

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Cerebral palsy in adults

The Department of Health in England has asked NICE to develop a new guideline on cerebral palsy in adults.

Different parts of this guideline will cover different age ranges (see also [section 3.1](#)):

- Recommendations about movement disorders will cover adults aged 19 and over with cerebral palsy (NICE has published a guideline on [spasticity in under 19s](#))
- Recommendations about other key issues in the scope will cover adults aged 25 and over with cerebral palsy (NICE has published a guideline on [cerebral palsy in under 25s](#)).

The guideline will be developed using the methods and processes outlined in [Developing NICE guidelines: the manual](#).

1 Why the guideline is needed

Cerebral palsy is the term used to describe permanent disorders of movement and posture caused by a non-progressive pathology that has affected the developing fetal or neonatal brain.

Cerebral palsy is often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, and by epilepsy and musculoskeletal problems. The recognition and management of these associated disorders is important in the management of cerebral palsy.

Abnormal movements, development of contractures and deformities, fatigue, pain and a variety of significant complications and comorbidities have an impact on health-related quality of life for people with cerebral palsy. Studies

with adults describe low energy levels, low functional ability, and loss of dexterity, strength and balance. Mobility and independence skills can deteriorate, with an impact on self-esteem, ability to concentrate and mental health.

Key facts and figures

- Cerebral palsy registers show a prevalence of 2.0 to 3.5 per 1000 live births in developed countries.
- Life expectancy for a person with cerebral palsy is similar to that of the general population, unless the person cannot change their position, is unable to eat and drink by mouth or has severe learning disabilities.
- Practical, financial and emotional support is vital for continued wellbeing for people with cerebral palsy.
- Strains placed on the body by living with cerebral palsy can lead to premature ageing, pain, fatigue and weakness – ‘post-impairment syndrome’ – as well as mental health problems.
- Difficulties in communication, feeding and continence can also occur, but can be overlooked.

Current practice

- There is wide variation in the recognition and management of the complications and comorbidities of cerebral palsy that affect both quality of life and life expectancy.
- Clinical and social problems associated with cerebral palsy in adulthood are varied. They depend on the severity of the underlying movement disorder, whether a learning disability is present, and the rates of complications such as feeding problems, gastrointestinal and respiratory disorders and communication skills.
- Life expectancy is increasing for adults with cerebral palsy who have substantial health and social care needs. This leads to challenges for health and social services to maintain people’s health and wellbeing and support their participation and integration in society.

- Treatments available for the movement disorder and for several complications and comorbidities associated with cerebral palsy have changed markedly over the last few decades.

Policy, legislation, regulation and commissioning

There is currently wide variation across the UK in commissioning and provision of specific services for adults with cerebral palsy. A number of legislative acts refer directly to standards of care and participation as well as social care, including the Disability Discrimination Act, the Equality Act and the Care Act. The aim of this guideline is to facilitate local and regional services to provide consistent clear pathways of clinical and social care for adults with cerebral palsy.

2 Who the guideline is for

People using services, their families and carers, and the public will be able to use the guideline to find out more about what NICE recommends, and help them make decisions.

This guideline is for:

- Professionals involved in assessing and managing cerebral palsy in adults. These may include the following professionals from primary and secondary care: GPs, orthopaedic surgeons, neurosurgeons, other doctors, nurses, and allied healthcare professionals such as physiotherapists, occupational therapists and speech and language therapists.
- Professionals in other health and non-health sectors who have direct contact with, or are involved in providing health or other services for, adults with cerebral palsy. These may include professionals who work in non-governmental organisations, the education sector or the voluntary sector.
- People responsible for planning services for adults with cerebral palsy and their families and carers, including directors of public health, NHS trust managers and managers in clinical commissioning groups.
- Adults with cerebral palsy and their families and carers.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to for example:

- people who are socially disadvantaged,
- people with different levels of functional ability (for example, differences in gross motor function)
- people with different levels of cognitive ability (for example, presence of learning disabilities)
- people living in residential care who no longer have family members able to act as their advocates
- people who have difficulties with reading, understanding or speaking English.

3 What the guideline will cover

3.1 *Who is the focus?*

Groups that will be covered

- Adults aged 25 and over with cerebral palsy (NICE has published a guideline on [cerebral palsy in under 25s](#)).
- Adults aged 19 and over with cerebral palsy, in relation only to the management of spasticity and associated movement disorders such as dystonia (NICE has published a guideline on [spasticity in under 19s](#)).

Subgroups

Specific consideration will be given to recognised subgroups within the cerebral palsy population:

- subgroups with different levels of functional disability (for example, Gross Motor Functional Classification System levels I to V)

Groups that will not be covered

- Children and young people under 25 with cerebral palsy, except for people aged 19 and over in relation to spasticity and associated movement disorders.
- Adults with a progressive movement disorder, spasticity or dystonia that is not associated with cerebral palsy.

3.2 Settings

Settings that will be covered

- All settings in which NHS and social care is provided.

3.3 Activities, services or aspects of care

Key areas that will be covered

We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all the areas.

- 1 Management of abnormal muscle tone in adults aged 19 and over with cerebral palsy, including spasticity and associated movement disorders such as dystonia:
 - pharmacological management
 - neurosurgical management.
- 2 Assessing and monitoring the following complications and comorbidities associated with cerebral palsy in adults aged and 25 over:
 - disorders of bones and joints, including osteoarthritis, osteoporosis and musculoskeletal deformity (especially of the neck, hip and spine)
 - mental health problems

- feeding and nutritional problems.
- 3 Identifying and managing respiratory disorders associated with cerebral palsy in adults aged 25 and over, including assisted ventilation.
- 4 Interventions that improve function and participation for adults aged 25 and over with cerebral palsy:
 - physical therapy programmes (such as sporting activity, strengthening programmes or training, task-oriented upper limb training)
 - augmentative and alternative communication systems
 - electronic assistive technology
 - equipment to help with mobility (such as orthotics)
 - vocational and independent living skills training
- 5 Identifying pain, such as musculoskeletal and gastrointestinal pain, in adults aged 25 and over with cerebral palsy.
- 6 Configuration of services for adults aged 25 and over with cerebral palsy:
 - specialist services
 - access to primary and secondary care.

Areas that will not be covered

- 1 Managing pain
- 2 Managing mental health problems.

Related NICE guidance

Published

- [Cerebral palsy in under 25s: assessment and management](#). NICE guideline NG62 (2017)
- [Epilepsies: diagnosis and management](#). NICE guideline CG137 (2016)
- [Multimorbidity: clinical assessment and management](#). NICE guideline NG56 (2016)
- [Mental health problems in people with learning disabilities: prevention, assessment and management](#). NICE guideline NG54 (2016)
- [Transition from children's to adults' services for young people using health or social care services](#). NICE guideline NG43 (2016)

- [Transition from inpatient hospital settings to community or care home settings for adults with social care needs](#). NICE guideline NG27 (2015)
- [Older people with social care needs and multiple long-term conditions](#). NICE guideline NG22 (2015)
- [Home care: delivering personal care and practical support to older people living in their own homes](#). NICE guideline NG21 (2015)[Managing medicines in care homes](#). NICE guideline SC1 (2014)
- [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges](#) . NICE guideline NG11 (2015)
- [Pressure ulcers: prevention and management](#). NICE guideline CG179 (2014)
- [Osteoarthritis: care and management](#). NICE guideline CG177 (2014)
- [Neuropathic pain in adults: pharmacological management in non-specialist settings](#). NICE guideline CG173 (2013)
- [Urinary incontinence in neurological disease: assessment and management](#). NICE guideline CG148 (2012)
- [Osteoporosis: assessing the risk of fragility fracture](#). NICE guideline CG146 (2012)
- [Spasticity in under 19s: management](#). NICE guideline CG145 (2012)
- [Common mental health problems: identification and pathways to care](#). NICE guideline CG123 (2011)
- [Generalised anxiety disorder and panic disorder in adults: management](#). NICE guideline CG113 (2011)
- [Depression in adults with a chronic physical health problem: recognition and management](#). NICE guideline CG91 (2009)
- [Faecal incontinence in adults: management](#). NICE guideline CG49 (2007)
- [Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition](#). NICE guideline CG32 (2006)
- [Selective dorsal rhizotomy for spasticity in cerebral palsy](#). NICE interventional procedure guidance 373 (2010)
- [Functional electrical stimulation for drop foot of central neurological origin](#). NICE interventional procedure guidance 278 (2009)

- [Deep brain stimulation for tremor and dystonia \(excluding Parkinson's disease\)](#). NICE interventional procedure guidance 188 (2006)
- [Selective peripheral denervation for cervical dystonia](#). NICE interventional procedure guidance 80 (2004)

In development

- [Workplace health: support for employees with disabilities and long term conditions](#). NICE guideline. Publication expected April 2017.
- [End of life care for adults in the last year of life: service delivery](#). NICE guideline. Publication expected January 2018.
- [Social work interventions for adults with complex needs \(including adults with learning disabilities\) and mental health needs](#). NICE guideline. Publication date to be confirmed.

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to adults with cerebral palsy:

- [Medicines optimisation](#) (2015) NICE guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76

3.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out analyses as appropriate. The preferred unit of effectiveness will be the quality-adjusted life year (QALY), and we will usually consider the costs from an NHS and personal social services (PSS) perspective, but we may conduct further

analyses to consider wider social costs associated with the care of adults with cerebral palsy.

3.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

- 1 Management of abnormal muscle tone in adults aged 19 and over with cerebral palsy, including spasticity and associated movement disorders such as dystonia:
 - 1.1 Which pharmacological treatments for spasticity (for example, enteral baclofen, tizanidine, diazepam, cannabinoids, botulinum toxin injections) are most effective for improving motor function, participation and quality of life in adults with cerebral palsy?
 - 1.2 For which adults with cerebral palsy is implantation of an intrathecal baclofen pump more effective than other treatments for spasticity?
 - 1.3 Which pharmacological treatments (for example, levodopa, anticholinergic drugs, botulinum toxin injections) are most effective for managing dystonia associated with spasticity in adults with cerebral palsy?
- 2 Assessing and monitoring complications and comorbidities associated with cerebral palsy in adults aged 25 and over:
 - 2.1 What is the most effective protocol for monitoring the following disorders of bones and joints in adults with cerebral palsy:
 - osteoarthritis
 - osteoporosis (including osteopenia and osteomalacia)
 - hip displacement
 - spinal deformity, including scoliosis, kyphosis and lordosis
 - cervical instability leading to cervical myelopathy?
 - 2.2 Which mental health assessment tools are clinically useful for adults with cerebral palsy?
 - 2.3 What is the most effective protocol for monitoring feeding and nutritional problems in adults with cerebral palsy?

- 3 Identifying and managing respiratory disorders associated with cerebral palsy in adults aged 25 and over, including assisted ventilation:
 - 3.1 What is the most effective protocol for monitoring respiratory health in adults with cerebral palsy?
 - 3.2 Does assisted ventilation improve quality of life for adults with cerebral palsy who have a chronic respiratory disorder (including respiratory failure)?
 - 3.3 Are prophylactic treatments (for example, antibiotics, chest physiotherapy, cough assistance) effective in preventing respiratory infections in adults with cerebral palsy?
- 4 Interventions that improve function and participation for adults aged 25 and over with cerebral palsy:
 - 4.1 Which interventions (for example, vocational and independent living skills training) promote participation in adults with cerebral palsy?
 - 4.2 Which interventions are effective for maintaining physical function in adults with cerebral palsy, for example:
 - sporting activity
 - strengthening programmes or training
 - orthotics
 - task-oriented upper limb training
 - orthopaedic surgery (including tendon lengthening and orthopaedic bony procedures in adulthood)?
 - 4.3 What is the role of electronic assistive technology in promoting independence in adults with cerebral palsy?
 - 4.4 Which interventions (for example augmentative and alternative communication systems) are effective in promoting communication for adults with cerebral palsy who have communication difficulties?
- 5 Identifying pain, such as musculoskeletal and gastrointestinal pain, in adults aged 25 and over with cerebral palsy.
 - 5.1 What is the most effective sequence of tests to identify causes of pain in an adult with cerebral palsy?
- 6 Configuration of services for adults aged 25 and over with cerebral palsy.

6.1 What are the necessary components of specialist services in the network of care and support for adults with cerebral palsy?

6.2 What are the barriers to access to primary and secondary care for adults with cerebral palsy?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

3.6 *Main outcomes*

The main outcomes that will be considered when searching for and assessing the evidence are:

- quality of life (both health- and social-related quality)
- functional independence (ability to carry out activities of daily living)
- pain
- psychological wellbeing
- participation
- frequency of falls
- hospital admission.

4 NICE quality standards and NICE Pathways

4.1 *NICE quality standards*

NICE quality standards that may need to be revised or updated when this guideline is published

- Cerebral palsy in children and young people. NICE quality standard. Publication expected October 2017.

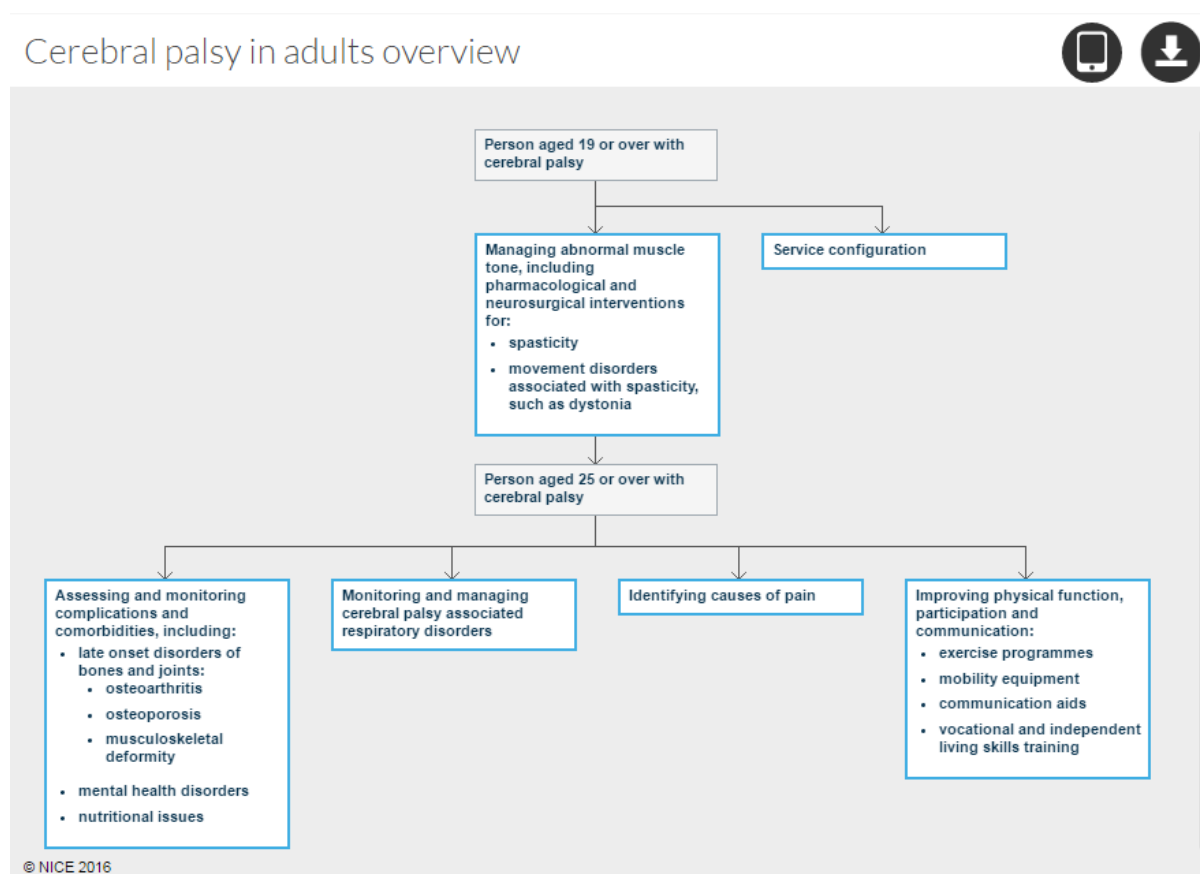
4.2 *NICE Pathways*

[NICE Pathways](#) bring together all NICE recommendations on a topic in an interactive flowchart.

When this guideline is published, the recommendations will be included in the NICE Pathway on cerebral palsy in under 25s. The revised pathway will be

renamed 'Cerebral palsy' to reflect the inclusion of recommendations for adults. Links to other relevant guidance will also be included as appropriate.

A pathway outline based on this scope only, showing the part of the pathway that will cover care for adults with cerebral palsy, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.



5 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in January 2019.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.