National Institute for Health and Care Excellence

NICE guideline on Cerebral palsy
Document cover sheet

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Cerebral palsy: diagnosis and management in children and young people under 25

NICE guideline: short version

Draft for consultation, August 2016

This guideline covers the diagnosis, assessment and management of cerebral palsy in children and young people from birth up to their 25th birthday. Recognised subgroups within the cerebral palsy population, depending on levels of functional and cognitive impairment (for example, Gross Motor Function Classification System levels I to V), have been considered where appropriate.

Who is it for?

- Healthcare professionals who care for children and young people with cerebral palsy.
- Social care professionals who come into contact with children and young

people with cerebral palsy and their families.

- Children and young people with cerebral palsy, and their families and carers.

This version of the guideline contains the draft recommendations, context and recommendations for research. Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the guideline committee's discussion and the evidence reviews (in the full guideline), the scope, and details of the committee and any declarations of interest.

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Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

1.1 Risk factors

1.1.1 Recognise the following as independent risk factors for cerebral palsy:

- antenatal factors:
  - preterm birth (with risk increasing with decreasing gestational age)[1]
  - 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.

[1] The NICE guideline on developmental follow-up of preterm babies (publication expected August 2017) will contain more information about risk factors specific to preterm birth.

1.1.2 Provide an enhanced clinical and developmental follow-up programme (see recommendation 1.3.1) for infants who have any of the risk factors listed in recommendation 1.1.1.

1.2 Causes of cerebral palsy

1.2.1 When assessing the likely cause of cerebral palsy in a child, recognise that a number of MRI-identified brain abnormalities have been reported at the following approximate prevalences in children with cerebral palsy:

- white matter damage: 45%
- basal ganglia or deep grey matter damage: 13%
- congenital malformation: 10%
- focal infarcts: 7%.

1.2.2 When assessing the likely cause of cerebral palsy, recognise that white matter damage, including periventricular leukomalacia shown on neuroimaging:

- is more common in children born preterm than in those born at term
- may occur in children with any functional level or motor subtype, but is more common in spastic than in dyskinetic cerebral palsy.

1.2.3 When assessing the likely cause of cerebral palsy, recognise that basal ganglia or deep grey matter damage is mostly associated with dyskinetic cerebral palsy.

1.2.4 When assessing the likely cause of cerebral palsy, recognise that congenital malformations as a cause of cerebral palsy:

- are more common in children born at term than in those born preterm
- may occur in children with any functional level or motor subtype
- are associated with higher levels of functional impairment than other causes.

1.2.5 Recognise that the clinical syndrome of neonatal encephalopathy can result from various pathological events, such as a hypoxic–ischaemic brain injury or sepsis, and if there has been more than one such event they may interact to damage the developing brain.

1.2.6 When assessing the likely cause of cerebral palsy, recognise that neonatal encephalopathy has been reported at the following approximate prevalences in children with cerebral palsy born after 35 weeks:

- attributed to a perinatal hypoxic–ischaemic injury: 20%
- not attributed to a perinatal hypoxic–ischaemic injury: 12%.

1.2.7 Recognise that for cerebral palsy associated with a perinatal hypoxic–ischaemic injury:

- the extent of long-term functional impairment is often related to the severity of the initial encephalopathy
- the dyskinetic motor subtype is more common than other subtypes.

1.2.8 Recognise that for cerebral palsy acquired after the neonatal period, the following causes and approximate prevalences have been reported:

- meningitis: 20%
- other infections: 30%
- head injury: 12%.

1.2.9 When assessing the likely cause of cerebral palsy, recognise that independent risk factors:

- can have a cumulative impact, adversely affecting the developing brain and resulting in cerebral palsy
- may have an impact at any stage of development, including the antenatal, perinatal and postnatal periods.

Using MRI to assess cause

1.2.10 Offer MRI for a child or young person with suspected or known cerebral palsy if the aetiology is not clear after consideration of:

- antenatal, perinatal and postnatal history
- their ongoing developmental and medical history
- findings on clinical examination
- early cranial ultrasound examinations.

1.2.11 Recognise that MRI will not accurately establish the timing of a hypoxic–ischaemic brain injury in a child with cerebral palsy.

1.2.12 When deciding the best age to perform an MRI scan for a child with cerebral palsy, 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 (see section 1.4).
- That a general anaesthetic is usually needed for young children having MRI.
- The views of the child or young person and their parents or carers.

1.2.13 Consider repeating the MRI scan if:

- there is a change in the expected clinical and developmental profile **or**
- any red flags for a progressive neurological disorder appear (see section 1.4).

1.2.14 Discuss with the child or young person and their parents or carers the reasons for performing MRI in each individual circumstance.

1.3 Looking for signs of cerebral palsy

1.3.1 Provide an enhanced clinical and developmental follow-up programme for infants and children who are at increased risk of developing cerebral palsy (see recommendation 1.1.1):

- From 0–6 months: consider using the General Movement Assessment (GMA) during routine neonatal follow-up assessments.
- From 6–24 months: use a multidisciplinary neurological assessment if continued follow-up assessments are needed.

1.3.2 Recognise the following as possible early motor features in the presentation of cerebral palsy:

- unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement
- abnormalities of tone, including hypotonia (floppiness), spasticity (stiffness) or dystonia (fluctuating tone)
- abnormal motor development, including late sitting, crawling or walking, or problems with feeding.

1.3.3 Recognise that the most common delayed motor milestones in infants and children with cerebral palsy are:

- late sitting (after 8 months)
- late walking (after 18 months)
- early asymmetry of hand function (hand preference before 1 year).

1.3.4 Refer all infants and children with delayed motor milestones to a child development service for further assessment.

1.3.5 Refer children who have obvious and persistent toe walking to a child development service for further assessment.

1.3.6 If there are concerns that an infant or child may have cerebral palsy but a definitive diagnosis cannot be made, discuss this with their parents or carers and explain that an enhanced clinical and developmental follow-up programme will be necessary to try to reach a definite conclusion.

1.4 Red flags for other neurological disorders

1.4.1 Review a diagnosis of cerebral palsy if clinical signs or the child's development over time do not follow the patterns expected for cerebral palsy, taking into account that the functional and neurological manifestations of cerebral palsy change over time.

1.4.2 Recognise the following as red flags for neurological disorders other than cerebral palsy, and refer the child or young person to a specialist in paediatric neurology if any of these are observed:

- absence of known risk factors (see recommendation 1.1.1)
- family history of a progressive neurological disorder
- loss of already attained cognitive or developmental abilities
- development of unexpected focal neurological signs
- MRI findings suggestive of a progressive neurological disorder
- MRI findings not in keeping with clinical signs of cerebral palsy.

1.5 Early multidisciplinary care

1.5.1 Refer all infants and children with suspected cerebral palsy immediately to a child development service for a multidisciplinary assessment, in order to facilitate early diagnosis and intervention.

1.5.2 Ensure that the child or young person has access to a multidisciplinary team that:

- is able to meet their individual needs
- can provide the following expertise, through a local network of care:
  - paediatric medicine

- adult medicine (as appropriate)
- nursing care
- physiotherapy and occupational therapy
- orthotics and rehabilitation (as appropriate)
- speech and language therapy
- dietetics
- psychology
- social care.

1.5.3 Ensure that routes for accessing specialist teams involved in managing comorbidities associated with cerebral palsy are clearly defined on a regional basis.

1.5.4 Recognise that ongoing communication between all levels of service provision in the care of children and young people with cerebral palsy is crucial, particularly involvement of primary care from diagnosis onwards.

1.5.5 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.

1.6 Information and support

1.6.1 Ensure that information and support focuses as much on the functional abilities of the child or young person with cerebral palsy as on any functional impairment.

1.6.2 Provide clear, timely and up-to-date information to parents or carers on the following topics:

- diagnosis (see section 1.3)
- aetiology (see section 1.2)
- prognosis (see section 1.7)
- natural history
- comorbidities (see section 1.17)
- specialist equipment that is available

- resources available and access to financial, respite, social care and other support for children and young people and their parents, carers and siblings (see also recommendations 1.18.4 and 1.18.8)
- educational placement
- transition (see section 1.19).

1.6.3 Ensure that clear information about the 'patient pathway' is shared with the child or young person and their parents or carers (for example, by providing them with copies of correspondence). Follow the principles in the recommendations about communication, information and shared decision-making in the NICE guideline on patient experience in adult NHS services.

1.6.4 Provide information to the child or young person with cerebral palsy, and their parents or carers, on an ongoing basis. Adapt the communication methods and information resources to take account of the needs and understanding of the child or young person and their parents or carers. For example, think about using 1 or more of the following:

- oral explanations
- written information and leaflets
- mobile technology, including apps
- augmentative and alternative communication systems (see section 1.9).

1.6.5 Work with the child or young person and their parents or carers 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. Information could include:

- early history
- motor subtype and limb involvement

- functional abilities
- interventions
- medication
- comorbidities
- preferred methods of communication
- any specialist equipment that is used or needed
- care plans
- emergency contact details.

1.6.6 Ensure that the child or young person and their parents or carers are given personalised information from a specialist about the following topics as appropriate:

- menstruation
- fertility
- contraception
- sex
- sexuality
- parenting.

1.6.7 Provide information to the child or young person and their parents or carers, and to all relevant teams around the child and young person, about the local and regional services available for children and young people with cerebral palsy, and how to access them.

1.6.8 Provide information about local support and advocacy groups to the child or young person and their parents or carers.

1.7 Information about prognosis

1.7.1 Provide the following information to parents or carers about the prognosis for walking for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the possibility of difficulties with walking.

- If a child can sit at 2 years of age it is likely, but not certain, that they will be able to walk unaided by age 6.
- If a child cannot sit but can roll at 2 years of age, there is a possibility that they may be able to walk unaided by age 6.
- If a child cannot sit or roll at 2 years of age, they are unlikely to be able to walk unaided.

1.7.2 Recognise the following in relation to prognosis for speech development in a child with cerebral palsy, and discuss this with parents or carers as appropriate:

- Around 1 in 2 children with cerebral palsy have some difficulty with elements of communication (see recommendation 1.9.1).
- Around 1 in 3 children have specific difficulties with speech and language.
- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of difficulties with speech and language.
- Uncontrolled epilepsy may be associated with difficulties with all forms of communication, including speech.
- A child with bilateral spastic, dyskinetic or ataxic cerebral palsy is more likely to have difficulties with speech and language than a child with unilateral spastic cerebral palsy.

1.7.3 Provide the following information to parents or carers, as appropriate, about prognosis for life expectancy for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of reduced life expectancy.
- There is an association between reduced life expectancy and the need for enteral tube feeding, but this reflects the severity of swallowing difficulties and is not because of the intervention.

Using MRI to assess prognosis

1.7.4 Take account of the likely cause of cerebral palsy and the findings from MRI (if performed) when discussing prognosis with the child or young person and their parents or carers.

1.7.5 Do not rely on MRI alone for predicting prognosis in infants and children with cerebral palsy.

1.8 Eating, drinking and swallowing difficulties

Assessment

1.8.1 If eating, drinking and swallowing difficulties are suspected in a child or young person with cerebral palsy, carry out a clinical assessment as first-line investigation to determine the safety, efficiency and enjoyment of eating and drinking. This should include:

- taking a relevant clinical history, including asking about any previous chest infections
- observation of eating and drinking in a normal mealtime environment by a speech and language therapist with training in assessing and treating dysphagia.

1.8.2 Refer the child or young person to a local specialist multidisciplinary team with training in assessing and treating dysphagia if there are clinical concerns about eating, drinking and swallowing, such as:

- coughing
- choking
- gagging
- change in colour during eating
- recurrent chest infection
- prolonged meal duration.

1.8.3 Do not use videofluoroscopy or fibroscopic endoscopy for the initial assessment of eating, drinking and swallowing difficulties in children and young people with cerebral palsy.

1.8.4 The specialist multidisciplinary team should consider videofluoroscopy if any of the following apply:

- There is uncertainty about the safety of eating, drinking and swallowing after specialist clinical assessment.
- The child or young person has recurrent chest infection without overt clinical signs of aspiration.
- There is deterioration in eating, drinking and swallowing ability with increasing age (particularly after adolescence).
- There is uncertainty about the impact of modifying food textures (for example, use of thickeners or pureeing).
- Parents or carers need support to understand eating, drinking and swallowing difficulties, to help with decision-making.

1.8.5 Videofluoroscopy should only be performed in a centre with a specialist multidisciplinary team who have experience and competence in using it with children and young people with cerebral palsy.

1.8.6 Do not routinely perform videofluoroscopy when considering starting enteral tube feeding in children and young people with cerebral palsy.

1.8.7 Ensure that children and young people with ongoing eating, drinking and swallowing difficulties have access to regional tertiary specialist assessment.

Management

1.8.8 Develop strategies and goals in partnership with the child or young person with cerebral palsy and their parents, carers and other family members for interventions to improve eating, drinking and swallowing.

1.8.9 Create an individualised plan for managing eating, drinking and swallowing difficulties in children and young people with cerebral palsy, taking into account the understanding, knowledge and skills of parents, carers and any other people involved in feeding the child or young person. Assess the role of the following:

- postural management and positioning when eating
- modifying fluid and food textures and flavours
- feeding techniques, such as pacing and spoon placement
- equipment, such as specialised feeding utensils
- optimising the mealtime environment
- strategies for managing behavioural problems associated with eating and drinking
- strategies for developing oral motor skills
- communication strategies
- modifications to accommodate visual or other sensory impairments that affect eating, drinking and swallowing
- the training needs of the people who care for the child or young person particularly outside the home.

1.8.10 Advise parents or carers that intra-oral devices have not been shown to improve eating, drinking and swallowing in children and young people with cerebral palsy.

1.8.11 Use outcome measures important to the child or young person and their parents or carers to review:

- whether individualised goals have been achieved
- the clinical and functional impact of interventions to improve eating, drinking and swallowing.

1.9 Speech, language and communication

Communication difficulties

1.9.1 Talk to children and young people and their parents or carers about communication difficulties that can be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- communication difficulties occur in around 1 in 2 children and young people with cerebral palsy
- at least 1 in 10 need augmentative and alternative communication (signs, symbols and speech generating devices)
- around 1 in 10 children and young people cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments communication difficulties
- communication difficulties may occur with any functional level or motor subtype, but are more common in children and young people with dyskinetic or severe bilateral spastic cerebral palsy
- communication difficulties do not necessarily correlate with learning disabilities.

Assessment and referral

1.9.2 Regularly assess children and young people with cerebral palsy during routine reviews to identify concerns about speech, language and communication, including speech intelligibility.

1.9.3 Refer children and young people with cerebral palsy for specialist assessment if there are concerns about speech, language and communication, including speech intelligibility.

1.9.4 Specialist assessment of the communication skills, including speech intelligibility, of children and young people with cerebral palsy should be conducted by a multidisciplinary team that includes a speech and language therapist.

Interventions

1.9.5 Offer interventions to improve speech intelligibility, for example targeting posture, breath control, voice production and rate of speech, to children and young people with cerebral palsy:

- who have a motor speech disorder and some intelligible speech **and**
- for whom speech is the primary means of communication **and**
- who can engage with the intervention.

1.9.6 Consider augmentative and alternative communication systems for children and young people with cerebral palsy who need support in understanding and producing speech. These may include pictures, objects, symbols and signs, and speech-generating devices.

1.9.7 If there are ongoing problems with using augmentative and alternative communication systems, refer the child or young person to a specialist service in order to tailor interventions to their individual needs, taking account of their cognitive, linguistic, motor, hearing and visual abilities.

1.9.8 Regularly review children and young people who are using augmentative and alternative communication systems, to monitor their progress and ensure that interventions continue to be appropriate for their needs.

1.9.9 Provide individualised training in communication techniques for families, carers, school staff and other people involved in the care of a child or young person with cerebral palsy.

1.10 Optimising nutritional status

1.10.1 Regularly review the nutritional status of children and young people with cerebral palsy, including taking anthropometric measurements.

1.10.2 Provide timely access to assessment and nutritional interventional support from a dietitian if there are concerns about oral intake, growth or nutritional status.

1.10.3 If oral intake is still insufficient to provide adequate nutrition after assessment and nutritional interventions, refer the child or young person to be assessed for enteral tube feeding by a multidisciplinary team with relevant expertise.

1.10.4 For guidance on nutritional interventions and enteral tube feeding in over 18s, see the NICE guideline on nutrition support for adults.

1.11 Managing saliva control

1.11.1 Assess factors that may affect drooling in children and young people with cerebral palsy, such as positioning, medication history, reflux and dental issues, before starting drug therapy.

1.11.2 To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider transdermal hyoscine hydrobromide[2].

1.11.3 If transdermal hyoscine hydrobromide is contraindicated, not tolerated or not effective, consider:

- glycopyrrolate[3] (oral or by enteral tube) **or**
- other anticholinergic drugs, such as trihexyphenidyl hydrochloride[4] for children with dyskinetic cerebral palsy, but only with input from specialist services.

[2] At the time of consultation (August 2016), transdermal hyoscine hydrobromide (scopolamine hydrobromide) did not have a UK marketing authorisation for use in children and young people under 18 for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[3] At the time of consultation (August 2016), glycopyrrolate did not have a UK marketing authorisation for use in children and young people under 18 for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

1.11.4 Regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control.

1.11.5 Refer the child or young person to a specialist service if the anticholinergic drug treatments outlined in recommendations 1.11.2 and 1.11.3 are contraindicated, not tolerated or not effective, to consider other treatments for saliva control.

1.11.6 Consider specialist assessment and use of botulinum toxin A injections[5] to the salivary glands with ultrasound guidance to reduce the severity and frequency of drooling if anticholinergic drugs provide insufficient benefit or are not tolerated.

1.11.7 Advise children and young people and their parents or carers that high-dose botulinum toxin A injection[6] to the salivary glands can rarely cause swallowing difficulties, and so they should return to hospital immediately if breathing or swallowing difficulties occur.

1.11.8 Consider referring young people for a surgical opinion, after an assessment confirming clinically safe swallow, if there is:

- a potential need for lifelong drug treatment **or**
- insufficient benefit or non-tolerance of anticholinergic drugs and botulinum toxin A injections.

[4] At the time of consultation (August 2016), trihexyphenidyl hydrochloride did not have a UK marketing authorisation for use in children and young people under 18 for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[5] At the time of consultation (August 2016), some botulinum toxin A products had a UK marketing authorisation for use in the treatment of focal spasticity in children, young people and adults, including the treatment of dynamic equinus foot deformity due to spasticity in ambulant paediatric cerebral palsy patients, 2 years of age or older. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

1.12 Low bone mineral density

Risk factors

1.12.1 Recognise that in children and young people with cerebral palsy the following are independent risk factors for low bone mineral density:

- non-ambulant (GMFCS level IV or V)
- vitamin D deficiency
- presence of eating, drinking and swallowing difficulties or concerns about nutritional status
- low weight for age (below the 2nd centile)
- history of low-impact fracture
- use of anticonvulsant medication.

1.12.2 Recognise that there is an increased risk of low-impact fractures in children and young people with cerebral palsy who are non-ambulant or have low bone mineral density.

1.12.3 Inform children and young people with cerebral palsy and their parents or carers if they are at an increased risk of low-impact fractures.

Management

1.12.4 If a child and young person with cerebral palsy has 1 or more risk factors for low bone mineral density (see recommendation 1.12.1):

- assess their dietary intake of calcium and vitamin D **and**
- consider the following laboratory investigations of calcium and vitamin D status:
  - serum calcium, phosphate and alkaline phosphatase
  - serum vitamin D
  - urinary calcium/creatinine ratio.

1.12.5 Create an individualised care plan for children and young people with cerebral palsy who have one or more risk factors for low bone mineral density (see recommendation 1.12.1).

1.12.6 Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures:

- an active movement programme
- active weight bearing
- dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation
- minimising risks associated with movement and handling.

1.12.7 Consider a DEXA scan under specialist guidance for children and young people with cerebral palsy who have had low-impact fracture.

1.12.8 Refer children and young people with cerebral palsy with reduced bone density and a history of low-impact fracture to a specialist centre for consideration of bisphosphonate therapy.

1.12.9 Do not offer standing frames solely to prevent low bone mineral density in children and young people with cerebral palsy.

1.12.10 Do not offer vibration therapy solely to prevent low bone mineral density in children and young people with cerebral palsy.

1.13 Pain, distress and discomfort

Causes

1.13.1 Explain that most children and young people with cerebral palsy experience pain regularly, and that the prevalence of pain increases with increasing severity of motor impairment.

1.13.2 Recognise that common causes of pain in all children and young people also affect those with cerebral palsy, and that difficulties with communication and perception may make identifying the

cause more challenging. Common types of pain in children and young people include:

- non-specific back pain
- headache
- non-specific abdominal pain
- dental pain
- dysmenorrhea.

1.13.3 Recognise that the most common condition-specific causes of pain in children and young people with cerebral palsy include:

- musculoskeletal problems (for example, scoliosis, hip subluxation and dislocation)
- increased muscle tone (including dystonia and spasticity)
- constipation
- vomiting and gastro-oesophageal reflux.

Assessment

1.13.4 Take into account that parents and familiar carers have a key role in recognising and assessing pain and discomfort in children and young people with cerebral palsy.

1.13.5 When assessing pain in children and young people with cerebral palsy:

- recognise that assessing the presence and degree of pain can be challenging, especially if there are communication difficulties or learning disabilities
- ask about signs of distress and sleep disturbances at every contact
- recognise that pain-related behaviour can present differently compared with that in the wider population.

1.13.6 Assess for other possible causes of distress in the absence of identifiable physical causes of pain and discomfort, such as:

- psychological and emotional distress
- increased sensitivity to environmental triggers
- thirst or hunger.

1.13.7 Consider using tools to identify pain or assess severity of pain in children and young people with cerebral palsy; for example:

- For children and young people with communication difficulties:
  - Paediatric Pain Profile
  - Non-communicating Children's Pain Checklist – postoperative version
- For children and young people without communication difficulties:
  - Numeric pain rating scale.

1.13.8 Refer the child or young person for a specialist multidisciplinary team assessment of pain, distress and sleep if the cause of pain or distress is not clear after routine assessment.

Management

1.13.9 For reversible causes of pain identified in children and young people with cerebral palsy, treat the cause where appropriate using targeted interventions in line with the following NICE guidelines:

- spasticity in under 19s
- constipation in children and young people
- gastro-oesophageal reflux disease in children and young people and gastro-oesophageal reflux disease and dyspepsia in adults
- headaches in over 12s
- low back pain in adults
- urinary tract infection in under 16s.

1.13.10 For common interventions used in the management of cerebral palsy (such as physical therapies, botulinum toxin A injections and surgery) that can cause acute pain:

- advise the child or young person and their parents or carers that these interventions may reduce discomfort in the long term
- minimise discomfort during these procedures.

1.13.11 In the absence of an identifiable cause of pain, discomfort or distress in a child or young person with cerebral palsy:

- consider a ‘stepped approach’ trial of simple analgesia (such as paracetamol and/or ibuprofen) for mild to moderate pain
- monitor the duration, pattern and severity of symptoms.

1.13.12 Refer the child or young person to a specialist pain multidisciplinary team for a more detailed assessment if a trial of analgesia is unsuccessful.

1.14 Sleep disturbances

Causes

1.14.1 Explain to parents or carers that, in children and young people with cerebral palsy, sleep disturbances (for example, difficulties with falling asleep and staying asleep and with daytime sleepiness):

- are common
- may be caused by factors such as environment, hunger and thirst.

1.14.2 Recognise that the most common condition-specific causes of sleep disturbances in children and young people with cerebral palsy include:

- sleep-induced breathing disorders, such as obstructive sleep apnoea
- seizures
- pain and discomfort
- need for repositioning because of immobility
- poor sleep hygiene (poor night-time routine and environment)

- night-time interventions, including overnight tube feeding or the use of orthoses
- comorbidities, including adverse effects of medication.

Assessment

1.14.3 When identifying and assessing sleep disturbances in children and young people with cerebral palsy:

- recognise that parents and familiar carers have the primary role in this
- consider using sleep questionnaires or diaries.

1.14.4 Always ask about pain, sleep and distress as part of any clinical consultation.

Management

1.14.5 Optimise sleep hygiene for children and young people with cerebral palsy.

1.14.6 Manage treatable causes of sleep disturbances that are identified in children and young people with cerebral palsy.

1.14.7 If no treatable cause is found, consider a trial of melatonin[7] to manage sleep disturbances for children and young people with cerebral palsy, particularly for problems with falling asleep.

1.14.8 Do not offer regular sedative medication to manage primary sleep disorders in children with cerebral palsy without seeking specialist advice.

1.14.9 Do not offer sleep positioning systems solely to manage primary sleep disorders in children and young people with cerebral palsy.

[7] At the time of consultation (August 2016), melatonin did not have a UK marketing authorisation for use in children and young people under 18 for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

1.14.10 Refer the child or young person to specialist sleep services for multidisciplinary team assessment and management if there are ongoing sleep disturbances.

1.15 Mental health problems

1.15.1 Follow the relevant NICE guidelines when identifying and managing mental health problems and psychological and neurodevelopmental disorders in children and young people with cerebral palsy:

- depression in children and young people
- depression in adults
- generalised anxiety disorder and panic disorder in adults
- challenging behaviour and learning disabilities
- antisocial behaviour and conduct disorders in children and young people
- mental health problems in people with learning disabilities[8]
- autism in under 19s and autism in adults
- attention deficit hyperactivity disorder.

Identification

1.15.2 Take into account that parents and familiar carers have a central role in recognising and assessing emotional difficulties and mental health problems in children and young people with cerebral palsy.

1.15.3 Recognise that children and young people with cerebral palsy have an increased prevalence of:

- mental health and psychological problems, including depression, anxiety and conduct disorders
- behaviours that challenge, which may be triggered by pain, discomfort or sleep disturbances

[8] Publication expected September 2016; the consultation draft of the guideline can be viewed here.

- neurodevelopmental disorders, including autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

1.15.4 Recognise that emotional and behavioural difficulties (for example, low self-esteem) are reported in up to 1 in 4 children and young people with cerebral palsy.

1.15.5 Any multidisciplinary team should:

- recognise that mental health problems and emotional difficulties can be as important as physical health problems for children and young people with cerebral palsy
- explore such difficulties during consultations
- recognise that assessing psychological problems can be challenging in children and young people with communication difficulties or learning disabilities.

1.15.6 Think about and address the following contributory factors if a change in emotional state occurs in a child or young person with cerebral palsy:

- pain or discomfort (see section 1.13)
- frustration associated with communication difficulties
- social factors, such as a change in home circumstances or care provision.

1.15.7 Use validated tools, such as the Child Health Questionnaire and the Strengths and Difficulties Questionnaire, to assess mental health problems in children and young people with cerebral palsy.

Management

1.15.8 Refer the child or young person for specialist psychological assessment and ongoing management if emotional and behavioural difficulties persist or there are concerns about their mental health.

1.15.9 Work in partnership with the child or young person with cerebral palsy, and their parents and primary carers, when assessing and managing mental health problems and setting goals.

1.15.10 When making an individual management plan to address the mental health needs of a child or young person with cerebral palsy, take into account ways of providing support to parents or carers.

1.15.11 Recognise that there are specific challenges in managing and minimising the impact of mental health problems in children and young people with cerebral palsy. These include:

- communication difficulties
- comorbidities, particularly epilepsy and pain
- side effects and drug interactions of multiple medications (polypharmacy)
- specific social care needs.

1.16 Sensory and perceptual difficulties

1.16.1 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. These may include:

- primary sensory disorders, such as the way visual or hearing information is processed
- complex disorders of sensory processing and perception, such as planning movements.

1.16.2 For children and young people with cerebral palsy who have difficulties with processing sensory and perceptual information:

- agree a functional, goal-orientated, individualised programme in partnership with parents or carers
- explain to parents or carers that there is a lack of evidence to support specific interventions.

1.17 Information on other comorbidities

1.17.1 Assess children and young people with cerebral palsy regularly for developmental and clinical comorbidities, and recognise that these can have an important impact on wellbeing, function and participation.

1.17.2 Manage comorbidities, and refer the child or young person for further specialist care if necessary (for example, if a management programme is unsuccessful).

Visual impairment

1.17.3 Talk to children and young people and their parents or carers about visual impairment that can be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- visual impairment occurs in around 1 in 2 children and young people with cerebral palsy
- it may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment
- it may include impairment of control of eye movements, ocular function and cerebral visual processing
- regular ongoing visual assessment is necessary.

1.17.4 Regularly assess children and young people with cerebral palsy for signs of cortical visual impairment, bearing in mind that this:

- occurs in around 1 in 5 children and young people with cerebral palsy
- may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment
- may be difficult to recognise in the early stages.

Hearing impairment

1.17.5 Talk to children and young people and their parents or carers about hearing impairment that can be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- hearing impairment occurs in around 1 in 10 children and young people with cerebral palsy
- it may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment
- it is more common in people with dyskinetic or ataxic cerebral palsy than in those with spastic cerebral palsy
- regular ongoing hearing assessment is necessary.

Learning disabilities

1.17.6 Talk to children and young people and their parents or carers about learning disabilities that can be associated with cerebral palsy (for example, problems with knowledge acquisition, memory and understanding and use of language). Information that may be useful to discuss includes the following:

- learning disabilities occur in around 1 in 2 children and young people with cerebral palsy
- severe learning disabilities (IQ below 50) occur in around 1 in 2 of these
- learning disabilities can be associated with any functional level, but prevalence increases with increasing severity of motor impairment:
  - GMFCS level I or II: around 1 in 3 have an IQ below 70
  - GMFCS level III, IV or V: around 2 in 3 have an IQ below 70.

Behavioural difficulties

1.17.7 Talk to children and young people and their parents or carers about behavioural difficulties that can be associated with cerebral palsy. Information that may be useful to discuss includes that around 2–3

in 10 children and young people with cerebral palsy have 1 or more of the following:

- emotional and behavioural difficulties that have an effect on the child or young person's function and participation
- problems with peer relationships
- difficulties with attention, concentration and hyperactivity
- conduct behavioural difficulties.

1.17.8 Support children and young people with cerebral palsy and their families and carers to recognise behavioural problems.

1.17.9 Manage routine behavioural problems within the multidisciplinary team, and refer the child or young person to specialist services if problems persist.

Vomiting, regurgitation and reflux

1.17.10 Advise parents or carers that vomiting, regurgitation and gastro-oesophageal reflux are common in infants, children and young people with cerebral palsy. If there is a marked change in the pattern of vomiting, assess for a clinical cause.

1.17.11 For guidance on identifying and managing gastro-oesophageal reflux disease, see the NICE guidelines on gastro-oesophageal reflux disease in children and young people and gastro-oesophageal reflux disease and dyspepsia in adults.

Constipation

1.17.12 Recognise that around 3 in 5 children and young people with cerebral palsy have chronic constipation, and:

- discuss this with children and young people and their parents or carers
- carry out regular clinical assessments for constipation.

1.17.13 For guidance on identifying and managing constipation in under 18s, see the NICE guideline on constipation in children and young people.

Epilepsy

1.17.14 Advise children and their parents or carers that epilepsy may be associated with cerebral palsy. Information that may be useful to discuss includes the following:

- epilepsy occurs in around 1 in 3 children with cerebral palsy
- it may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment
- it is reported in around 1 in 2 children with dyskinetic cerebral palsy.

1.17.15 Ensure that dyskinetic movements are not misinterpreted as epilepsy in children with cerebral palsy.

1.17.16 For guidance on identifying and managing epilepsy, see the NICE guideline on epilepsies: diagnosis and management.

1.18 Care needs

1.18.1 Recognise the importance of social care needs in facilitating participation and independent living for children and young people with cerebral palsy.

1.18.2 Assess the care needs of every child with cerebral palsy, and of their parents or carers, at diagnosis, and reassess regularly if appropriate.

1.18.3 Provide information on the following areas of care at diagnosis of cerebral palsy and as appropriate thereafter:

- social care services
- financial support, welfare rights and charities

- support groups (including emotional support for the child or young person and their families and carers, including siblings).

1.18.4 Address and review the specific needs of the child or young person with cerebral palsy in relation to accessing their physical environment (for example, home, school, healthcare, workplace, community), in order to optimise their functional participation. Think about the following aspects:

- mobility
- equipment, particularly wheelchairs and hoists
- transport
- toileting and changing facilities.

1.18.5 Ensure effective communication and integrated team working between health and social care providers.

1.18.6 When assessing care needs, take into account the role of any social, cultural, spiritual or religious networks that support the child or young person with cerebral palsy and their family.

1.18.7 Take into account that English may not be the first language of children and young people with cerebral palsy or their parents or carers. Provide an interpreter if necessary. Follow the principles in the NICE guideline on patient experience in adult NHS services.

1.18.8 Explore with the child or young person and their parents or carers the value of respite services, such as carer support either at home or in another setting.

1.18.9 Ensure that individual, tailored care pathways (including pain management, rehabilitation and equipment) are in place after any major surgical intervention for children and young people with cerebral palsy (see also the NICE guideline on spasticity in under 19s).

1.19 Transition to adults' services

1.19.1 Follow the NICE guideline on transition from children's to adults' services for young people using health or social care services.

Overarching principles

1.19.2 Recognise that challenges for young people with cerebral palsy continue into adulthood, and ensure that their individual developmental, social and health needs, particularly those relating to learning and communication, are addressed when planning and delivering transition.

1.19.3 Recognise that for young people with cerebral palsy there may be more than one transition period in health and social care settings; for example, college, resident educational and adult home settings.

Transition planning

1.19.4 Develop clear pathways for transition that involve:

- the young person's GP **and**
- named paediatricians and named clinicians in adults' services, both locally and regionally, who have an interest in the management of cerebral palsy.

1.19.5 Ensure that professionals involved in providing future care for young people with cerebral palsy have sufficient training in order to address all their health and social care needs.

1.19.6 As a minimum standard of care, ensure that the young person has access to adults' services both locally and regionally that include healthcare professionals with an understanding of managing cerebral palsy.

1.19.7 Ensure that all relevant information is communicated at each point of transition; for example, using a personal 'folder' containing relevant information as described in recommendation 1.6.5 (see

also recommendations about support before transfer in the NICE guideline on transition from children's to adults' services).

1.19.8 Recognise that functional challenges (including those involving eating, drinking and swallowing, communication and mobility) and physical problems (including pain and discomfort) may change over time for people with cerebral palsy, and take this into account in transition planning.

1.19.9 Provide a named worker to facilitate timely and effective transition, and recognise the importance of continuity of care (see also recommendations about transition planning in the NICE guideline on transition from children's to adults' services and about continuity of care and relationships in the NICE guideline on patient experience in adult NHS services).

Terms used in this guideline

Anthropometric measurements

Body measurements that include weight, height, knee height, mid-upper arm circumference, waist circumference, head circumference and skinfold thickness measurements.

Child

A person aged between 1 and 11 years of age.

Infant

A person older than 28 days but younger than 1 year of age.

Walk unaided

The ability to walk independently in the community without the need for supportive devices such as a walking frame, tripod sticks or crutches.

Young person

A person aged between 12 and 24 years of age.

Putting this guideline into practice

[This section will be completed after consultation]

NICE has produced tools and resources [link to tools and resources tab] to help you put this guideline into practice.

Putting recommendations into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes recommended for clinical practice that can be done quickly – like changes in prescribing practice – should be shared quickly. This is because healthcare professionals should use guidelines to guide their work – as is required by professional regulating bodies such as the General Medical and Nursing and Midwifery Councils.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help organisations put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.

2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.

4. **Think about what data you need to measure improvement** and plan how you will collect it. You may want to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.

5. **Develop an action plan**, with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.

6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.

7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.

8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See our into practice pages for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) Achieving high quality care – practical experience from NICE. Chichester: Wiley.

Context

Cerebral palsy is the most common cause of physical disability in children and young people in the developed world, with a prevalence of around 2–2.5 per 1000. The term describes a group of permanent, non-progressive abnormalities of the developing fetal or infant brain that lead primarily to disorders of movement and posture, causing 'activity limitation' and 'functional impact'.

The interaction of primary neurological and secondary physiological factors leads to challenges in terms of both early recognition of cerebral palsy and lifelong management for the person and their families. Infants with cerebral palsy generally present to services in 1 of 2 ways: either by identification of atypical motor patterns in those considered at high risk because of antenatal or perinatal complications, or because of atypical motor development picked up during background population assessment.

Recognition of clinical risk and management for people with cerebral palsy change throughout their lives. Understanding the aetiology of the condition, and so minimising the risk and early impact on the brain, may directly affect lifelong outcomes.

The management of cerebral palsy is a two-pronged approach, and is provided by a variety of multidisciplinary services with a focus on maximising individual function, choice and independence. The first of these is optimising movement and posture while minimising potential secondary musculoskeletal deformity. The second is recognising and intervening to address the many developmental and clinical comorbidities that are associated with cerebral palsy. The former is dealt with by NICE guideline CG145 on spasticity in under 19s, which concentrates on the motor disorder of cerebral palsy.

This guideline focuses on the second of these aspects, particularly where there may be variation in practice and in patient and family experience across England and Wales. It looks at practical areas of management that are important to children and young people with cerebral palsy, their families and carers, and a wide variety of healthcare and other professionals. These

include causation, recognition and prognosis, as well as the associated developmental and clinical comorbidities.

More information

To find out what NICE has said on topics related to this guideline, see our web pages on cerebral palsy and spasticity.

Recommendations for research

The guideline committee has made the following recommendations for research. The committee's full set of research recommendations is detailed in the full guideline.

1 Optimising nutritional status in children with cerebral palsy

What is the clinical and cost effectiveness of early interventions for optimising protein, energy and micronutrient nutritional status in children with cerebral palsy?

Why this is important

Most children with cerebral palsy have clinically significant oral motor dysfunction, and around 20% of children with cerebral palsy are undernourished. Provision of high-calorie and high-protein diets, either orally or via tube feeding, is well established to improve weight gain. Supplementation with micronutrients (such as vitamin D) is also necessary to ensure nutritional adequacy and prevent deficiencies.

There is a lack of evidence about whether a more proactive approach to nutrition support in infants and young children with cerebral palsy would improve growth and other aspects of clinical and developmental function. There is also insufficient evidence to determine whether higher intake of individual nutrients may have additional benefits; for example, there is emerging evidence that increased protein intake improves muscle strength, albeit in a different population (healthy older adults). A multicentre randomised controlled trial is needed that assesses the clinical and cost effectiveness of

early interventions to optimise protein, energy and micronutrient nutritional status in this population.

2 Managing communication difficulties in children cerebral palsy

What is the clinical and cost effectiveness of interventions for managing communication difficulties in children with cerebral palsy?

Why this is important

Communication is an essential life skill that is recognised as a human right. Some children with cerebral palsy find communication difficult because they have little or no clear speech, resulting in social isolation. Alternative and augmentative communication (AAC; including signing, symbols, communication charts and computer-based speech generating devices) is now an established part of clinical practice, but the evidence base to inform good practice is very limited. Research evidence in this area is largely limited to single case studies, with a focus on acquisition of skills (for example, recognising symbols or making requests).

A multicentre randomised controlled trial is needed to look at the effectiveness of interventions that include AAC methods and carer training in improving the participation of children at different stages of communication development.

3 Recognition and early management of pain in children and young people with cerebral palsy

Does use of pain assessment tools by parents or carers improve the recognition and early management of pain in children and young people with cerebral palsy in a community setting?

Why this is important

Pain and discomfort are increasingly recognised as having a major impact on quality of life for children and young people with cerebral palsy and their parents or carers. A variety of assessment tools have been developed to quantify qualitative pain behaviours in children and young people with cerebral

palsy who cannot communicate. The use of these tools in hospital to help identify signs and symptoms of pain and discomfort associated with specific intervention has become widespread. These tools may also help parents or carers recognise pain and discomfort in children and young people with cerebral palsy in community settings. Reducing pain and discomfort outside hospital is of clear importance to help with all aspects of quality of life, including learning, development and clinical wellbeing. A prospective cohort study is needed that looks at whether use of pain assessment tools by parents or carers improves the recognition and early management of pain.

4 Association between treating infections in pregnancy and rates of cerebral palsy

What is the association between different antibiotic regimes to treat genito-urinary and respiratory tract infections in pregnant women and subsequent rates of cerebral palsy in children?

Why this is important

Treating infection in pregnancy is of prime importance for the woman's health. In large population studies of pregnant women, chorioamnionitis, other genito-urinary infections and respiratory tract infections that result in admission to hospital are significant risk factors for the child being diagnosed with cerebral palsy. The mechanisms are uncertain, but include cytokine-induced damage to developing white matter leading to periventricular leukomalacia and sensitisation of the fetal brain to damage from hypoxia. A prospective multicentre study is needed that looks at the effects of different antibiotic regimes for treating genito-urinary infections in pregnant women on subsequent rates of cerebral palsy.

5 Prevalence of mental health problems in young people (up to the age of 25) with cerebral palsy

What is the prevalence of mental health problems in young people (up to the age of 25) with cerebral palsy?

Why this is important

A number of factors predispose young people with cerebral palsy to an increased risk of mental health problems, which will have a marked impact on their quality of life and challenges of care. However, there is a lack of evidence about the prevalence of such problems in this population. Improved guidance would allow greater access to suitable services for young people with cerebral palsy. In addition, given the link between mental and physical health, improvements in mental healthcare could potentially influence physical health and comorbidities. A prospective cohort study or cross-sectional study is needed that looks at the prevalence of mental health problems in this population.