at Coral House..

Recognize that difficulties in communication and perception may make identifying the cause to be more challenging.Please refer to NICE guideline[2] (Section 1.13, 1.15 and1.17).

5.4.7 Sleep

When assessing sleep disturbances in children and young people with cerebral palsy ask about pain/distress and sleep and consider the concerns of parents and familiar carers. Clinicians can consider using sleep questionnaires or diaries to gather further information and referring to local acute paediatric services for a sleep study if needed.

Treatable causes of sleep disturbances that are identified should be managed. Discuss with families how to optimise sleep hygiene for children and young people with cerebral palsy.

If no treatable cause is found and sleep hygiene is optimised, consider a trial of melatonin particularly for problems with falling asleep[2]. Please refer to local guideline (Guidance for use of melatonin for children with severe sleep disorders Oct 2016 Dr Butterworth[14]) for further information.

5.4.8 Mental Health

Refer the child or young person when there are concerns regarding mental health issues for specialist psychological assessment and ongoing management to local CAMHS or Learning Difficulty teams (please see trust intranet for further contact details for Telford and Shrewsbury).

Further information on managing mental health problems and psychological and neurodevelopmental disorders in children and young people with cerebral palsy can be found in NICE guideline[2] (Section 1.15).

5.4.9 Sensory information

Clinicians should explain to children and young people with cerebral palsy and their parents or carers that difficulties with learning and movement may be exacerbated by difficulties with registering or processing sensory information[2]. This may have an adverse effect on learning and participation. Contact local children's occupational therapy teams for advice on sensory processing difficulties.

Sensory Impairments.

Children and young people with hearing and visual difficulties should be referred to the Sensory Inclusion Services at Shrewsbury or Telford Hospital) for assessment and further support.

6 Consultation

This clinical guideline has been distributed widely for discussion amongst community paediatricians: Dr Ganesh, Dr Meran, Dr Buch, Dr Butterworth, Dr Posting, Dr Ogilvie,Dr Unsworth G Minnaar and Dr Raveendran. This guideline has been shared with the Medicines Management Team, which includes wider community nursing and therapy colleagues.

7 Dissemination and Implementation

This clinical guideline will be distributed to relevant staff groups by managers and published on the Trust website.

These guidelines will be disseminated by the following methods:

- Managers Informed via DATIX system who then confirm they have disseminated to staff as appropriate
- Staff via Team Brief
- Published to the staff zone of the trust website

8 Monitoring Compliance

Compliance will be monitored by review of any concerns raised about the service by staff or patients.

An audit of the guidelines will be done one year after implementation.

An audit of notes will be done an a few years' time to see if relevant information is being included in correspondence and that correspondence is disseminated to relevant professionals

9 References

For all NICE guidelines please refer to www.nice.org.uk for the latest updates

For all RCPCH guidelines please refer to www.rcpch.ac.uk for the latest updates

1) Surveillance of Cerebral Palsy in Europe http://www.scpenetwork.eu
2) National Institute for Health and Care Excellence, Jan 2017, Cerebral Palsy in under 25s: assessment and management [NG62]
3) National Institute for Health and Care Excellence, Aug 2017, Developmental follow-up of children and young people born preterm [NG72]
4) Ganesan et al, RCPCH Stroke in Children: Clinical Guidelines in Diagnosis, Management, and rehabilitation, 2017
5) Cerebral Palsy Integrated Pathway UK https://apcp.csp.org.uk/content/cpip-uk-national network
6) Gross Motor Functional Classification Scales, Cerebral Palsy Integrated Pathway Scotland: Origins and development, core dataset, clinical assessment manual 2017 https://apcp.csp.org.uk/content/cpip-uk-training-manual-assessment-forms
7) Functional Mobility Scale, Cerebral Palsy Integrated Pathway Scotland: Origins and development, core dataset, clinical assessment manual, 2017 https://apcp.csp.org.uk/content/cpip-uk-training-manual-assessment-forms
8) Baird G, Allen E, Scruton D, et al, Mortality from 1 to 16–18 years in bilateral cerebral palsy, Archives of Disease in Childhood 2011;96:1077-1081
9) National Institute for Health and Care Excellence, March 2015, Medicines optimisation: the safe and effective use of medicines to enable the best possible outcomes [NG5]
10) National Institute for Health and Care Excellence, July 2012, Spasticity in under 19s: management [CG145]
11) National Institute for Health and Care Excellence, Feb 2006, Nutrition support for

adults: oral nutrition support, enteral tube feeding and parenteral nutrition [CG32]

12) National Institute for Health and Care Excellence, Feb 2017, Severe sialorrhoea (drooling) in children and young people with chronic neurological disorders: oral glycopyrronium bromide [ES5]

13) Short D, Fracture risk management in vulnerable children, Shropshire Community Health Trust, Sept 2016

14) Butterworth J, Guidance for use of melatonin for children with severe sleep disorders, Shropshire Community Trust, Oct 2016

10 Associated Documents

Cerebral Palsy Clinical Guideline DRAFT v4 Sep 10

Fracture risk management in vulnerable children Sept 2016 Dr Short

Guidance for use of melatonin for children with severe sleep disorders Oct 2016 Dr Butterworth

11 Appendices

APPENDIX 1: Risk factors from NICE guideline[2]

Recognise the following as independent risk factors for cerebral palsy:

- **antenatal** factors:
  - preterm birth (with risk increasing with decreasing gestational age) [1],[2]
  - chorioamnionitis
  - maternal respiratory tract or Genito-urinary infection treated in hospital

- **perinatal** factors:
  - low birth weight
  - chorioamnionitis
  - neonatal encephalopathy
  - neonatal sepsis (particularly with a birth weight below 1.5 kg)
  - maternal respiratory tract or Genito-urinary infection treated in hospital

- **postnatal** factors:
  - meningitis