

# Cerebral palsy in under 25s: assessment and management

NICE guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

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This guideline is the basis of QS162.

## Overview

This guideline covers diagnosing, assessing and managing cerebral palsy in children and young people from birth up to their 25th birthday. It aims to make sure they get the care and treatment they need for the developmental and clinical comorbidities associated with cerebral palsy, so that they can be as active and independent as possible.

NICE has also produced a guideline on [spasticity in under 19s](#).

## *Who is it for?*

- Healthcare professionals
- Social care professionals
- Children and young people with cerebral palsy, and their families and carers

## 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)<sup>[1],[2]</sup>
  - 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.

#### 1.1.2 Provide an enhanced clinical and developmental follow-up programme (see [section 1.3](#)) for children 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 1 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 to investigate aetiology in a child or young person with suspected or known cerebral palsy if this is not clear from:

- antenatal, perinatal and postnatal history
- their developmental progress
- findings on clinical examination



- results of 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 general anaesthesia or sedation is usually needed for young children having MRI.
- The views of the child or young person and their parents or carers.

1.2.13 Explain to parents or carers and the child or young person with cerebral palsy that it is not always possible to identify a cause for cerebral palsy.

1.2.14 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](#)).

1.2.15 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 by a multidisciplinary team for children up to 2 years (corrected for gestational age) who are at increased risk of developing cerebral palsy (see [recommendation 1.1.1](#)).

1.3.2 Consider using the General Movement Assessment (GMA) during routine neonatal follow-up assessments for children between 0 and 3 months who are at increased risk of developing cerebral palsy.

1.3.3 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 head control, rolling and crawling
- feeding difficulties.

1.3.4 Refer children who are at increased risk of developing cerebral palsy and who have any of the abnormal features listed in recommendation 1.3.3 to a child development service for an urgent assessment.

1.3.5 Recognise that the most common delayed motor milestones in children with cerebral palsy are:

- not sitting by 8 months (corrected for gestational age)
- not walking by 18 months (corrected for gestational age)
- early asymmetry of hand function (hand preference) before 1 year (corrected for gestational age).

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

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

1.3.8 If there are concerns that a 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 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 *Multidisciplinary care*

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

1.5.2 Recognise that children and young people with cerebral palsy and their parents or carers have a central role in decision-making and care planning.

1.5.3 Ensure that the child or young person with cerebral palsy has access to a local integrated core multidisciplinary team that:

- is able to meet their individual needs within agreed care pathways
- can provide the following expertise, as appropriate, through a local network of care:
  - paediatric or adult medicine
  - nursing care
  - physiotherapy
  - occupational therapy

- – speech and language therapy
- dietetics
- psychology
- can enable access to other services within their local or regional network as appropriate, including:
  - paediatric or adult 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).

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

1.5.5 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.

## Medicines optimisation

1.5.6 For guidance on the safe and effective use of medicines, see the NICE guideline on [medicines optimisation](#).

## Movement and posture

1.5.7 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](#))
  - expected developmental progress
  - comorbidities
  - availability of specialist equipment
  - 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 [1.18.3](#) and [1.18.8](#))
  - educational placement (including specialist preschool and early years settings)
  - 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 recommendations [1.9.7](#) to [1.9.10](#)).

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 (electronic or otherwise) 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 provided with information, by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs:

- menstruation
- fertility and contraception
- sex and sexuality

- parenting.

1.6.7 Provide information to the child or young person and their parents or carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) 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 Do not rely on MRI alone for predicting prognosis in children with cerebral palsy.

1.7.5 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.

## 1.8 *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, altered breathing pattern or change in colour while eating



- or drinking
  - recurrent chest infection
  - mealtimes regularly being stressful or distressing for the child or young person or their parents or carers
  - 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 tertiary specialist assessment, including advice from other services (such as paediatric surgery and respiratory

paediatrics).

## 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 difficulties 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 cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments and 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 disability (intellectual disability).

### 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 Recognise the importance of early intervention to improve the communication skills of children and young people with cerebral palsy.
- 1.9.6 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.
- 1.9.7 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.
- 1.9.8 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.
- 1.9.9 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.
- 1.9.10 Provide individualised training in communication techniques for families, carers, preschool and 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 measuring their height and weight (or consider alternative [anthropometric measurements](#), particularly if height and weight cannot be measured).
- 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 the use of anticholinergic medication:
- glycopyrronium bromide<sup>[3]</sup> (oral or by enteral tube) or
  - transdermal hyoscine hydrobromide<sup>[4]</sup> or
  - trihexyphenidyl hydrochloride<sup>[5]</sup> for children with dyskinetic cerebral palsy, but only with input from specialist services.

When choosing which medicine to use, take into account the preferences of the child or young person and their parents or carers, and the age range and indication covered by the marketing authorisations.

- 1.11.3 Regularly review the effectiveness, tolerability and side effects of all drug

treatments used for saliva control.

- 1.11.4 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.
- 1.11.5 Consider specialist assessment and use of botulinum toxin A injections<sup>[6]</sup> to the salivary glands with ultrasound guidance to reduce the severity and frequency of drooling in children and young people with cerebral palsy if anticholinergic drugs provide insufficient benefit or are not tolerated.
- 1.11.6 Advise children and young people and their parents or carers that high-dose botulinum toxin A injection<sup>[6]</sup> to the salivary glands can rarely cause swallowing difficulties, and so they should return to hospital immediately if breathing or swallowing difficulties occur.
- 1.11.7 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.

## 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 1 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 a 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, discomfort and distress*

#### Causes

- 1.13.1 Explain to children and young people with cerebral palsy and their parents or carers that pain is common in people with cerebral palsy, especially those with more severe motor impairment, and this should be recognised and addressed.
- 1.13.2 Recognise that common condition-specific causes of pain, discomfort and distress 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)
  - muscle fatigue and immobility
  - constipation
  - vomiting
  - gastro-oesophageal reflux disease.
- 1.13.3 Recognise that usual causes of pain, discomfort and distress that affect children and young people generally also occur in 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.

## Assessment

1.13.4 Take into account that parents and familiar carers have a key role in recognising and assessing pain, discomfort and distress 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 disability (intellectual disability)
  - there are difficulties with registering or processing sensory information (see [section 1.16](#))
- ask about signs of pain, discomfort, distress and sleep disturbances (see [section 1.14](#)) 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, discomfort, distress and sleep if the cause of these is not clear after routine assessment.

## Management

1.13.9 For reversible causes of pain, discomfort and distress identified in children and young people with cerebral palsy, treat the cause as 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 and sciatica in over 16s](#)
- [urinary incontinence in neurological disease](#)
- [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:

- take into account the impact of anxiety, depression or other possible mental health problems
- 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 If a trial of analgesia is unsuccessful, refer the child or young person to a specialist pain multidisciplinary team, which may be a palliative care service, for a more detailed assessment.

## 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, staying asleep or 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<sup>[7]</sup> 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.
- 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](#) and [depression in adults](#)

- with a chronic physical health problem
- 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
- autism spectrum disorder in under 19s: recognition, referral and diagnosis, autism spectrum disorder in under 19s: support and management and autism spectrum disorder 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
  - 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 disability (intellectual disability).
- 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 with cerebral palsy 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 medicines (polypharmacy)
- adverse effects of medicines used for managing mental health problems on motor function
- adverse effects of medicines used for managing motor function on mental health
- specific social care needs.

## 1.16 *Registering and processing sensory information*

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, which can affect function and participation. Sensory difficulties may include:

- primary sensory disorders in any of the sensory systems, such as processing of visual or auditory information (for example, difficulties with depth perception may affect the ability to walk on stairs) (see recommendations [1.17.3](#) to [1.17.8](#))
- disorders of sensory processing and perception, such as planning movements or being able to concentrate and pay attention.

1.16.2 For children and young people with cerebral palsy who have difficulties with registering and processing sensory 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 Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.
- 1.17.4 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:
- around 1 in 2 children and young people with cerebral palsy will have some form of visual impairment
  - visual impairment may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment.
- 1.17.5 Talk to children and young people and their parents or carers about the different types of visual impairment that can be associated with cerebral palsy. Explain that these could include 1 or more of the following:
- problems with controlling eye movements
  - strabismus (squint)
  - refractive errors (short or long sighted or distorted image)
  - problems of eye function, including retinopathy of prematurity
  - impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision)
  - visual field defects (loss of the part of usual field of vision).
- 1.17.6 If concerns about visual impairment are raised by parents, carers or members of the care team, consider referring the child or young person with cerebral palsy to a specialist team for evaluation of the whole visual system (including eye health, eye movements, refraction, squint and visual acuity), especially if there are communication difficulties.
- 1.17.7 Regularly assess children and young people with cerebral palsy for signs of cerebral 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

1.17.8 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 disability (intellectual disability)

1.17.9 Talk to children and young people and their parents or carers about learning disability (intellectual disability) 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 disability (IQ below 70) occurs in around 1 in 2 children and young people with cerebral palsy
- severe learning disability (IQ below 50) occurs in around 1 in 4 children and young people with cerebral palsy
- learning disability 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

- 1.17.10 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 to 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.
- 1.17.11 Recognise that difficulties with registering or processing sensory information (see [section 1.16](#)) may present as behavioural difficulties.
- 1.17.12 Support children and young people with cerebral palsy and their families and carers to recognise behavioural difficulties.
- 1.17.13 Manage routine behavioural difficulties within the multidisciplinary team, and refer the child or young person to specialist services if difficulties persist.

## Vomiting, regurgitation and reflux

- 1.17.14 Advise parents or carers that vomiting, regurgitation and gastro-oesophageal reflux are common in children and young people with cerebral palsy. If there is a marked change in the pattern of vomiting, assess for a clinical cause.
- 1.17.15 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

- 1.17.16 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.

1.17.17 For guidance on identifying and managing constipation in under 18s, see the NICE guideline on [constipation in children and young people](#).

## Epilepsy

1.17.18 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.

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

1.17.20 For guidance on identifying and managing epilepsy, see the NICE guideline on [epilepsies: diagnosis and management](#).

## 1.18 Care needs

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

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

1.18.3 Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter:

- social care services
- financial support, welfare rights and voluntary organisations

- support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings)
  - respite and hospice services.
- 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 11 years or younger.

### **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.

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<sup>[1]</sup> 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.

<sup>[2]</sup> The NICE guideline on [preterm labour and birth](#) covers preventing or delaying preterm birth, steroid treatment for maturation of fetal lungs and neuroprotection for the baby.

<sup>[3]</sup> At the time of publication (January 2017), glycopyrronium bromide (oral solution) did not have a

UK marketing authorisation for use in children under 3 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.

<sup>[4]</sup> At the time of publication (January 2017), 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.

<sup>[5]</sup> At the time of publication (January 2017), 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.

<sup>[6]</sup> At the time of publication (January 2017), 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.

<sup>[7]</sup> At the time of publication (January 2017), 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.

## Putting this guideline into practice

NICE has produced [tools and resources](#) 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 to 2.5 per 1,000. The term describes a group of permanent, non-progressive abnormalities of the developing fetal or neonatal 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. Children 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. This is dealt with by NICE guideline CG145 on [spasticity in under 19s](#), which concentrates on the motor disorder of cerebral palsy.

The second aspect of management is recognising and intervening to address the many developmental and clinical comorbidities that are associated with cerebral palsy. This is the subject of this guideline, with particular focus on 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 and recognition of cerebral palsy, prognosis and the associated developmental and clinical comorbidities.

## *More information*

You can also see this guideline in the NICE pathway on [cerebral palsy in under 25s](#).

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

See also the guideline committee's discussion and the evidence reviews (in the [full guideline](#)), and information about [how the guideline was developed](#), including details of the committee.

## 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 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 with 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 (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 alternative and augmentative communication 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 interventions 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.

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#### *Accreditation*

