

# Cerebral palsy in adults

NICE guideline

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## Your responsibility

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

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

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

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

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This guideline is the basis of QS191.

## Overview

This guideline covers care and support for adults with cerebral palsy. It aims to improve health and wellbeing, promote access to services and support participation and independent living.

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 in 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

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about 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

### Access to services

- 1.1.1 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.
- 1.1.2 Recognise that reassessment by the multidisciplinary team may be needed by adults with cerebral palsy at different points in their lives to ensure that their changing needs are met (for example, pregnancy and parenting, decreased mobility due to hip arthritis, and loss of care and support from a parent).
- 1.1.3 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, occupational therapy, speech and language therapy, and dietetics)
  - wheelchair services.
- 1.1.4 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.
- 1.1.5 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 (see [NICE's guideline on supporting adult carers](#)).
- 1.1.6 For advice on access to services when adults with cerebral palsy transfer from hospital to home, refer to the [NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs](#). For the principles of social care provision, see the [NICE guideline on people's experience in adult social care services](#).
- 1.1.7 Recognise and address any personal barriers to accessing primary and secondary care for adults with cerebral palsy. For example, this may involve:
- ensuring healthcare professionals have the skills and training to overcome communication difficulties
  - providing treatment and support for mental health problems

- ensuring that the person has an advocate, if needed
  - providing support to help with social and emotional factors, such as fear of stigma, lack of motivation and exhaustion.
- 1.1.8 Recognise and address any physical and organisational barriers to accessing primary and secondary care for adults with cerebral palsy. For example, this may involve:
- improving physical access to buildings
  - providing advice and information on accessible transport services, for example, local community transport services
  - ensuring that appropriate equipment (for example, hoists and wheelchair weighing scales) and adequate changing and toilet facilities are available
  - extending appointment times, if needed.
- 1.1.9 When an adult with cerebral palsy is admitted to hospital, the staff should always offer advocacy, and health and personal care (including toileting, washing, nutrition and hydration) even if the person has a family member, carer or advocate there to support them.
- 1.1.10 Give information to people with cerebral palsy about national screening services (for example, breast, colon and cervical cancer screening) and encourage them to attend screening appointments. Explain that screening services will have to make arrangements to provide screening services that are accessible to people with cerebral palsy.

## Moving into adults' services

- 1.1.11 For young adults with cerebral palsy moving from children's services, ensure that transitions are managed in line with [transition to adults' services in the NICE guideline on cerebral palsy in under 25s](#) and the [NICE guideline on transition from children's to adults' services for young people using health or social care services](#).



For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on access to services and moving into adults' services](#).

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](#).

## Ongoing care

- 1.1.12 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.
- 1.1.13 Offer an annual review of the person's clinical and functional needs, carried out by a healthcare professional with expertise in neurodisabilities, for people with cerebral palsy who have complex needs (such as [Gross Motor Function Classification System \[GMFCS\]](#) levels IV and V) and any of the following:
- communication difficulties
  - learning disabilities
  - living in long-term care settings
  - living in the community without sufficient practical and social support (for example, being cared for by elderly, frail parents)
  - multiple comorbidities.
- 1.1.14 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).
- 1.1.15 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.

- 1.1.16 Identify who will be the main point of contact for the person with cerebral palsy (and their family and carers, if agreed) between reviews, and provide information on how to contact them.
- 1.1.17 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).
- 1.1.18 For adults with cerebral palsy and learning disabilities, follow the recommendations in [NICE's guideline on care and support of people growing older with learning disabilities](#).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on ongoing care](#).

Full details of the evidence and the committee's discussion are in [evidence review F1: configuration of services for adults with cerebral palsy](#).

## 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 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.

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

1.2.6 Refer adults with cerebral palsy who have communication difficulties to speech and language therapy services to assess their need for intervention, which may include:

- use of alternative or augmentative communication systems
- intensive speech therapy to improve the intelligibility of their speech.

See also [communication and information in the NICE guideline on patient experience in adult NHS services](#).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on communication](#).

Full details of the evidence and the committee's discussion are in [evidence review D4: interventions to promote participation: communication](#).

## Vocational skills and independent living

1.2.7 Identify and address any factors that prevent people with cerebral palsy from participating in activities, including:

- physical barriers, for example, access to buildings
- personal barriers, for example, carers with unmet training needs
- organisational barriers, for example, policies and situations that put people with cerebral palsy at a disadvantage.

1.2.8 Ask adults with cerebral palsy what they enjoy doing and if they find 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.

- 1.2.9 If adults with cerebral palsy have complex physical, cognitive, language or sensory needs, consider 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 services](#) for details of the information that local authorities should provide).
- 1.2.11 Refer adults with cerebral palsy who would like to live independently to a professional with expertise in independent living (for example, an occupational therapist). Give information and advice, which could include:
- adaptations to their home
  - housing
  - leisure activities
  - statutory welfare benefits.
- 1.2.12 Refer adults with cerebral palsy who would like to work, or who are already working, to a professional with expertise in vocational skills and independent living (for example, an occupational therapist). Give information and advice, which could include:
- continued education
  - job seeking or access to work schemes
  - employment support to include workplace training and job retention
  - 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on vocational skills and independent living](#).

Full details of the evidence and the committee's discussion are in [evidence review D1: interventions to promote participation – vocational and independent living skills](#).

## Electronic assistive technology

- 1.2.13 Discuss with adults with cerebral palsy the potential role of [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 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.
- 1.2.16 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.
- 1.2.17 Ensure that training is provided for adults with cerebral palsy using electronic

assistive technology, and for their families or carers, if appropriate.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on electronic assistive technology](#).

Full details of the evidence and the committee's discussion are in [evidence review D3: electronic assistive technology](#).

## 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 accessible 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 any of the following services:
- physiotherapy
  - occupational therapy
  - orthotic and functional electronic stimulation services
  - rehabilitation engineering services
  - wheelchair services.

## Orthopaedic surgery

- 1.2.21 If people with cerebral palsy have problems participating in physical activities

because of pain or joint problems that do not respond to any other treatments, consider referring them to a musculoskeletal specialist or an orthopaedic surgeon with experience and expertise in managing musculoskeletal problems in adults with cerebral palsy.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on physical activity, orthopaedic surgery and orthotics](#).

Full details of the evidence and the committee's discussion are in [evidence review D2: interventions that improve or maintain physical function and participation](#).

## 1.3 Managing abnormal muscle tone

### Agreeing goals for treatment

1.3.1 Discuss with the adult with cerebral palsy (and their family and carers, if agreed) treatments for spasticity or dystonia, including:

- personal treatment goals (which should be documented) **and**
- the benefits and risks of treatments (for example, the risk of deterioration in function) as part of their multidisciplinary treatment strategy.

See also [enabling patients to actively participate in their care in the NICE guidelines on patient experience in adult NHS services and shared decision making](#).

1.3.2 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.

## Initial management of spasticity and dystonia

- 1.3.3 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.
- 1.3.4 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.
- 1.3.5 Before discussing further management options for spasticity or dystonia with a person with cerebral palsy:
- address any modifiable factors identified that may be exacerbating the spasticity or dystonia **and**
  - review their physical management programme.



For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on agreeing goals for treatment and initial management of spasticity and dystonia](#).

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](#).

## Spasticity

### Enteral muscle relaxant drug treatments

In January 2019, giving baclofen via an enteral feeding tube was an off-label use. See [NICE's information on prescribing medicines](#).

- 1.3.6 Consider [enteral](#) baclofen 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 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 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, particularly if adults with cerebral palsy have taken them for more than 2 months or at a high dosage. Reduce the dosage gradually to avoid withdrawal symptoms.

If using a benzodiazepine (such as diazepam) as a muscle relaxant for spasticity, see [NICE's guideline on medicines associated with dependence or withdrawal symptoms for guidance on safe prescribing](#).

## 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.

In January 2019, there were several different preparations of botulinum toxin type A and the licensed indications varied between them. See [NICE's information on prescribing medicines](#).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on drug treatments for spasticity](#).

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

## 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 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 and 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 and whether treatment is likely to achieve their treatment goals.

### Selective dorsal rhizotomy

- 1.3.17 Only consider selective dorsal rhizotomy for adults with cerebral palsy and spasticity if other treatments have been unsuccessful or are contraindicated, and 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 procedures guidance on selective dorsal rhizotomy for spasticity in cerebral palsy](#).

- 1.3.18 Discuss the impact of selective dorsal rhizotomy with the person (and their family and carers, if agreed) when it is a proposed treatment option and provide information. 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on neurosurgical treatments to reduce spasticity](#).

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

## 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 treatments

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

In January 2019, this was an off-label use of levodopa. See [NICE's information on prescribing medicines](#).

- 1.3.21 Do not rapidly withdraw enteral drugs for treating dystonia, particularly if adults with cerebral palsy have taken them for more than 2 months or at a high dosage. Reduce the dosage gradually to avoid withdrawal symptoms.

In January 2019, giving anti-dystonic drugs via an enteral feeding tube was an off-label use. See [NICE's information on prescribing medicines](#).

### Botulinum toxin type A injections

In January 2019, the recommendations in this section were for an off-label use of botulinum toxin type A. See [NICE's information on prescribing medicines](#).

- 1.3.22 Only consider botulinum toxin type A treatment for focal dystonia in adults with cerebral palsy when:
- the person is under the supervision of a tone or spasticity management service, and it is part of a wider programme of therapy **and**
  - focal dystonia is:
    - affecting their care (such as hygiene or dressing) **or**

- causing pain **or**
- impairing activity and participation.

1.3.23 If botulinum toxin type A is a proposed treatment option, 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on drug treatments for dystonia](#).

Full details of the evidence and the committee's discussion are in [evidence review A3: treatments to reduce dystonia](#).

## Neurosurgical treatment to reduce dystonia

### Intrathecal baclofen

1.3.24 Only consider continuous pump-administered intrathecal baclofen if people with cerebral palsy still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A treatment. Provide information and discuss the procedure, including intrathecal baclofen testing, with the person (and their family or carer, if agreed) as described in [recommendations 1.3.13 to 1.3.16](#).

In January 2019, this was an off-label use for intrathecal baclofen and botulinum toxin type A. See [NICE's information on prescribing medicines](#).

### 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 procedures guidance on deep brain stimulation for tremor and dystonia \(excluding Parkinson's disease\)](#).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on neurosurgical treatments to reduce dystonia](#).

Full details of the evidence and the committee's discussion are in [evidence review A3: treatments to reduce dystonia](#).

## 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 1.4.3), 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 (including athetosis)
- 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on bone and joint disorders](#).

Full details of the evidence and the committee's discussion are in [evidence review B1: disorders of bones and joints](#).

## 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 with cerebral palsy, 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
  - sleep
  - 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 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 functions](#)

- 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on mental health problems](#).

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

## Difficulties with eating and nutritional problems

1.4.16 Offer adults with cerebral palsy a regular weight check, and BMI or another [anthropometric measurement](#), 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 if there have been any changes in their eating habits or bowel function. Ask about issues including:

- changes in appetite
- changes in the person's ability to feed themselves
- constipation
- 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
- depression
- pain
- 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, such as a dietitian or speech and language therapist, if assessment suggests they have difficulties with eating or malnutrition.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on difficulties with eating and nutritional problems](#).

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

## 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 ([GMFCS level IV or V](#)), such as:

- aspiration pneumonia
- chronic cardiorespiratory 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 1.4.22 and 1.4.23](#)) 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on identifying and monitoring respiratory disorders](#).

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

## 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, Public Health England](#) for further information).
- 1.4.27 Do not offer prophylactic antibiotics for lower respiratory tract infections in adults with cerebral palsy, unless:
- the person is at high risk of respiratory impairment (see [recommendation 1.4.23](#)) **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 lower respiratory tract 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on prophylactic treatments for respiratory infections](#).

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

## 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 with cerebral palsy 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 If a person with cerebral palsy is having non-invasive ventilation, discuss with them (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 agreed treatment goals are not met by non-invasive ventilation, consider alternative treatment options, such as tracheostomy or [supportive care](#), and discuss them with the person with cerebral palsy, taking into account their 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 recommendations on continuous positive airway pressure in [sections 1.5 and 1.6 of the NICE guideline on obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s](#) for when to offer assisted ventilation.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on discussing the management of respiratory failure, and assisted ventilation for respiratory failure and sleep apnoea](#).

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

## Saliva control

- 1.4.36 Xeomin (botulinum neurotoxin type A) is recommended as an option in NICE technology appraisal guidance for treating chronic sialorrhoea caused by neurological conditions in adults. For full details, see the [guidance on Xeomin \(TA605, 2019\)](#).

## Pain

- 1.4.37 Be aware that some adults with cerebral palsy have difficulty communicating or are unable to communicate that they are in pain.
- 1.4.38 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.

1.4.39 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 [communication in the NICE guideline on patient experience in adult NHS services](#).

1.4.40 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.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the [rationale and impact section on pain](#).

Full details of the evidence and the committee's discussion are in [evidence review E: identifying pain, such as musculoskeletal and gastrointestinal pain](#).

## 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.' See [Defining advance care planning for adults \(Sudore et al. 2017\)](#).

## **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 communication can be used as an alternative to speech or to supplement it.

## **Anthropometric measurements**

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

## **Comorbidities**

In the context of cerebral palsy, comorbidities are health problems caused by the brain disorder that also caused the motor impairment that is the core problem of cerebral palsy, but are not a direct complication of the motor disorder. For example, visual impairment and epilepsy are described as comorbidities because they are caused by the brain disorder. Hip dislocation and scoliosis are complications of the motor disorder and would not be described as comorbidities.

## **Electronic assistive technology**

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

## **Enteral drug treatment**

Drugs given by mouth (oral), or via a nasogastric 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

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.

The GMFCS is not validated for use in adults. However, the GMFCS level at age 12 has been shown to be a good predictor of mobility into adulthood, especially at the milder and most severe levels. It is used here in the absence of a validated system for use in adults because it is readily understood by people with cerebral palsy, their families and carers, and health professionals involved in the care of adults with cerebral palsy.

## Key communication partners

People who regularly interact with the person 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 or multidisciplinary team. 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 also allows the opportunity to address general health issues that affect people as they grow older.

## **Review of 24-hour 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, including postures to allow for participation in daily activities. 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 clinically and cost effective than ultrasound-guided injections or clinical positioning for localisation of injections in treating focal spasticity in adults with cerebral palsy?

For a short explanation of why the committee made the recommendation for research, see the [rationale on drug treatments for spasticity](#).

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

### 2 Selective dorsal rhizotomy treatment to reduce spasticity

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

For a short explanation of why the committee made the recommendation for research, see the [rationale on neurosurgical treatments to reduce spasticity](#).

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

### 3 Detection and management of respiratory disorders in primary

## and community care

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

For a short explanation of why the committee made the recommendation for research, see the [rationale on identifying and monitoring respiratory disorders](#).

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

## 4 Prophylactic antibiotics for respiratory disorders

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

For a short explanation of why the committee made the recommendation for research, see the [rationale on prophylactic treatments for respiratory infections](#).

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

## 5 Splinting to improve or maintain posture or function

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

For a short explanation of why the committee made the recommendation for research, see the [rationale on physical activity, orthopaedic surgery and orthotics](#).

Full details of the evidence and the committee's discussion are in [evidence review D2: interventions that improve or maintain physical function and participation](#).

## 6 Augmentative and alternative communication systems

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

For a short explanation of why the committee made the recommendation for research, see the [rationale on communication](#).

Full details of the evidence and the committee's discussion are in [evidence review D4: interventions to promote participation: communication](#).

# 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.

## Access to services and moving into adults' services

[Recommendations 1.1.1 to 1.1.11](#)

### Why the committee made the recommendations

#### 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 [United Nations \(UN\) 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 (for example, due to pain) 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 because of changing needs at different points in their lives, for example, changes in physical, environmental, or personal care or support needs. The committee highlighted this to raise awareness that people may need access to different services if their needs change.

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 examples of how these might be addressed are highlighted in the recommendations to help raise awareness among healthcare professionals. The committee agreed that healthcare professionals should recognise and address any barriers 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. In addition, some adults with cerebral palsy reported that their family members were expected to act as their carers when they were admitted to hospital. 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 that people with cerebral palsy experience barriers in access to national screening programmes, for example, lack of equipment for breast screening for women in wheelchairs, especially those with limited upper body strength, or lack of knowledge about how to perform cervical screening for women with lower limb spasticity. However, national screening services have an obligation to make arrangements so that screening is accessible to everyone. The committee agreed that increasing awareness about accessibility of these services and encouraging people to attend screening appointments would help to improve uptake of these services.

## **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 recommendations about access to services and service organisation.

## 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 variation in referrals.

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## Ongoing care

[Recommendations 1.1.12 to 1.1.18](#)

## 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 committee agreed that annual review is likely to prevent an emergency department visit for this group and so would be cost effective. The committee decided that the annual review should be carried out by a healthcare professional with expertise in neurodisabilities who would have the skills and experience needed to identify potential issues that could lead to an emergency department visit. It was noted that adults with learning disabilities should already be offered an annual health check in primary care.

As an example of complex needs, the Gross Motor Function Classification System (GMFCS) levels IV and V were used. The committee acknowledged that the GMFCS is not validated for use in adults. However, it has been shown that at age 12, a GMFCS level I strongly predicts that the person with cerebral palsy will retain good mobility into adult years and a GMFCS level V strongly predicts that the person will be a wheelchair user in adult life. Therefore, at the mild and severe ends of the spectrum of mobility in cerebral palsy, there is stability of GMFCS levels into adulthood. In the absence of an alternative descriptive system validated for use in adults, the GMFCS is used here because it is readily understood by people with cerebral palsy, their families and carers, and health professionals involved in the care of adults with cerebral palsy.

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 to 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

Adults with severe impairment are already likely to have more frequent contact with services. Therefore, providing an annual review for adults with severe impairment is likely to result in a minor change in practice and reduce variation. 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.

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## Communication

[Recommendations 1.2.1 to 1.2.6](#)

### 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 the members' experience, the committee 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.

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.

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.

The committee also noted that the recommendations support the fundamental rights of people with disabilities to freedom of expression and opinion, and access to information as set out in [Article 21 of the UN Convention on the rights of persons with disabilities](#).

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 [recommendation for research 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. However, the benefits of being able to communicate would outweigh the additional costs of increased use of augmentative and alternative communication systems.

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## Vocational skills and independent living

[Recommendations 1.2.7 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 highlighted that people with cerebral palsy should be asked what they enjoy doing. If they have problems in participating in their chosen activity, they 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. There will be a

cost associated with addressing external factors (such as access to buildings). However, this must be done to comply with government policy and legislation. Where they are not currently being implemented, some services may need additional investment in resources.

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## Electronic assistive technology

[Recommendations 1.2.13 to 1.2.17](#)

### 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 service specifications on environmental control equipment for patients with complex disability \(all ages\)](#).

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.

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## 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 walking](#)



[aids, wheelchairs and mobility 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 [recommendation for research 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.

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# 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. The committee 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 dependent 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:

- identifying and managing any factors that might be exacerbating a person's symptoms
- reviewing their physical management programme
- considering enteral (oral or via a feeding tube) drug treatment and referral if spasticity and dystonia are still inadequately managed
- considering more invasive treatment options.

## How the recommendations might affect practice

The recommendations reflect current good practice and will help to eliminate variation.

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# 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 drug treatment for generalised spasticity causing functional impairment, pain or spasms. The committee were unable to make a stronger recommendation because there was no comparative clinical evidence that baclofen was the most effective option.

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 under 19s 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. Based on their experience and knowledge, the committee decided that withdrawal symptoms are more likely if the person has been taking them for over 2 months or the prescribed dosage is high.

## 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 example, for equipment and training. Therefore, the committee developed a [recommendation for research 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 drug treatment to manage spasticity should not lead to a large increase in costs because enteral baclofen is relatively cheap and already widely used. 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.

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## Neurosurgical treatments to reduce spasticity

[Recommendations 1.3.12 to 1.3.18](#)

### 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 pump-related complications (for example, battery failure or catheter leakage), infections, and baclofen withdrawal or overdose. It is also more costly than other drug treatments. 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.

Because of the complexity of this procedure, adults with cerebral palsy need sufficient information to make an informed choice. The committee noted that this is not always consistently provided in current practice. A number of issues specifically related to this surgical procedure were highlighted by the committee as important to discuss when considering this treatment.

The response to intrathecal baclofen needs to be tested before a pump can be implanted. The committee agreed that it would be useful to highlight this. However, they noted that

testing is described in detail in the BNF. The committee agreed to include advice on assessing and discussing the test results to ensure that a pump is only implanted when the benefits are 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. They also took into account NICE's interventional procedures guidance on selective dorsal rhizotomy for spasticity in cerebral palsy, published in 2010, which recommends the involvement of a multidisciplinary team. Although they noted that the evidence for the interventional procedures guidance was in children, the committee agreed that selective dorsal rhizotomy should only be considered if other treatments have been unsuccessful or are contraindicated, and after multidisciplinary assessment in a specialist spasticity service. They noted that this is an infrequent procedure and therefore recommended that the team has specialist training and expertise in the care of spasticity.

The committee were aware that some young adults are being offered selective dorsal rhizotomy for tone management, sometimes as an alternative to replacing an intrathecal baclofen pump. In the absence of evidence for selective dorsal rhizotomy in this age group, the committee agreed that they could not make a recommendation specifically for young adults.

The committee agreed that, it is important that adults with cerebral palsy (and their family or carers, if agreed) are fully informed about the procedure, including the possibility of complications and that there is uncertainty about long-term benefits of treatment.

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.

The committee noted that the NICE guideline on spasticity in under 19s recommends the collection of national outcome data for all patients assessed for selective dorsal rhizotomy, which may also help to inform future guidance.

## 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.

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## Drug treatments for dystonia

[Recommendations 1.3.19 to 1.3.23](#)

### 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 sometimes be useful to identify the rare but treatable condition of dopa-responsive dystonia.

No evidence was identified for other enteral anti-dystonic drug treatments, so the committee agreed that they could not advise on their use. However, based on their experience of current practice, the committee acknowledged that there are options available that might be beneficial for some people and these could be considered by a specialist service. If enteral anti-dystonic drugs are then prescribed, they noted that severe symptoms, such as life-threatening seizures, are associated with rapid withdrawal of enteral anti-dystonic drugs, so the committee highlighted the importance of gradual

withdrawal of these treatments. Based on their experience and knowledge, the committee decided that withdrawal symptoms are more likely if the person with cerebral palsy has been taking them for over 2 months or the prescribed dosage is high.

### **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 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 noted 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.

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## **Neurosurgical treatments to reduce dystonia**

[Recommendations 1.3.24 and 1.3.25](#)

### **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 pump-related complications (for example, battery failure or catheter leakage), infections, and baclofen withdrawal or overdose. 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. They agreed that the recommendations on intrathecal baclofen testing for spasticity would also apply to dystonia.

## 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.

Two studies, identified as part of the economic evidence, suggested that deep brain stimulation improved quality of life. However, one showed that it was likely to be cost effective whereas the other suggested it was not. The committee agreed that the study showing cost effectiveness was more relevant because it better reflected current technology. It also had a longer follow-up and the results for quality of life matched the committee's expectations based on their clinical experience. However, it was noted that deep brain stimulation is only likely to be a treatment option when drug treatment is unsuccessful. This was more consistent with the patient group for the other study but current technology and appropriate quality of life at the outset was considered to be more important. 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 be considered when drug

treatment has been unsuccessful. However, because of the possible complications, it should only be an option 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.

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## 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, or abnormal movements leading to degenerative change, such as cervical myelopathy. 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, the committee 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 function.

### **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 osteoporosis.

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.

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## 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 and help to eliminate variation.

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## 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 checks and BMI or anthropometric measurement, and talking to the person and their families and carers about eating problems and other factors affecting nutrition 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 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 and help to eliminate variation.

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## 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 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 and managing respiratory disorders in adults with cerebral palsy would be helpful. They developed a [recommendation for research to determine the most effective methods of detecting and managing respiratory disorders in primary and community care.](#)

## 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.

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# Prophylactic treatments for respiratory infections

Recommendations 1.4.26 to 1.4.29

## Why the committee made the recommendations

No evidence was identified on preventing respiratory infections in adults with cerebral palsy. However, adults with cerebral palsy are at an increased risk of respiratory impairments and respiratory failure, so the committee agreed that adults with cerebral palsy and their family and carers should receive vaccinations, such as the flu vaccination, as a prophylactic measure to prevent respiratory infections.

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 with expertise in neurodisability management. For example, this might be in people with recurrent chest infections and bacterial colonisation identified on sputum culture. The aim for these people 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 [recommendation for research to determine the role of prophylactic antibiotics in improving quality of life and preventing hospital stays in people with or without persistent bacterial airway colonisation](#).

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 also 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.

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

[Recommendations 1.4.30 to 1.4.35](#)

### 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 the person's 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 to 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 such as 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 recommendations on continuous positive airway pressure in [sections 1.5 and 1.6 of the NICE guideline on obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s](#) for when to offer assisted ventilation.

## How the recommendations might affect practice

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

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## Pain

[Recommendations 1.4.37 to 1.4.40](#)

### Why the committee made the recommendations

The committee acknowledged 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 numerical, visual analogue and faces pain scales had similarly good reliability and validity for assessing pain in adults with cerebral palsy. 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 acknowledged that families and carers have valuable insight into identifying whether a person is in pain, and this is especially important if the person has communication difficulties. For adults with cerebral palsy who have difficulty communicating, the committee agreed that observational and descriptive pain scales would be appropriate and useful. The committee agreed that in practice, the method of pain assessment chosen would depend on the person's individual needs and circumstances, in particular, their ability to communicate.

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.

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## 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.

Adults with cerebral palsy and associated comorbidities may have difficulties with all

aspects of health and daily living. However, this guideline has not been able to look at the evidence and develop recommendations for all areas of care. Areas that are not covered include bowel and bladder continence, sexual health and dental health. The principles of access to services, providing information and appropriate referral, discussed in the guideline, apply not only to areas directly addressed but also equally to other areas of care.

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 United Nations (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 committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic pages on cerebral palsy and spasticity](#).

For full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

# Update information

## Minor changes since publication

**September 2024:** We added links to relevant technology appraisal guidance in the [section on saliva control](#).

**May 2022:** We added a link to NICE's guideline on medicines associated with dependence or withdrawal symptoms in section 1.3.10.

**October 2021:** We added a link to NICE's guideline on shared decision making in recommendation 1.3.1.

**August 2021:** Cross reference to NICE's guideline on obstructive sleep apnoea/hypopnoea syndrome and obesity hypoventilation syndrome in over 16s added to recommendation 1.4.35 and the related rationale.

**June 2020:** Cross reference to NICE's guideline on supporting adult carers added to recommendation 1.1.5.

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