NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline

Cerebral palsy in adults

Draft for consultation, July 2018

This guideline covers care and support for adults with cerebral palsy. It focuses on recognising, assessing and managing muscle tone as well as common complications and comorbidities. It also covers improving participation and service organisation. It aims to improve the health and wellbeing of adults with cerebral palsy.

NICE has also produced guidelines on cerebral palsy in under 25s: assessment and management and spasticity in under 19s: management.

Who is it for?

- Healthcare professionals from primary and secondary care
- Social care practitioners and professionals from other sectors, such as non-governmental, education and voluntary organisations
- People responsible for planning services, commissioners and providers
- Adults with cerebral palsy their families and carers

This draft guideline contains:

- the draft recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice
- the guideline context.

Information about how the guideline was developed is on the guideline's page on the NICE website. This includes the evidence reviews, the scope, and details of the committee and any declarations of interest.

Contents

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 Service organisation

Moving into adults' services

1.1.1 For young adults moving from children's to adults' services, ensure that transitions to adult services are managed in line with the NICE guidelines on cerebral palsy in under 25s and transition from children's to adults' services for young people using health or social care services.

Access to services

1.1.2 Refer adults with cerebral palsy to a multidisciplinary team experienced in the management of neurological impairments if:

- their ability to carry out their usual daily activities deteriorates **or**
- a neurosurgical or orthopaedic procedure is being considered that may affect their ability to carry out their usual daily activities.

1.1.3 Recognise that reassessment by the multidisciplinary team and different clinical services may be needed by adults with cerebral palsy to ensure that their care meets their changing needs at different points in their lives.

1.1.4 Commissioners and service providers should develop pathways that allow adults with cerebral palsy access to a local network of care that includes:

- advocacy support
- learning disability services

- mental health services
- orthopaedic surgery (and post-surgery rehabilitation)
- rehabilitation engineering services
- rehabilitation medicine or specialist neurology services
- secondary care expertise for managing comorbidities (for example, respiratory, gastrointestinal and urology services)
- social care
- specialist therapy services (for example physiotherapy and occupational therapy)
- wheelchair services.

1.1.5 Ensure that adults with cerebral palsy, their families and carers, and their primary care teams are provided with information about their local network of specialist services.

1.1.6 Explain to the person with cerebral palsy and their family members and carers their right to a care and support needs assessment, in line with the Care Act 2014, and discuss with them the type of support available.

1.1.7 Recognise and address barriers to accessing primary and secondary care for adults with cerebral palsy. These may include:

- personal barriers, such as:
  - communication difficulties between the adult and healthcare professionals
  - mental health-related factors such as depression, anxiety
  - lack of an advocate (for example, a family member, carer or friend) if needed
  - social and emotional factors such as fear of stigma, lack of motivation and exhaustion
- physical barriers, such as:
  - inadequate physical access to buildings
  - difficulties with transport
- organisational barriers, such as:

  - lack of availability of appropriate equipment (for example, hoists and wheelchair weighing scales) and adequate changing and toilet facilities
  - inadequate time given in appointments, for example, to allow for hoisting and dressing.

1.1.8 When an adult with cerebral palsy is admitted to hospital, the staff should always offer advocacy, health and personal care (toileting, washing, nutrition and hydration) even if the person has a family member, carer or advocate there to support them.

1.1.9 Provide information about national screening services (for example breast, colon and cervical cancer screening) to adults with cerebral palsy.

To find out why the committee made recommendations on moving into adults' services and access to services and how they might affect practice, see rationale and impact.

Ongoing care

1.1.10 Consider regular reviews for adults with cerebral palsy, tailored to their needs and preferences. Agree with the person the frequency of review and which services should be involved based on their needs and preferences.

1.1.11 Offer an annual review of the person's clinical and functional needs, carried out by a member of the clinical team, for people with cerebral palsy who have complex needs (such as GMFCS levels IV and V) and any of the following:

- with communication difficulties
- with learning disabilities
- in long-term care settings
- living in the community without sufficient practical and social support (for example, being cared for by elderly, frail parents)
- with multiple comorbidities.

1.1.12 Discuss with the person with cerebral palsy (and their family and carers, if agreed) what information should inform the regular or annual review, and who should receive clinical information following review (for example their GP).

1.1.13 Record details of the person's review and share the information with relevant people (for example healthcare professionals and social care practitioners), with the person's permission.

1.1.14 Discuss with the person with cerebral palsy (and their family and carers, if agreed) who will be their main point of contact between reviews.

1.1.15 If an adult with cerebral palsy chooses not to have regular reviews, offer the person (and their family and carers, if agreed) information on when to contact a healthcare professional and how to access the specialist services that they may need. Ensure that the person's GP and multidisciplinary team are aware that they do not want to be reviewed regularly (with the person's permission).

1.1.16 For adults with cerebral palsy and learning disabilities, offer an annual health check in primary care (see NHS England's information on annual health checks and NICE's guidelines on care and support of people growing older with learning disabilities and challenging behaviour and learning disabilities). Ensure that a referral to specialist services is made if a need for this is identified.

To find out why the committee made recommendations on ongoing care and how they might affect practice, see rationale and impact.

1.2 Function and participation

Communication

1.2.1 Be aware that speech and communication needs in adults with cerebral palsy may change with time and social circumstances.

1.2.2 At every review, ask adults with cerebral palsy (and their families and carers, if agreed) about any changes in their hearing, speech and communication.

1.2.3 Explore with the person with cerebral palsy who has communication difficulties whether they have a potential need for alternative and augmentative communication systems.

1.2.4 Be aware that adults with cerebral palsy and poor intelligibility of speech may still prefer to use speech as their main means of communication.

1.2.5 Refer adults with cerebral palsy who have communication difficulties to speech therapy services to assess their need for:

- alternative or augmentative communication systems **or**
- intensive speech therapy to improve their speech or expressive language.

1.2.6 Ensure that training is provided for people with cerebral palsy using alternative and augmentative communication systems and their families, carers and other key communication partners in home, care, social or work environments.

1.2.7 See also NICE's guideline on patient experience in adult NHS services for general advice on how to provide information and communicate with adults receiving care.

To find out why the committee made the recommendations on communication and how they might affect practice, see rationale and impact.

Vocational and independent living skills

1.2.8 Recognise and address external factors that prevent people with cerebral palsy from participating in activities, including:

- environmental barriers, for example access to buildings
- social barriers, for example carers with unmet training needs

- institutional barriers, for example policies and situations that put people with cerebral palsy at a disadvantage.

1.2.9 If adults with cerebral palsy have complex physical, cognitive, language or sensory needs, consider offering referral to occupational therapy services to assess the person's functional needs and provide individualised support.

1.2.10 Give adults with cerebral palsy information about assessments of vocational and independent living skills that is tailored to the person's functional abilities and goals (see NICE's guideline on patient experience in adult NHS services for advice on information giving and NICE's guideline on people's experience in adult social care service for advice and information provision).

1.2.11 If an adult with cerebral palsy finds it difficult to participate in a chosen activity, assess their physical and mental health and address any factors identified that may be affecting participation, if possible.

1.2.12 Refer adults with cerebral palsy who would like to work or live independently, or who are already working, to a professional with expertise in vocational and independent living skills. Give information and advice, which could include:

- 'Access to work' schemes
- employment support to include workplace training and job retention
- leisure activities
- occupational health assessment or workplace assessment
- statutory welfare benefits
- supporting a planned exit from the workforce if it becomes too difficult to continue working
- vocational rehabilitation
- voluntary work.

See also NICE's guideline on workplace health: management practices for advice on improving the health and wellbeing of employees.

To find out why the committee made the recommendations on vocational and independent living skills and how they might affect practice, see rationale and impact.

Electronic assistive technology

1.2.13 Discuss with adults with cerebral palsy the potential need for electronic assistive technology if they have problems with participation and independence.

1.2.14 If adults with cerebral palsy have complex physical, cognitive, language or sensory needs, consider referring them to services providing information, assessment and provision of electronic assistive technology.

1.2.15 If adults with cerebral palsy are already using electronic assistive technology, discuss at every review any:

- problems or concerns they have with their equipment
- potential changes in their needs.

1.2.16 Be aware that using electronic assistive technology may mean that the person with cerebral palsy needs less contact with their carers, which may reduce their social interaction.

1.2.17 Ensure that training is provided for adults with cerebral palsy using electronic assistive technology, and for their families or carers, if appropriate.

To find out why the committee made the recommendations on electronic assistive technology and how they might affect practice, see rationale and impact.

Physical activity

1.2.18 Discuss with adults with cerebral palsy (and their families or carers, if agreed) the importance of physical activity in maintaining general fitness and physical and mental health.

1.2.19 Provide information on local services that support people with cerebral palsy to take part in physical activity.

1.2.20 Consider referring people with cerebral palsy to services with experience and expertise in neurological impairments that can provide support with physical activities (including sport) and tasks of daily living. Depending on local service provision and the person's needs, this may be to one of the following services:

- physiotherapy
- occupational therapy
- rehabilitation engineering services
- wheelchair services.

Orthopaedic surgery

1.2.21 If participation in physical activities is limited by pain or joint problems that do not respond to any other treatments, consider referring the person to a musculoskeletal specialist or an orthopaedic surgeon with experience and expertise in managing musculoskeletal problems in adults with cerebral palsy.

To find out why the committee made the recommendations on physical activity and how they might affect practice, see rationale and impact.

1.3 Managing abnormal muscle tone

Agreeing goals for treatment

1.3.1 When considering any treatments for spasticity or dystonia, discuss with the adult with cerebral palsy (and their family and carers, if agreed):

- treatment goals (and document them) **and**
- the benefits and risks of treatments (for example, the risk of deterioration in function) as part of their multidisciplinary treatment strategy.

For further information on supporting people to actively participate in their care and shared decision-making see NICE's guideline on patient experience in adult NHS services.

Initial management of spasticity and dystonia

1.3.2 Be aware that adults with cerebral palsy may have both spasticity and dystonia. The severity of symptoms for both conditions may fluctuate in response to health, social and emotional wellbeing, and environmental factors.

1.3.3 At every review discuss with the person with cerebral palsy (and their family and carers, if agreed) factors that may exacerbate their spasticity or dystonia, such as:

- bladder problems (for example, urinary tract infection or bladder stones)
- constipation
- emotional distress
- pain
- posture
- pressure sores
- changes in home or work environments, including seating
- medication changes and side effects.

1.3.4 Address any modifiable factors identified that may be exacerbating spasticity or dystonia before discussing further management options with the adult with cerebral palsy.

1.3.5 Discuss with the person with cerebral palsy (and their family and carers, if agreed) the balance between the benefits and harms of treating spasticity and dystonia. In particular, explain that some people use their spasticity or dystonia to help their posture and ability to stand, walk or transfer, and that treatment may affect this.

To find out why the committee made the recommendations on agreeing goals for treatment and initial management of spasticity and dystonia, and how they might affect practice, see rationale and impact.

Spasticity

Enteral muscle relaxant drug[1] treatments

1.3.6 Consider enteral baclofen[1] as the first-line drug treatment for adults with cerebral palsy and generalised spasticity causing:

- functional impairment **or**
- pain **or**
- spasms.

1.3.7 Start enteral baclofen[1] treatment with a low dose and increase the dose gradually over about 4 weeks to achieve the optimum therapeutic effect.

1.3.8 If enteral baclofen[1] is ineffective or not tolerated by adults with cerebral palsy and generalised spasticity:

- refer the person to a tone or spasticity management service **or**
- discuss other drug treatment options (including other enteral muscle relaxants) with a tone management specialist.

1.3.9 Do not offer diazepam for spasticity in adults with cerebral palsy, except in an acute situation when spasticity is causing severe pain or anxiety.

1.3.10 Do not rapidly withdraw muscle relaxant drugs if the adult with cerebral palsy has been taking them for more than a few weeks. Reduce the dose gradually to avoid withdrawal symptoms.

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[1] At the time of consultation (July 2018) oral formulations of muscle relaxant drugs are usually not licensed to be given via an enteral feeding tube so administration via this route would be off-label. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

Botulinum toxin type A injections

1.3.11 Consider referring adults with cerebral palsy for botulinum toxin type A treatment if:

- they have spasticity in a limited number of muscle groups that is:
  - affecting their care (such as hygiene or dressing) **or**
  - causing pain **or**
  - impairing activity and participation, **or**
- a tone management specialist agrees that treatment targeted to focal muscle groups is likely to improve their function and symptoms.

To find out why the committee made the recommendations on drug treatments for spasticity, and how they might affect practice, see rationale and impact.

Neurosurgical treatments to reduce spasticity

Intrathecal baclofen

1.3.12 Consider referring adults with cerebral palsy to a tone or spasticity management service offering continuous pump-administered intrathecal baclofen therapy if they still have difficulties with spasticity, despite enteral muscle relaxant drug treatment or botulinum toxin type A treatment.

1.3.13 When considering continuous pump-administered intrathecal baclofen, give the person (and their family and carers, if agreed) information and discuss the procedure with them. This should include:

- the need for an intrathecal baclofen test to ensure treatment is suitable
- the surgical procedure for implanting the pump
- the need for regular hospital follow-up visits to ensure optimal dosage and pump refill
- the risks of implanting a pump and pump-related complications (for example battery failure or catheter leakage), which can result in baclofen withdrawal or overdose
- a review of 24-hour postural needs.

1.3.14 If continuous pump-administered intrathecal baclofen is being considered for an adult with cerebral palsy, perform an intrathecal baclofen test to assess if it is suitable before implanting a pump. This should involve:

- a test dose or doses of intrathecal baclofen given to the person by lumbar puncture **or**
- a test dose or doses of intrathecal baclofen given to the person through a spinal catheter.

1.3.15 Assess the effect of the test dose or doses of intrathecal baclofen on:

- reducing increased muscle tone
- reducing pain
- reducing the frequency of muscle spasms
- motor function, such as sitting, standing, walking.

1.3.16 Discuss with the adult with cerebral palsy (and their family and carers, if agreed) their views on the response to the intrathecal baclofen test.

Selective dorsal rhizotomy

1.3.17 Only consider selective dorsal rhizotomy for adults with cerebral palsy and spasticity after they have been assessed by a multidisciplinary team with:

- specialist training and expertise in the care of spasticity **and**
- access to the full range of treatment options.

See also NICE interventional procedure guidance on selective dorsal rhizotomy for spasticity in cerebral palsy.

1.3.18 When considering selective dorsal rhizotomy, give the person (and their family and carers, if agreed) information and discuss the impact of the procedure with them. This should include:

- that the procedure cannot be reversed
- the possible complications
- the need for prolonged physiotherapy and aftercare

- the possible impact on function
- that the long-term benefits are uncertain.

To find out why the committee made the recommendations on neurosurgical treatments to reduce spasticity, and how they might affect practice, see rationale and impact.

Dystonia

1.3.19 Refer adults with cerebral palsy and problematic dystonia (for example, causing problems with function, pain or participation) to a tone or spasticity management service to consider treatment options.

Enteral anti-dystonic drug[2] treatments

1.3.20 Do not prescribe levodopa[3] to manage dystonia in adults with cerebral palsy, except in the rare situation when it is used for a therapeutic trial in dopa-responsive dystonia.

1.3.21 Do not rapidly withdraw enteral drugs for treating dystonia if the person has been taking them for more than a few weeks. Reduce the dosage gradually to avoid withdrawal symptoms.

Botulinum toxin type A injections

1.3.22 Only consider botulinum toxin type A[4] treatment for focal dystonia in adults with cerebral palsy when:

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[2] At the time of consultation (July 2018) oral formulations of anti-dystonic drugs are usually not licensed to be given via an enteral feeding tube so administration via this route would be off-label. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[3] At the time of consultation (July 2018), levodopa did not have a UK marketing authorisation 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.

[4] At the time of consultation (July 2018), botulinum toxin type A did not have a UK marketing authorisation 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.

- the person is under the supervision of a tone or spasticity management service, and it is part of a wider programme of therapy **and**
- local dystonia is:
  - affecting their care (such as hygiene or dressing), **or**
  - causing pain **or**
  - impairing activity and participation.

1.3.23 When considering botulinum toxin type A[5] treatment, take into account and explain to the adult with cerebral palsy (and their family and carers, if agreed):

- that the severity and pattern of dystonia may change after treatment **and**
- the potential impact of treatment on function.

To find out why the committee made the recommendations on drug treatments for dystonia, and how they might affect practice, see rationale and impact.

Neurosurgical treatment to reduce dystonia

Intrathecal baclofen

1.3.24 Only consider continuous pump-administered intrathecal baclofen[6] if people with cerebral palsy still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment. Provide information and discuss the procedure, including

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[5] At the time of consultation (July 2018), botulinum toxin type A did not have a UK marketing authorisation 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.

[6] Although intrathecal baclofen is licensed in UK clinical practice for severe spasticity, at the time of consultation (July 2018) it did not have a UK marketing authorisation 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.

intrathecal baclofen testing, with the person (and their family or carer, if agreed) as described in recommendations 1.3.13 to 1.3.16.

Deep brain stimulation

1.3.25 If adults with cerebral palsy continue to have severe and painful dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A treatment, consider referring them to a specialised centre with experience in providing deep brain stimulation. See also NICE interventional procedure guidance on deep brain stimulation for tremor and dystonia (excluding Parkinson's disease).

To find out why the committee made the recommendations on treatments for dystonia, and how they might affect practice, see rationale and impact.

1.4 Assessment and monitoring of clinical complications and comorbidities

Bone and joint disorders

1.4.1 Discuss with adults with cerebral palsy (and their families or carers, if agreed) that:

- their musculoskeletal function may deteriorate gradually, and any changes should be investigated to identify treatable causes
- early recognition of bone and joint disorders enables early treatment, which may improve outcomes.

Osteoporosis and fracture risk

1.4.2 Be aware that low bone mineral density is common in adults with cerebral palsy, particularly in people:

- with reduced mobility or reduced weight bearing
- taking anticonvulsants or proton pump inhibitors
- who have had a previous low-impact fracture.

1.4.3 Consider assessing for risk of fractures secondary to osteoporosis in adults with cerebral palsy. Risk factors to assess include:

- needing help with moving or having to be moved, for example hoisting
- history of falls
- low BMI
- history of low-impact fractures
- other medical factors, for example steroid use, that may adversely affect bone health.

For more information about assessment of fracture risk, see NICE's guideline on osteoporosis: assessing the risk of fragility fracture.

1.4.4 Consider a dual-energy X-ray absorptiometry (DXA) assessment in adults with cerebral palsy who have 2 or more risk factors (see recommendation 1.2.3), particularly if they have had a previous low-impact fracture.

1.4.5 Consider referring adults with cerebral palsy for specialist assessment and management, for example, to a rheumatology, endocrinology or bone health service, if they have:

- a high fracture risk **or**
- a positive DXA result.

Disorders caused by abnormal musculoskeletal development

1.4.6 Be aware that, because of abnormal musculoskeletal development, adults with cerebral palsy are more likely to have bone and joint disorders.

1.4.7 Refer adults with cerebral palsy to a specialist orthopaedic or musculoskeletal service if a bone or joint disorder is suspected and causing pain or affecting posture or function. These may include:

- osteoarthritis
- cervical instability or spondylosis
- spinal deformity (including scoliosis, kyphosis and lordosis
- subluxation of the hips, wrist and shoulders

- biomechanical knee problems
- abnormalities of the foot structure.

1.4.8 Do not offer an X-ray to assess for hip subluxation or curvature of the spine in adults with cerebral palsy, unless the person is in pain or their posture or function is affected.

To find out why the committee made the recommendations on bone and joint disorders, and how they might affect practice, see rationale and impact.

Mental health problems

1.4.9 Identify and address mental health problems alongside physical health problems. Recognise that the impact of mental health problems and emotional difficulties can be as important as physical health problems for adults with cerebral palsy.

1.4.10 Follow NICE guidelines on identifying and managing specific mental health problems, and psychological and neurodevelopmental disorders in adults who have cerebral palsy, for example:

- attention deficit hyperactivity disorder
- depression in adults and depression in adults with a chronic physical health problem
- generalised anxiety disorder and panic disorder in adults.
- autism spectrum disorder in adults
- challenging behaviour and learning disabilities
- mental health problems in people with learning disabilities.

1.4.11 Tailor the identification and assessment of mental health problems and emotional difficulties to the needs and abilities of the person, in particular take into account communication difficulties or learning disabilities.

1.4.12 At every review explore with the adult with cerebral palsy (and their family and carers, if agreed) if they have any concerns about, for example, their:

- mood

- irritability
- behaviour
- social interaction
- general level of function.

1.4.13 Involve families and carers, when agreed, in identifying and assessing mental health problems and emotional difficulties in adults with cerebral palsy.

1.4.14 Take into account the specific factors that might affect the identifying, assessing and managing mental health problems and emotional difficulties in people with cerebral palsy. These may include:

- adverse effects of medicines (including the effects of medicines used for managing mental health problems on motor function or those used for managing motor function on mental health)
- communication difficulties
- learning disabilities
- impaired neuropsychological and executive function
- comorbidities, particularly epilepsy and pain
- side effects and drug interactions of multiple medicines (polypharmacy).

1.4.15 Discuss with the adult with cerebral palsy (and their family and carers, if agreed) if physical problems, such as pain, or frustration from communication difficulties or lack of stimulation are contributing to emotional distress or challenging behaviour.

To find out why the committee made the recommendations on mental health problems, and how they might affect practice, see rationale and impact.

Difficulties with eating and nutritional problems

1.4.16 Offer adults with cerebral palsy a regular weight check and BMI evaluation, and identify people who may be at risk of undernutrition or obesity (see also the NICE guideline on obesity: identification, assessment and management).

1.4.17 At every review, discuss with adults with cerebral palsy (and their family and carers, if agreed) whether they have difficulties with eating or there have been any changes in their eating habits. Ask about issues including:

- changes in appetite
- changes in the person's ability to feed themselves
- coughing or choking when eating
- food refusal
- increased frequency of chest infections (which may be related to swallowing difficulties or gastro-oesophageal reflux)
- an increase in the length of meal times.

1.4.18 Discuss if any of the following factors might be affecting the person's appetite, eating habits or weight:

- changes in carer support
- pain and depression
- reduced physical activity
- side effects of medications.

1.4.19 Be aware that adults with cerebral palsy with severe spasticity and dyskinesia may have an increased metabolic rate and a higher risk of malnutrition.

1.4.20 Follow the recommendations on screening for malnutrition, indications for nutrition support, and education and training of staff and carers related to nutrition in NICE's guideline on nutrition support for adults.

1.4.21 Refer adults with cerebral palsy to a relevant clinical specialist if assessment suggests they have difficulties with eating or malnutrition.

To find out why the committee made the recommendations on difficulties with eating and nutritional problems, and how they might affect practice, see rationale and impact.

Respiratory disorders

Identifying and monitoring respiratory disorders

1.4.22 Be aware that adults with cerebral palsy are at increased risk of respiratory failure. Symptoms may include:

- breathlessness
- changes in behaviour (such as irritability or inability to concentrate)
- daytime drowsiness
- worsening epilepsy
- headaches on waking
- increasing frequency of chest infections
- poor sleep pattern
- sleep apnoea.

1.4.23 Recognise that some risk factors for respiratory impairment are more common in adults with severe cerebral palsy (Gross Motor Function Classification System [GMFCS] level IV or V), such as:

- aspiration pneumonia
- chronic cardio-respiratory disorders (for example, cor pulmonale or pulmonary circulation hypertension)
- chronic suppurative lung disease
- kyphoscoliosis
- poor saliva control
- recurrent chest infections.

1.4.24 Refer adults with cerebral palsy and persistent or multiple signs and symptoms of respiratory impairment, or risk factors for respiratory impairment (see recommendations 1.2.22 and 1.2.23) to specialist services.

1.4.25 Consider assessment with spirometry for adults with cerebral palsy who are suspected to be at high risk of respiratory impairment.

To find out why the committee made the recommendations on identifying and monitoring respiratory disorders, and how they might affect practice, see rationale and impact.

Prophylactic treatments for respiratory infections

1.4.26 Offer vaccinations to adults with cerebral palsy and their carers, in line with the national immunisation programme (see the Green book for further information).

1.4.27 Do not offer prophylactic antibiotics for respiratory infections in adults with cerebral palsy, unless:

- the person is at high risk of respiratory infection (see recommendation 1.2.23) **and**
- they are offered on the advice of a respiratory specialist with expertise in neurodisability management.

1.4.28 If an adult with cerebral palsy is at high risk of respiratory infection, consider a prophylactic physiotherapy chest care review. This may include:

- postural management
- advice on exercise
- advice on training and care for family members and carers.

1.4.29 Refer adults with cerebral palsy and recurrent chest infections, if dysphagia is suspected, to a speech and language therapist with training in dysphagia to assess swallowing.

To find out why the committee made the recommendations on prophylactic treatments for respiratory disorders, and how they might affect practice, see rationale and impact.

Discussing the management of respiratory failure

1.4.30 If a person with cerebral palsy has symptoms of respiratory failure, or is at high risk of developing respiratory failure, discuss their management plan with them (and their family or carers if agreed), including:

- assessing the effectiveness and tolerability of treatment
- treatment goals and escalation plan of treatment
- managing complications
- options for managing progressive respiratory failure.

Assisted ventilation for respiratory failure

1.4.31 Consider home-based non-invasive ventilation for adults with cerebral palsy and respiratory failure.

1.4.32 If a person is having home-based non-invasive ventilation, carry out a review with a multidisciplinary team every 3 to 6 months. Assess and discuss with the person (and their family and carers, if agreed) the effectiveness, tolerability and whether agreed goals are being met.

1.4.33 Discuss with the person having non-invasive ventilation (and their family or carers, if agreed) their preferences for future treatment. Agree a plan for what should happen if an intercurrent infection (occurring during the progress of respiratory failure) causes an acute deterioration in respiratory function and record this in the person’s advance care plan.

1.4.34 If the person’s agreed treatment goals are not met by non-invasive ventilation, consider alternative treatment options such as tracheostomy or supportive care, taking into account the person’s preferences for future treatment (see recommendation 1.4.33).

Assisted ventilation for sleep apnoea

1.4.35 If an adult with cerebral palsy has sleep apnoea follow the advice in the NICE technology appraisal guidance on continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome.

> To find out why the committee made the recommendations on discussing the management of respiratory failure, and assisted ventilation for respiratory failure and sleep apnoea, and how they might affect practice, see rationale and impact.

Pain

1.4.36 Be aware that some adults with cerebral palsy have difficulty communicating, or are unable to communicate, that they are in pain.

1.4.37 Assess for the presence, severity and location of pain in adults with cerebral palsy using pain assessment tools such as:

- numerical rating scales
- visual analogue scales
- faces pain scales
- body maps.

1.4.38 If an adult with cerebral palsy has difficulty communicating:

- discuss with their family or carers how best to identify pain and include this information in their care plan
- use observational or descriptive pain scales to assess the presence, severity and location of pain.

See also NICE's guideline on patient experience in adult NHS services for advice on communication.

1.4.39 Ensure that health and social care staff (and families and carers, if appropriate) caring for adults with cerebral palsy have access to a range of pain assessment tools and that they have been trained in their use.

To find out why the committee made the recommendations on pain, and how they might affect practice, see rationale and impact.

Terms used in this guideline

Advance care plan

Defined by international consensus as ‘A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences about future medical care. The goal of an advance care plan is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.’ (Sudore et al [2017] Defining advance care planning for adults).

Alternative and augmentative communication systems

Alternative and augmentative communication systems are a variety of methods (for example signing, use of visual symbols and eye gaze technology) that can be used to help people with disabilities communicate with others. These systems or methods of communications can be used as an alternative to speech or to supplement it.

Electronic assistive technology

Any piece of equipment, or system, that is electronically powered (mains electricity and/or battery), with the purpose to increase, maintain, or improve function of individuals with disabilities. These may include communication aids, environmental controls and access to computers.

Enteral drug treatment

Drugs given by mouth (oral), via a naso-gastric tube, gastrostomy tube or jejunostomy tube.

Escalation plan

A record of the interventions that a person would find acceptable, in line with their values, goals and preferences. It can be used to indicate that more intensive or invasive interventions would be unacceptable to the person. For example, an escalation plan of ward-based care only, indicates that the person would not want invasive monitoring, intubation and ventilation, which are undertaken as part of intensive care.

Executive functions

Cognitive processes that are important for the control of behaviour. These include planning, organising and monitoring behaviours leading to goal attainment, inhibitory control, working memory and cognitive flexibility. As a result of injuries to the frontal lobes of the brain these processes can be disrupted.

Gross Motor Function Classification System (GMFCS)

A 5-level clinical classification system that describes the gross motor function of people with cerebral palsy based on self-initiated movement abilities. People assessed as level I are the most able and people assessed as level V are dependent on others for all their mobility needs.

Key communication partners

People who regularly interact with the adult with cerebral palsy in any environment. Communication may be by speech, using communication aids, signing, facial expression or a combination of these.

Rehabilitation engineering services

Centres that design, develop and adapt technological solutions to overcome challenges to function, activity and participation for individuals with disability. This includes assessment and provision of assistive devices to help with posture, mobility and communication (for example electronic assistive technology).

Review

A planned clinical appointment between an adult with cerebral palsy and a healthcare professional. They may explore common concerns, physical symptoms, mental health, pain, nutrition and communication to ensure an individualised approach to care. The healthcare professional may be a GP, specialist nurse, rehabilitation specialist or therapist. This allows also the opportunity to address general health issues in the population as they grow older.

Review of 24-hours postural needs

Part of a 24-hour posture review that considers all the relevant postures that an individual has the ability to adopt over the 24-hours of any given day. The 3 core postural orientations are lying, sitting and standing. An example of a postural need is support and positioning in bed.

Supportive care

Care focused on relieving symptoms caused by serious illnesses such as respiratory failure. It can be given at any point during a person's illness to help them feel more comfortable and improve their quality of life.

Transferring

Moving from one surface to another (for example, from a bed to a wheelchair) independently or with assistance.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Method of botulinum toxin type A injection in treating focal spasticity

Is guided botulinum toxin type A injection using electrical localisation (electrostimulation or electromyography) of muscles more effective and cost effective than ultrasound-guided injections or clinical positioning for localisation of injections in treating focal spasticity in adults with cerebral palsy?

To find out why the committee made the research recommendation on the method of botulinum toxin type A injection in treating focal spasticity see rationale and impact.

2 Selective dorsal rhizotomy treatment to reduce spasticity

What is the effectiveness and cost effectiveness of selective dorsal rhizotomy compared with intrathecal baclofen to reduce spasticity in adults with cerebral palsy?

To find out why the committee made the research recommendation on selective dorsal rhizotomy treatment to reduce spasticity see rationale and impact.

3 Detection and management of respiratory disorders in primary and community care

Can detection and management of respiratory disorder in adults with cerebral palsy be improved in primary and community care?

To find out why the committee made the research recommendation on the detection and management of respiratory disorders in primary and community care see rationale and impact.

4 Prophylactic antibiotics for respiratory disorders

Are prophylactic antibiotics effective and cost effective in the management of respiratory symptoms in adults with cerebral palsy with significant respiratory comorbidity?

To find out why the committee made the research recommendation on prophylactic antibiotics for respiratory disorders see rationale and impact.

5 Splinting to improve or maintain posture or function

What is the optimum regime for splints applied to the upper limb in adults with cerebral palsy to improve or maintain posture or function?

To find out why the committee made the research recommendation on splinting to improve or maintain posture or function see rationale and impact.

6 Augmentative and alternative communication systems

Are augmentative and alternative communication systems effective and cost effective in promoting communication for adults with cerebral palsy who have communication difficulties?

To find out why the committee made the research recommendation on augmentative and alternative communication systems see rationale and impact.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice. They link to details of the evidence and a full description of the committee's discussion.

Moving into adults' services and access to services

Recommendations 1.1.1 to 1.1.9

Why the committee made the recommendations

Moving into adults' services

The committee discussed that specialist cerebral palsy services are provided for children and young people, but there is insufficient specialist service provision for adults, with variation and a lack of continuity in care. The committee highlighted that it is important that services continue to meet the people's needs when they move into adults' services, in line with recommendations in the NICE guidelines on cerebral palsy in under 25s and transition from children's to adults' services for young people using health or social care services. To ensure that needs are met for adults with cerebral palsy the committee made separate recommendations about service organisations (see below).

Access to services

Disabled people have the same rights to access healthcare services as other people. These rights are outlined in the Equality Act 2010 and the UN Convention on the rights of persons with disabilities. To support this, the committee highlighted that there should be local pathways to enable access to a range of services for adults with cerebral palsy. The committee agreed that referral to specialist services is needed for some treatment options. Based on their discussions about treating spasticity and dystonia (see evidence reviews A1, A2 and A3), the committee agreed that access to specialist multidisciplinary teams is particularly important when a person with cerebral palsy experiences a deterioration in their ability to carry out usual daily activities, or when a neurosurgical or orthopaedic procedure is being considered that may affect their abilities. Adults with cerebral palsy may also need reassessment by the multidisciplinary team to take into account their changing needs at different life stages. The committee highlighted this and to raise awareness that people may need to access to different services if their needs change. These should include access to a multidisciplinary team if the person's functional abilities deteriorate or if the person's needs change.

The committee agreed that appropriate specialist services would need to be able to address a wide variety of impairments and comorbidities, and that their needs are likely to change at different stages of their life. To achieve good access to the relevant specialists, local networks of care are needed. The committee also noted that both people with cerebral palsy and healthcare professionals often lack awareness of the services available. Based on their experience, they agreed that provision of information about local networks of services would help to improve access.

The committee also acknowledged that carers are often unaware of their right to a local authority assessment of their own needs, including physical and mental health, and to an assessment of their need for respite care under the Care Act 2014. They agreed that highlighting this would help carers to access support if needed.

The evidence showed that adults with cerebral palsy experience many obstacles to equal access to services. Some of the barriers identified by the evidence are highlighted in the recommendations to help raise awareness among healthcare professionals. The committee agreed that healthcare professionals should ensure that any barriers are addressed to enable equitable access to services and provide timely care. This will improve quality of life and health outcomes for adults with cerebral palsy.

The committee also noted that access to services may be limited for adults with cerebral palsy who need practical support and advocacy. There was some evidence that lack of an advocate could disadvantage people, especially when they are admitted to hospital. The evidence also showed that some adults with cerebral palsy reported that when they are admitted to hospital family members were expected to act as their carers. The committee agreed that it should not be assumed that family members should provide personal care in a healthcare setting and that advocacy and health and personal care should always be offered to people when they are admitted to hospital.

Based on their knowledge and experience, the committee noted inequalities in access to national screening programmes for adults with cerebral palsy. They agreed that increasing awareness would help to improve uptake of these services.

The committee acknowledged that there may be other barriers to screening, for example providing breast screening for women in wheelchairs, especially those with limited upper body strength, but they noted that interventions to improve screening services was outside of the scope of the guideline.

How the recommendations might affect practice

The recommendations on access to services reinforce legislation and best current practice.

Service organisation for networks of care is variable, so changes to practice will depend on the availability of services within a particular local area. Providing information about local networks of care may incur an initial cost to set-up.

There may be an increase in the number of referrals. Training will also be needed to ensure healthcare professionals can manage referrals rapidly because there is a limited number of healthcare professionals with expertise in neurological disorders. However, recommendations with criteria for referral will help to reduce inappropriate referrals and variations in referrals.

Full details of the evidence and the committee's discussion are in evidence review F1: Configuration of services for adults with cerebral palsy and evidence review F2: Barriers to access to primary and secondary care.

Return to recommendations

Ongoing care

Recommendations 1.1.10 to 1.1.15

Why the committee made the recommendations

There was limited evidence for the effectiveness of different service configurations. One study suggested that fewer visits to emergency departments and hospital visits were associated with having consistent outpatient care provided by a single doctor. Although, the committee recognised that this may reflect the value of continuity of care, they agreed that the quality of the evidence was not good enough to make a recommendation.

Further evidence showed that changing the configuration of services to include the time and staff for an annual review, could be cost-effective if there is a reduction of at least 1 emergency department visit per year per person. It was not clear from the evidence that this could be achieved when offered to all people with cerebral palsy. The committee discussed the variation in the needs of people with cerebral palsy and, based on their experience and knowledge, identified groups with more severe or complex health and social care needs who would most benefit from being offered an annual review. The evidence suggested annual review would be cost effective for this group because they decided that this would on average prevent one emergency department visit. It was noted that adults with learning disabilities should already be offered an annual health check in primary care.

Although the evidence did not support annual reviews for all people with cerebral palsy, the committee agreed that regular reviews are important to check for any new problems and ensure that people’s needs continue to be met. They agreed that regular reviews should be considered, tailored to the person’s needs. The frequency of review was not specified because it will depend on person’s needs and wishes.

It is important to discuss who should be involved in the review with the adult with cerebral palsy. Information from different healthcare professionals and social care staff may be essential to fully understand the person’s clinical needs. Good record keeping and sharing of information ensures that the outcome of the review is known to all relevant people and that the appropriate actions are taken. The committee also agreed that information about the review and any changes to the person’s needs should be shared to ensure integrated care.

To help maintain continuity of care between reviews, the committee agreed that there should be a single point of contact, which could be a department or service in primary or secondary care.

The committee recognised that some people may not need or wish to have regular reviews. To ensure that they still have access specialist services when needed, the committee agreed that they should be given information on how and when to do this.

How the recommendations might affect practice

Providing an annual review for adults with severe impairment will result in a minor change in practice and reduce variation.

Many adults with severe impairments will already receive an annual health check in accordance with the NICE guidelines on care and support of people growing older with learning disabilities and challenging behaviour and learning disabilities and NHS England's information on annual health checks.

There may be bigger changes in practice for people with less severe impairment if they are reviewed more often. However, the costs of this will be offset by the benefits of more frequent checks, such as early identification and management of new impairments or deterioration of function.

Full details of the evidence and the committee's discussion are in evidence review F1: Configuration of services for adults with cerebral palsy.

Return to recommendations

Communication

Recommendations 1.2.1 to 1.2.7

Why the committee made the recommendations

There was limited evidence to support interventions to improve communication between adults with cerebral palsy and their communication partners. However, the committee acknowledged that communication is a basic human right and that adults with cerebral palsy should be supported to communicate, express themselves and live as independently as possible.

The committee was concerned that communication difficulties and changes to communication needs are sometimes missed. Based on their experience, they agreed that increased awareness of this and a check for any changes to speech, hearing and communication at every review would help ensure that communication needs are recognised.

There was some evidence that intensive speech therapy or supplemented speech (using topic and alphabet cues) improved speech intelligibility, but the committee agreed that it was not sufficient to recommend these specific interventions. However, using this evidence and their knowledge and experience, the committee agreed that referral to speech therapy services would enable adults with communication difficulties to be assessed and offered suitable interventions.

Based on their experience and knowledge, the committee agreed that alternative and augmentative communication systems may help some adults with cerebral palsy to meet their communication needs, support independence and improve quality of life and social relationships. Therefore the need for these systems should be discussed with adults who have communication difficulties. The committee noted that there is variation in the availability of training in these techniques, which is vital for their effective use. They also highlighted that personal preference is important, and that some people may not wish to use alternative or augmentative communication systems in place of speech as their main means of communication.

The committee discussed that there was a need for more research on alternative and augmentative communication systems. Current practice is to offer these systems in preference to intensive speech and language therapy for people with cerebral palsy and communication difficulties. However, there is only limited evidence to support this in children with cerebral palsy and no evidence was identified for adults. The committee developed a research recommendation to determine the effectiveness of augmentative and alternative communication systems in promoting communication for adults with cerebral palsy and communication difficulties.

How the recommendations might affect practice

There is currently variation in practice and the recommendations will help to address this and reinforce best practice.

Initially, an increase in referrals to speech therapy services and subsequent management is likely. However this will decline as variations in practice are reduced.

There may be an increase in the use of augmentative and alternative communication equipment, and related training, which will involve additional costs.

Full details of the evidence and the committee's discussion are in evidence review D4: Interventions to promote participation: communication.

Return to recommendations

Vocational and independent living skills

Recommendations 1.2.8 to 1.2.12

Why the committee made the recommendations

There was very little evidence on specific interventions for vocational or independent living skills training. However, the committee acknowledged the benefits of increased independence, social and occupational integration, participation in the community and access to work for adults with cerebral palsy. Based on their experience and knowledge, the committee agreed that people with problems participating in an activity should have access to support. This should include assessing for and addressing any barriers to participation and support, and may involve referral to occupational therapy services, particularly for people with complex needs.

For adults who wish to work or live independently, the committee agreed that referral for specialist support to access training, work placements and leisure activities would be beneficial. Some evidence showed that people with higher educational attainment and fewer physical complications were more likely to gain paid employment, but the committee agreed that support should be an option regardless of ability, to enable all adults to reach their full potential. For adults with cerebral palsy who are in work, referral could support access to workplace and equipment assessment and workplace and job retention training. The NICE guideline on workplace health: management practices was highlighted by the committee as an important resource to refer to.

The recommendations support compliance with the Equality Act 2010 to protect people from discrimination in employment, training and education. They also reflect the fundamental rights of people with disabilities to independence, social and occupational integration, participation in the community, access to training and to engage in work, as set out in the UN Convention on the rights of persons with disabilities.

How the recommendations might affect practice

These recommendations are intended to reinforce good current practice, and support government policy and legislation. Where they are not currently being implemented, some services may need additional investment in resources.

Full details of the evidence and the committee's discussion are in evidence review D1: Interventions to promote participation: vocational and independent living skills.

Return to recommendations

Electronic assistive technology

Recommendations 1.2.14 to 1.2.18

Why the committee made the recommendations

There was no evidence identified on electronic assistive technology for adults with cerebral palsy. Based on their experience, the committee agreed that adults with cerebral palsy and complex disabilities would benefit from access to electronic assisted technology, which may enhance their independence, quality of life and improve their opportunities for employment. The recommendations support legislation such as The Human Rights Act 1998 and the Equality Act 2010. The recommendation on referral to services providing electronic assistive technology is also in line with the NHS England commissioning document on complex disability.

The committee was unable to recommend any specific electronic assistive technology devices because of the lack of evidence. They agreed that services providing electronic assistive technology should provide devices tailored to the person's needs.

Variation in training and ongoing reviews of electronic assistive technology equipment were highlighted by the committee. Training is important for both the adult with cerebral palsy and their family and carers to ensure that the devices are used to their full benefit. By discussing the use of their equipment at each review, the healthcare professional can ensure that any problems with equipment or changes to the person's needs are identified.

The committee noted that people using electronic assistive technology may need less support from their carers and healthcare workers. This may reduce the person's social contact, which can have a negative impact. Based on their experience, the committee agreed that it is important that healthcare professionals take this into account when discussing the risks and benefits of electronic assistive technology with the adult with cerebral palsy, their family and carers.

How the recommendations might affect practice

These recommendations are intended to reinforce good current practice, and support government policy and legislation. Where they are not currently being implemented, some services may need additional investment in resources.

Full details of the evidence and the committee's discussion are in evidence review D3: Electronic assistive technology.

Return to recommendations

Physical activity, orthopaedic surgery and orthotics

Recommendations 1.2.18 to 1.2.21

Why the committee made the recommendations

Physical activity

There was limited evidence on physical activity interventions for adults with cerebral palsy, and what there was showed little or no improvements in, for example, mobility, function and participation. However, based on their experience the committee agreed that physical activity can help people with cerebral palsy with strength and range of movement, as well as maintaining their general fitness and a healthy weight. Evidence in the general population also shows that physical activity is of benefit to people's overall health and wellbeing. The evidence did show that the risk of injury or other adverse events for people with cerebral palsy was not increased by doing physical activities such as strength training.

The committee agreed that physical activity should be promoted by providing information and discussing the benefits with the adult with cerebral palsy. This would also be in line with current government strategies for the wider population (for example the Start Active, Stay Active report on physical activity in the UK).

Some adults with cerebral palsy may need extra support to overcome barriers to participation in physical activities. Based on their experience, the committee agreed that referral to a relevant service is likely to be helpful for some people; for example, for assessment by a physiotherapist or occupational therapist to agree suitable interventions. The recommendation also supports improved access to mobility aids, including wheelchairs. The committee noted that a referral is in line with NHS guidance on choosing mobility equipment, wheelchairs and scooters for people long-term or permanent difficulty with mobility.

Orthopaedic surgery

There was little evidence on orthopaedic surgery. However, the committee recognised that some adults with cerebral palsy who have painful musculoskeletal problems might benefit from surgery if other treatments are not effective. The committee agreed that referral to an experienced orthopaedic surgeon could be considered to review possible surgical options.

Orthotics

There was no evidence identified on the effectiveness of orthotic devices for adults with cerebral palsy. The committee discussed that there is variation in how orthoses are used in current practice and decided that further research in this area is a priority. Orthotic devices, such as splints, are used to help improve positioning and function. They can be used alongside other treatments or separately. The committee developed a research recommendation to determine the effectiveness of different splinting regimens in improving and maintaining posture or functional abilities in the upper limb.

How the recommendations might affect practice

The recommendations on interventions to maintain physical function reinforce current best practice and should not lead to additional resource use. Any initial costs of specialist advice would be outweighed by the potential savings from avoiding complications, injuries and maintaining a wider range of abilities.

Full details of the evidence and the committee's discussion are in evidence review D2: Interventions that improve or maintain physical function and participation.

Return to recommendations

Agreeing goals for treatment and initial management of spasticity and dystonia

Recommendations 1.3.1 to 1.3.5

Why the committee made the recommendations

The committee noted that there is a lack of understanding about the relationship between spasticity and dystonia. Based on their experience, they agreed that a better understanding of these conditions and the factors that affect them is likely to lead to more effective decisions about management. They discussed factors that commonly trigger or worsen symptoms of both spasticity and dystonia, and their concerns that these may sometimes go unrecognised.

The committee also discussed the balance of benefits and risks of treatment to reduce spasticity and dystonia. In particular, some people with cerebral palsy make functional use of their increased muscle tone from spasticity and dystonia, for example to help them walk or transfer independently. For these people a reduction in spasticity or dystonia could have a negative impact on function. To ensure informed decision-making, the risks and benefits of treatment should be discussed with each person and specific treatment goals should be agreed.

There was limited evidence on treatments for spasticity and dystonia in adults with cerebral palsy, but based on their experience and expertise the committee agreed on a stepwise approach to treatment dependant on tolerability and effectiveness. This is from the least invasive to the most invasive treatment option, which is reflected in the order of recommendations in the individual sections:

- first identifying and managing any factors that might be exacerbating their symptoms and considering a physical management programme
- next considering enteral (oral or via a feeding tube) drug treatment and referral
- then considering more invasive options.

How the recommendations might affect practice

The recommendations reflect current good practice.

Full details of the evidence and the committee's discussion are in evidence review A1: pharmacological treatments for spasticity and evidence review A3: interventions for dystonia.

Return to recommendations

Drug treatments for spasticity

Recommendations 1.3.6 to 1.3.11

Why the committee made the recommendations

Enteral muscle relaxant drug treatments

No evidence was identified on using enteral baclofen for treating spasticity in adults with cerebral palsy. However, the committee discussed the evidence reviewed for NICE's guideline on spasticity in under 19s, and agreed that this could be extrapolated to the adult population. There was limited evidence of effectiveness in children and young people, but the committee agreed that it was sufficient, supported by their experience, for enteral baclofen to be considered as a first-line treatment for generalised spasticity causing functional impairment, pain or spasms.

The evidence on enteral diazepam showed no improvement in muscle tone, and side effects such as drowsiness, vomiting and abdominal pain were recorded. The committee agreed that it should not be offered routinely to treat spasticity because of the risk of adverse events and also of dependency. However, evidence from NICE's guideline on spasticity in children and young people and the committee's experience suggested that diazepam can be beneficial in the short-term management of pain and anxiety in acute situations.

There was no evidence for any other medicines. However, based on their experience of current practice, the committee acknowledged that alternative drug treatments are available that might be beneficial for some people if enteral baclofen is ineffective or not tolerated. The committee agreed that in these situations specialist advice or referral to specialist services is warranted to consider further treatment options.

Severe symptoms, such as life-threatening seizures, are associated with rapid withdrawal of enteral muscle relaxants, so the committee highlighted the importance of gradual withdrawal of these treatments.

Botulinum toxin type A injections

There was some evidence that botulinum toxin type A injections improved muscle tone in adults with cerebral palsy and spasticity. However, the evidence was limited, and this treatment is more invasive and costly than alternative muscle relaxant drug treatment. For these reasons, the committee agreed that it should only be considered for people with focal spasticity and difficulties with their symptoms, who might gain the most benefit from the treatment, or if a specialist agrees that it is likely to be of benefit.

The committee discussed that botulinum toxin type A injections should be given by an experienced specialist. This is important because the injections need to be accurately placed for successful treatment and to avoid side effects. They acknowledged that some healthcare professionals use ultrasound, electrical stimulation or electromyography to help guide the injections, but noted that the benefits and cost effectiveness of these techniques are uncertain. Additional resources are associated with these techniques; for equipment and training, and for an ultrasonographer or radiologist for ultrasound-guided injections. Therefore, the committee developed a research recommendation to help determine the most effective method for ensuring accurate positioning of these injections.

How the recommendations might affect practice

Overall, the recommendations reflect current good practice and will help to eliminate variation, particularly in referrals to tone or spasticity management services.

The recommendation to consider enteral baclofen as a first-line option to manage spasticity should not lead to a large increase in costs as enteral baclofen is relatively cheap and is already widely used as a first-line option. Despite this, the committee were unable to make a stronger recommendation because there was no comparative clinical evidence that baclofen was the most effective option.

There was clinical evidence to suggest the cost of botulinum toxin could be outweighed by its benefits when treating focal spasticity. The focus on referral for focal spasticity that is causing pain, impacting care, or impairing activity is likely to reduce the number of inappropriate referrals.

Any additional costs of specialist input is expected to be balanced by a reduction in potentially inappropriate treatment and related adverse effects. There may be a change to practice because enteral diazepam will no longer be prescribed routinely, and this may result in a small cost saving.

Full details of the evidence and the committee's discussion are in evidence review A1: pharmacological treatments for spasticity.

Return to recommendations

Neurosurgical treatments to reduce spasticity

Recommendations 1.3.12 to 1.3.17

Why the committee made the recommendations

There was some limited evidence with high uncertainty suggesting that both intrathecal baclofen and selective dorsal rhizotomy are effective in reducing muscle tone in adults with spasticity. However, there are risks involved, both in having surgery and of long-term complications. The committee highlighted the importance of discussing the procedure with the person and their family or carers, so that they fully understand what the treatment involves and the potential risks and benefits.

Intrathecal baclofen

Using the evidence and their experience of current practice, the committee agreed that intrathecal baclofen pumps can be beneficial for treating spasticity in some adults with cerebral palsy. However, they should only be considered by a specialist service that can safely carry out the procedure and has the expertise to assess whether it is a suitable treatment for the person. There are potential risks of intrathecal baclofen pump treatment. these include infections, catheter breakage, seizures, constipation and anxiety or depression. After selective dorsal rhizotomy there may be a deterioration in walking ability or bladder function, and later spinal deformity. Taking into account these factors, the committee agreed that referral should only be considered if a person still has difficulties with spasticity after trying enteral muscle relaxant drug treatment or botulinum toxin type A injections. Due to the complex nature of this procedure the committee noted that the adult with cerebral palsy will need sufficient information to make an informed choice and that this is not always consistently provided. A number of issues should be considered when providing information specifically related to this surgical procedure, such as the need for a test dose preimplantation, requirement of pump refill and regular follow-ups, the details of what the surgical procedure involves, and a review of their 24 hour postural needs.

The committee recognised that the response to intrathecal baclofen needs to be tested before the pump would be implanted. They therefore highlighted a couple of particular points about how the test dose (or doses if the person does not respond to the initial test dose) would be administered. The committee did not want to be too detailed about dosage and how the testing would be carried out because this is described in the British National Formulary (BNF). The response should then be assessed and discussed with the adult with cerebral palsy to ensure that a pump is only implanted when a benefit is established in advance.

Selective dorsal rhizotomy

The committee were aware that there is a risk of complications with selective dorsal rhizotomy, including deterioration in walking ability and bladder function, and later spinal deformity. Because of this and the limited evidence, the committee also took into account NICE's interventional procedures guidance on selective dorsal rhizotomy for spasticity in cerebral palsy, published in 2010. Although they noted that the evidence for the interventional procedure guidance was mostly in children. The committee agreed that selective dorsal rhizotomy should only be considered after multidisciplinary assessment in a specialist spasticity service, in line with the NICE interventional procedures guidance.

The committee also recommended further research, comparing the safety and effectiveness of selective dorsal rhizotomy with continuous intrathecal baclofen pump treatment. Both procedures are currently used to treat spasticity in people with cerebral palsy and there is some evidence that both are effective. However, the committee noted that the procedures, and their risks and benefits, are very different. They agreed that a comparative study would be helpful to inform decision-making.

How the recommendations might affect practice

The recommendations reinforce current best practice and should not lead to additional resource use. Specialist services already exist and neurosurgical procedures are currently available for the treatment of spasticity. Including specific criteria for referral should reduce the number of inappropriate referrals to these services.

Full details of the evidence and the committee's discussion are in evidence review A2: neurosurgical treatments for spasticity.

Return to recommendations

Drug treatments for dystonia

Recommendations 1.3.18 to 1.3.22

Why the committee made the recommendations

There was limited evidence on treating dystonia in adults with cerebral palsy. The committee discussed that it is a specialist clinical area and that the benefits and harms of treatments would need to be assessed by a person with expertise in tone management. Therefore, the committee agreed that adults with cerebral palsy should be referred for specialist management if they have problematic dystonia.

Enteral anti-dystonic drug treatments

The evidence for levodopa was limited, although there was some evidence that it was not effective for reducing dystonia in adults with severe impairment. Taking into account the lack of evidence of effectiveness, and also the potential for side effects and the cost of long-term treatment to the NHS, the committee agreed that levodopa should not be prescribed routinely for dystonia in adults with cerebral palsy. However, the committee agreed that a trial of levodopa can be useful to exclude the rare but treatable condition of dopa-responsive dystonia.

No evidence was identified for other enteral anti-dystonic drug treatments. However, based on their experience of current practice, the committee acknowledged that there are other options available that might be beneficial for some people. They agreed that first-line treatment options should depend on the person's symptoms and treatment goals, and should only be considered by a specialist service.

Botulinum toxin type A injections

No evidence was identified on using botulinum toxin type A injections for treating dystonia in adults with cerebral palsy. However, based on their knowledge and experience, the committee agreed that it can be of benefit to some people with focal dystonia. Because there was no evidence and this treatment is more invasive and costly than other enteral anti-dystonic drug treatments, the committee agreed that it should only be considered under specialist supervision for people with focal dystonia and difficulties with symptoms, who might gain the most benefit from the treatment. They also agreed that it should only be used as part of a programme of therapy. This would usually involve a physical management programme, for example, including physiotherapy and splinting.

The committee emphasised that botulinum toxin type A injections should be given by an experienced specialist. This is important because the injections need to be accurately placed for successful treatment and to avoid side effects.

How the recommendations might affect practice

Overall, the recommendations reflect current good practice and will help to eliminate variation, particularly in referral. There may be a change to practice because levodopa will no longer be prescribed routinely, and this may result in a small cost saving.

Full details of the evidence and the committee's discussion are in evidence review A3: neurosurgical treatments for spasticity.

Return to recommendations

Neurosurgical treatments to reduce dystonia

Recommendations 1.3.23 to 1.3.24

Why the committee made the recommendations

Intrathecal baclofen

Despite a lack of evidence, the committee agreed that their knowledge and experience of current practice supported the use of intrathecal baclofen pumps for treating dystonia in some adults with cerebral palsy. However, they should only be considered by a specialist service that can safely carry out the procedure and has the expertise to assess whether it is a suitable treatment for the person. There are potential risks of intrathecal baclofen pump treatment. These include infections, catheter breakage, seizures, constipation and anxiety or depression. It is also more costly than other drug treatments. Taking into account these factors, the committee agreed that it should only be considered when a person still has difficulties with dystonia after trying enteral anti-dystonic drug treatment or botulinum toxin type A injections.

The committee also highlighted the importance of discussing the procedure with the person and their family or carer, so that they fully understand what the treatment involves and the potential risks and benefits.

The committee agreed that the same considerations about intrathecal baclofen testing that have been made for spasticity also apply to dystonia and therefore cross referenced to the relevant recommendations.

Deep brain stimulation

Although there was limited and sometimes incongruous evidence for deep brain stimulation, it did suggest some improvement in dystonia after treatment. However, some complications were noted, including problems with speech, pain, numbness and anxiety, as well as problems with the equipment. Deep brain stimulation is expensive. Two studies identified as part economic evidence, suggested it would improve quality of life. However, the economic evidence was inconsistent, showing that it was likely to be cost effective in people with dystonia that has not improved with other treatments when based on the outcomes of one quality of life study but not cost effective using the other. The committee also took into account NICE's interventional procedures guidance on deep brain stimulation for tremor and dystonia (excluding Parkinson's disease) published in 2006, which supports its use with the involvement of a multidisciplinary team. Based on the evidence on improvements in quality of life and the committee's knowledge and experience, they agreed that deep brain stimulation should only be considered for people who have severe and painful dystonia, and only carried out at an experienced specialised centre.

How the recommendations might affect practice

Overall, the recommendations reflect current good practice and will help to eliminate variation.

Full details of the evidence and the committee's discussion are in evidence review A3: neurosurgical treatments for spasticity.

Return to recommendations

Bone and joint disorders

Recommendations 1.4.1 to 1.4.8

Why the committee made the recommendations

Based on their experience, the committee noted that there is a lack of awareness, both among adults with cerebral palsy and healthcare professionals, that people with cerebral palsy are at increased risk of bone and joint complications, and that musculoskeletal function may worsen over time. Common complications include osteoporosis and conditions caused by abnormal musculoskeletal development, such as scoliosis and subluxation of joints. Increasing awareness and discussing this with adults with cerebral palsy will enable early identification and management of these conditions.

Osteoporosis and fracture risk

The committee agreed that assessing fracture risk is important for adults with cerebral palsy who are at increased risk of osteoporosis to enable action to be taken to manage osteoporosis and prevent fractures. Based on their experience and knowledge the committee identified factors that are associated with increased risk and agreed that fracture risk assessment should be considered for adults with cerebral palsy with these factors. In addition to the risk factors related to cerebral palsy (such as reduced weight bearing), risk factors for the general population also apply. These are described in NICE's guideline on osteoporosis: assessing the risk of fragility fracture along with information about assessing fracture risk.

There was some evidence that dual-energy X-ray absorptiometry (DXA) scanning can be effective in identifying reduced bone density in adults with cerebral palsy. However, the committee noted that these scans can often be uncomfortable and the results difficult to interpret in people with cerebral palsy. The risks of treatment may also outweigh the benefits in people without symptoms. For these reasons they agreed that it should only be considered for people with more than 1 risk factor, suggesting a high risk of fractures and osteoporosis.

Based on their experience, the committee agreed that assessment and management of osteoporosis in adults with cerebral palsy is highly complex, and that referral to a specialist service is often necessary. For some people this may be to a rheumatology or bone health service, for others referral to endocrinology may be considered to explore whether a hormonal condition could be affecting their bones.

Disorders caused by abnormal musculoskeletal development

Adults with cerebral palsy may develop joint abnormalities due to problems of tone, movement and posture. No evidence was identified on monitoring for these disorders. However, the committee agreed that specialist referral is needed for assessment and management if these conditions are suspected and causing problematic symptoms. They highlighted some of the more common disorders to help increase awareness and improve recognition.

The committee were aware that hip and spine X-rays may be offered routinely to children and young people in paediatric services. However, ongoing surveillance is not necessary for adults once growth is complete, and X-rays should not be offered unless there are new problems of pain, posture or difficulties with care.

How the recommendations might affect practice

The recommendations for risk assessment and DXA scanning are unlikely to change current practice. DXA scans should already be considered under NICE's guideline on assessing the risk of fragility fracture.

The recommendations could increase referrals to specialist services. However, the impact of this is likely to be balanced by better treatment and prevention of hospital stays.

Full details of the evidence and the committee's discussion are in evidence review B1: disorders of bones and joints.

Return to recommendations

Mental health problems

Recommendations 1.4.9 to 1.4.15

Why the committee made the recommendations

No evidence was found on assessing and monitoring mental health in adults with cerebral palsy. However, from their experience, the committee acknowledged that healthcare services for adults with cerebral palsy tend to focus on physical rather than mental health. Greater awareness of mental health problems and the specific challenges of identifying and managing them in adults with cerebral palsy would help to ensure that such problems are recognised and managed. Alongside this, the committee highlighted that discussing the person's mental wellbeing at each review would help to identify any concerns and ensure that support for mental health problems is included in the person's care plan. Important insights about a person's mental health can often be gained from people close to them, so the committee agreed that (with consent from the person) family members or carers should also be asked if they have any concerns.

Physical problems and common frustrations that can affect emotional wellbeing in adults with cerebral palsy were highlighted by the committee because they are often overlooked, but can negatively affect mental health and behaviour.

The committee noted that there are many relevant NICE guidelines related to mental health conditions that would apply to adults with cerebral palsy, and other NICE guidelines relevant to those with communication difficulties or learning disabilities.

How the recommendations might affect practice

The recommendations will reinforce current best practice.

Full details of the evidence and the committee's discussion are in evidence review B2: monitoring and assessing mental health.

Return to recommendations

Difficulties with eating and nutritional problems

Recommendations 1.4.16 to 1.4.21

Why the committee made the recommendations

There was some evidence on tools for assessing nutritional status in adults with cerebral palsy, but the committee concluded that the evidence was not good enough to recommend a specific tool. In addition, many factors can affect feeding and nutrition, so they agreed that a single tool is unlikely to be suitable for everyone.

Based on their experience, the committee agreed that assessment should be individualised to reflect each adult's needs and circumstances. Current good practice includes regular weight and BMI checks, and talking to the person and their families and carers about feeding behaviour and other factors affecting feeding and weight. People identified as at risk of undernutrition or with eating difficulties can then be referred to a specialist to assess for and treat specific feeding or nutrition problems. Because the recommendations focus on individualised assessment, the committee agreed that specific tools for assessing nutrition are not a priority for further research.

The committee discussed the role of people caring for adults with cerebral palsy and agreed that training should be provided in line with the NICE guideline on nutrition support for adults, to help pick up any problems between reviews.

The committee noted that adults with dyskinetic cerebral palsy or severe spasticity may have an increased metabolic rate and need to increase their calorie intake to prevent malnutrition. The committee recognised that reduction in dyskinesia or spasticity by treatment such as intrathecal baclofen may result in weight gain. They agreed that, from their experience, this can go unrecognised and that greater awareness could help people get the support they need.

How the recommendations might affect practice

The recommendations will reinforce current best practice.

Full details of the evidence and the committee's discussion are in evidence review B3: monitoring feeding and nutritional problems.

Return to recommendations

Identifying and monitoring respiratory disorders

Recommendations 1.4.22 to 1.4.25

Why the committee made the recommendations

No evidence was found on monitoring respiratory health in adults with cerebral palsy. Adults with cerebral palsy are at an increased risk of respiratory failure, which can be life-threatening. However, based on their experience and knowledge, the committee agreed that the early symptoms of respiratory impairment may sometimes go unrecognised. Greater awareness and earlier recognition and treatment may result in treatment that prevents progression to respiratory failure.

Based on their experience and some limited evidence, the committee agreed that better awareness of the risk factors for respiratory impairment would help to ensure early recognition and appropriate referral. They also wanted to highlight that these are more common in adults with severe impairment, such as a high Gross Motor Function Classification System (GMFCS) score. They agreed that referral for specialist assessment would enable prevention or treatment of respiratory complications in people at high-risk.

The committee discussed that reduced lung volume is an important factor contributing to respiratory impairment. However, there was limited evidence available on the value of spirometry in assessing respiratory function in adults with cerebral palsy. Based on their experience and expertise, the committee agreed that spirometry should be considered for people at high risk of respiratory impairment to help identify people who may need treatment.

The committee agreed that further research on identifying respiratory impairment in adults with cerebral palsy would be helpful. They developed a research recommendation to determine the most effective methods of detecting and managing respiratory impairment in the community.

How the recommendations might affect practice

Better survival of children with cerebral palsy into adulthood means that this is an emerging area of practice. There are relatively few respiratory specialists with a special interest in adults with cerebral palsy. There may be an increase in referrals, which might place increased pressure on limited specialist services. However, earlier recognition and treatment will lead to improved outcomes. Respiratory conditions can often lead to hospital admission and reducing the need for this would potentially lead to cost savings.

Full details of the evidence and the committee's discussion are in evidence review C1: protocols for monitoring respiratory health.

Return to recommendations

Prophylactic treatments for respiratory infections

Recommendations 1.4.26 to 1.4.30

Why the committee made the recommendations

No evidence was identified on preventing respiratory infections in adults with cerebral palsy. The committee agreed that adults with cerebral palsy and their carers should receive vaccinations in line with national guidance from the government, as set out in the Green book (this could for example be the flu vaccination).

Applying their clinical expertise and experience, the committee agreed that the role of antibiotics is limited for prophylaxis of respiratory infections in adults with cerebral palsy. Taking into account potential adverse effects and the principles of antibiotic stewardship, the committee agreed that antibiotic prophylaxis should only be used in people at high risk of infection when it is advised by the respiratory specialist. For example, this might be in people with recurrent chest infections and bacterial colonisation identified on sputum culture. The aim in these cases would be to reduce acute antibiotic use and limit symptom burden.

The committee agreed that the prevention of respiratory infections is an important area for research. Many people with cerebral palsy have respiratory symptoms caused by sputum retention or recurrent respiratory infection, possibly related to aspiration. A smaller number have chronic bacterial airway colonisation with increased respiratory symptom burden and recurrent infections. The committee developed a research recommendation to determine the role of prophylactic antibiotics in those with, and without, persistent bacterial airway colonisation with, the aim of improving their quality of life and preventing hospital stays.

Although, there was no evidence for chest physiotherapy to prevent respiratory infections, the committee discussed the potential benefits of postural management and exercise. Based on their experience and expertise, they agreed that a physiotherapy chest care review should be considered for adults with cerebral palsy who are at high risk of respiratory infection. The committee also noted that families and carers can help with ongoing chest care, but may not always receive adequate support to enable this. They agreed that it would be beneficial for this to be included as part of the chest care review. This could include advice on posture, position change, opportunities to move, interventions to assist ventilation and secretion control management.

Effective swallowing (and saliva control) is important to prevent respiratory infections in adults with cerebral palsy. The committee agreed that assessment by a dysphagia-trained speech and language therapist should be considered for people with recurrent chest infections that may be caused by dysphagia.

How the recommendations might affect practice

The recommendations on vaccination reinforce current best practice.

Referral to a respiratory team for adults with cerebral palsy will reinforce best practice. However, there may be an increase in referrals, which could put additional pressure on already limited specialist services.

The recommendation on prophylactic antibiotic use is not considered to be a change in practice. However, there may be a small decrease in use of prophylactic antibiotics, which could lead to cost savings.

The recommendations on chest physiotherapy review and referral to dysphagia-trained speech and language therapist are unlikely to have a big impact on current practice. There may be a small increase in the number of referrals. This is likely to be balanced by improved prevention of respiratory infections. There may also be an increase in provision of training and support for families and carers. However, this is likely to be balanced by improved ongoing chest care which would reduce respiratory infections and the costs associated with them.

Full details of the evidence and the committee's discussion are in evidence review C3: prophylactic treatments for respiratory disorders.

Return to recommendations

Discussing the management of respiratory failure, and assisted ventilation for respiratory failure and sleep apnoea

Recommendations 1.4.30 to 1.4.36

Why the committee made the recommendations

The management of respiratory failure varies according to individual circumstances and preferences. The committee noted that having discussions about the effectiveness and tolerability of treatments (for example, non-invasive ventilation can be uncomfortable), as well as planning for future treatment and what to do if their condition worsens, helps to identify the most appropriate treatment pathway.

Although no evidence was identified on assisted ventilation for adults with cerebral palsy, the committee noted that there is evidence supporting non-invasive ventilation in people with progressive neuromuscular conditions. The committee discussed that the course and symptoms of respiratory failure may be similar across the different conditions. They agreed that non-invasive ventilation could be beneficial, based on evidence extrapolated from these populations and the committee's experience. The committee also agreed that it is important to review management every 3–6 months, which is consistent with standard practice.

The committee discussed that people's goals and preferences for management after acute deterioration in respiratory function will vary. Based on their experience and expertise, the committee highlighted the importance of agreeing a management plan with the person (and their family or carers, if agreed) for future care in this situation. This should be documented in the person's advance care plan. A full understanding of the options available and the person's values, preferences and goals will lead to better shared decision-making and more informed choices about care.

Based on their experience and expertise, the committee discussed that when treatment goals are not met by non-invasive techniques, alternative options like tracheostomy or supportive care could be considered. There was no evidence available in adults with cerebral palsy, but the committee agreed that tracheostomy can be effective for some patients in maintaining quality of life.

The committee recognised that sleep apnoea is common in adults with cerebral palsy. It can affect sleep quality and therefore quality of life. They agreed that treatment would be the same for adults with cerebral palsy as in the general population and cross-referred to the NICE technology appraisal guidance on continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome.

How the recommendations might affect practice

The recommendations in this section reinforce the current best practice and will help to standardise practice.

Full details of the evidence and the committee's discussion are in evidence review C2: assisted ventilation for respiratory failure.

Return to recommendations

Pain

Recommendations 1.4.36 to 1.4.39

Why the committee made the recommendations

The committee agreed that it can be difficult to recognise pain in people with communication difficulties. They agreed that better awareness of this would help to prevent under-identification of pain.

The evidence indicated that for adults with cerebral palsy who are able to communicate the numerical, visual analogue and faces pain scales had similarly good reliability and validity. Although the use of body maps was not evaluated in the evidence, the committee agreed they would also be a useful way to help localise the source of any pain. The committee acknowledge that families and carers have valuable insight into the best ways to tell whether an individual was experiencing pain, and this is especially important if the person has communication difficulties. For adults with cerebral palsy who are unable to communicate, the committee agreed that observational and descriptive pain scales would be appropriate and useful. The committee agreed that in practice the method chosen would depend on the person's individual needs and circumstances, in particular, their ability to communicate.

The committee highlighted that signs of distress from pain may sometimes be mistaken for other symptoms. By improving awareness of pain and highlighting the role of families and carers in recognising pain the committee aim to reduce the under-identification of pain.

The committee were also aware that people caring for adults with cerebral palsy do not always have access to suitable pain assessment tools or the training that is needed for their use. Based on their experience, they agreed that these are important to enable pain to be recognised, localised pain identified and treatment targeted effectively.

How the recommendations might affect practice

The recommendations reflect the current practice of selecting an appropriate measure from a range of pain assessment methods, depending on the person's ability to communicate. The committee acknowledged that although learning disability nurses currently train carers in generic pain assessment techniques, individualised training and documentation of how best to identify pain in the care plan would be a change in practice in some centres and may have a cost impact.

Full details of the evidence and the committee's discussion are in evidence review E: Identifying pain, such as musculoskeletal and gastrointestinal pain.

Return to recommendations

Context

Cerebral palsy is a disorder of motor development caused by a non-progressive pathology that affects the developing brain. People with cerebral palsy may also have disorders of communication, learning, feeding and vision, and epilepsy. Cerebral palsy is a lifelong condition and there is not yet a cure for the underlying brain disorder.

There are now more adults living with cerebral palsy than there are children with cerebral palsy. Adults with cerebral palsy have a wide range of abilities – from full independence in everyday life to needing 24-hour care and attention.

New interventions are coming into routine clinical practice for the management of premature babies and babies in a poor condition at birth who are at high risk of developing cerebral palsy. These may change the pattern of cerebral palsy and its related comorbidities. With improved survival, more children with severe and complex cerebral palsy are likely to live beyond childhood and into adult life. As they become young adults and transfer into adult services this group will continue to need regular monitoring of their health and wellbeing.

Adults with cerebral palsy should be able to become as functionally independent as possible. Many may wish to go into further education, gain employment, participate in leisure activities and contribute fully to society. Barriers to these goals should be minimised so that adults with cerebral palsy have equal access to all opportunities.

Adults with cerebral palsy tend to have less fluctuation in their motor skills than children. However, their mobility may decrease because of factors, such as muscle tone, weakness and pain. Comorbid symptoms, such as pain, mental health problems, communication difficulties and nutritional problems can, individually and in combination, affect participation and quality of life. These should also be a high priority for management.

As adults with cerebral palsy who have ongoing care needs grow older, there may be changes in their care arrangements. It may not be possible for their parents to continue to be the main carers and other support may be needed, either in the community or a residential setting. There is always the need for ongoing training and support for those who are caring for adults with cerebral palsy.

The care and support needs of adults with cerebral palsy depend on the severity of impairment and the presence or absence of comorbidities. There is significant variation in how services are currently provided to meet these needs. However, there is not a single system appropriate for all adults with cerebral palsy. In line with the Equality Act 2010 and the UN Convention on the rights of persons with disabilities, this guideline aims to ensure that adults with cerebral palsy have easy access to equitable, cost-efficient services, with a clear network of referral to more specialised services as appropriate.

Finding more information and resources

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