

# 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 over 25 with cerebral palsy (NICE is developing a guideline on cerebral palsy on under 25s; publication expected January 2017).

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 static pathology that has affected the foetal or infant 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 are important in the management of cerebral palsy.

Abnormal movements, development of contractures and deformities, fatigue 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

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

#### 4 **Key facts and figures**

- 5 • Cerebral palsy registers show a prevalence of 2.0 to 3.5 per 1000 live  
6 births in developed countries.
- 7 • Life expectancy for a person with cerebral palsy is similar to the general  
8 population unless the person has no ability to change their position, are  
9 unable to feed by mouth, and have severe learning disabilities.
- 10 • Practical, financial and emotional support is vital for continued wellbeing for  
11 people with cerebral palsy.
- 12 • Strains placed on the body by living with cerebral palsy can lead to  
13 premature ageing, pain, fatigue and weakness – ‘post-impairment  
14 syndrome’ – as well as mental health problems.
- 15 • Difficulties in communication, feeding and continence can also be  
16 overlooked.

#### 17 **Current practice**

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

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

#### 4 **Policy, legislation, regulation and commissioning**

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

## 11 **2 Who the guideline is for**

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

15 This guideline is for:

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

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

#### 4 ***Equality considerations***

5 NICE has carried out [an equality impact assessment](#) [add hyperlink in final  
6 [version](#)] during scoping. The assessment:

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

9 The guideline will look at inequalities relating to people who are socially  
10 disadvantaged, people with different levels of functional ability (for example,  
11 differences in gross motor function) or cognitive ability (for example, presence  
12 of learning disabilities) and people who have difficulties with reading,  
13 understanding or speaking English.

### 14 **3 What the guideline will cover**

#### 15 **3.1 Who is the focus?**

##### 16 **Groups that will be covered**

- 17 • Adults aged 25 and over with cerebral palsy, in line with [Cerebral palsy in](#)  
18 [under 25s](#). CGXX.
- 19 • Adults aged 19 and over with cerebral palsy regarding the management of  
20 spasticity and associated movement disorders, such as dystonia, in line  
21 with [Spasticity in under 19s: management](#). NICE guideline CG145 (2012).

##### 22 **Subgroups**

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

- 25 • subgroups within the cerebral palsy population, dependent on level of  
26 functional disability (for example, Gross Motor Functional Classification  
27 System I–V)

- 1 • subgroups of adults with spasticity and associated movement disorders,  
2 such as dystonia.

### 3 **Groups that will not be covered**

- 4 • Children and young adults under 25 except for adults over 19 in relation to  
5 their movement disorder  
6 • Adults with a progressive movement disorder, spasticity and dystonia not  
7 associated with cerebral palsy.

## 8 **3.2 Settings**

### 9 **Settings that will be covered**

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

## 11 **3.3 Activities, services or aspects of care**

### 12 **Key areas that will be covered**

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

- 15 1 Management of abnormal muscle tone in adults over 19 with cerebral  
16 palsy, including spasticity and any coexisting movement disorders such  
17 as dystonia:  
18 – pharmacological management  
19 – neurosurgical management.
- 20 2 Assessing and monitoring complications and comorbidities associated  
21 with cerebral palsy in adults over 25, prioritised as:  
22 – disorders of bones and joints, including osteoarthritis, osteoporosis  
23 and musculoskeletal deformity (especially of the neck, hip and spine)  
24 – mental health problems  
25 – nutritional complications.
- 26 3 Identifying and managing respiratory disorders associated with cerebral  
27 palsy in adults over 25, including assisted ventilation

- 1 4 Interventions that improve function and participation for adults over 25  
2 with cerebral palsy:
- 3 – exercise programmes
  - 4 – augmentative and alternative communication systems
  - 5 – equipment to help with mobility
  - 6 – vocational and independent living skills training
- 7 5 Identifying pain, such as musculoskeletal and gastrointestinal pain, in  
8 adults over 25 with cerebral palsy
- 9 6 Configuration of services for adults over 25 with cerebral palsy:
- 10 – specialist services
  - 11 – access to primary and secondary care.

## 12 **Areas that will not be covered**

- 13 1 Managing pain
- 14 2 Managing mental health problems.

## 15 **Related NICE guidance**

### 16 ***Published***

- 17 • [Epilepsies: diagnosis and management](#). NICE guideline CG137 (2016)
- 18 • [Multimorbidity: clinical assessment and management](#). NICE guideline  
19 NG56 (2016)
- 20 • [Mental health problems in people with learning disabilities: prevention,  
21 assessment and management](#). NICE guideline NG54 (2016)
- 22 • [Transition from children's to adults' services for young people using health  
23 or social care services](#). NICE guideline NG43 (2016)
- 24 • [Older people with social care needs and multiple long-term conditions](#).  
25 NICE guideline NG22 (2015)
- 26 • [Home care: delivering personal care and practical support to older people  
27 living in their own homes](#). NICE guideline NG21 (2015)
- 28 • [Challenging behaviour and learning disabilities: prevention and  
29 interventions for people with learning disabilities whose behaviour  
30 challenges](#) . NICE guideline NG11 (2015)

- 1 • [Pressure ulcers: prevention and management](#). NICE guideline CG179
- 2 (2014)
- 3 • [Osteoarthritis: care and management](#). NICE guideline CG177 (2014)
- 4 • [Neuropathic pain in adults: pharmacological management in non-specialist](#)
- 5 [settings](#). NICE guideline CG173 (2013)
- 6 • [Urinary incontinence in neurological disease: assessment and](#)
- 7 [management](#). NICE guideline CG148 (2012)
- 8 • [Osteoporosis: assessing the risk of fragility fracture](#). NICE guideline CG146
- 9 (2012)
- 10 • [Spasticity in under 19s: management](#). NICE guideline CG145 (2012)
- 11 • [Common mental health problems: identification and pathways to care](#).
- 12 NICE guideline CG123 (2011)
- 13 • [Generalised anxiety disorder and panic disorder in adults: management](#).
- 14 NICE guideline CG113 (2011)
- 15 • [Depression in adults with a chronic physical health problem: recognition](#)
- 16 [and management](#). NICE guideline CG91 (2009)
- 17 • [Faecal incontinence in adults: management](#). NICE guideline CG49 (2007)
- 18 • [Nutrition support for adults: oral nutrition support, enteral tube feeding and](#)
- 19 [parenteral nutrition](#). NICE guideline CG32 (2006)
- 20 • [Selective dorsal rhizotomy for spasticity in cerebral palsy](#). NICE
- 21 interventional procedure guidance IPG373 (2010)
- 22 • [Functional electrical stimulation for drop foot of central neurological origin](#).
- 23 NICE interventional procedure guidance IPG278 (2009)
- 24 • [Deep brain stimulation for tremor and dystonia \(excluding Parkinson's](#)
- 25 [disease\)](#). NICE interventional procedure guidance IPG188 (2006)
- 26 • [Selective peripheral denervation for cervical dystonia](#). NICE interventional
- 27 procedure guidance IPG80 (2004)

## 28 ***In development***

- 29 • [Cerebral palsy in under 25s](#). NICE guideline. Publication expected January
- 30 2017.
- 31 • [Workplace health: support for employees with disabilities and long term](#)
- 32 [conditions](#). NICE public health guideline. Publication expected April 2017.

- 1 • [End of life care for adults in the last year of life: service delivery](#). NICE  
2 guideline. Publication expected January 2018.
- 3 • [Social work interventions for adults with complex needs \(including adults  
4 with learning disabilities\) and mental health needs](#). NICE guideline.  
5 Publication date to be confirmed.

## 6 **NICE guidance about the experience of people using NHS services**

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

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

### 15 **3.4 Economic aspects**

16 We will take economic aspects into account when making recommendations.  
17 We will develop an economic plan that states for each review question (or key  
18 area in the scope) whether economic considerations are relevant, and if so  
19 whether this is an area that should be prioritised for economic modelling and  
20 analysis. A review of the economic evidence will be conducted and analyses  
21 will be carried out as appropriate. The preferred unit of effectiveness is the  
22 quality-adjusted life year (QALY), and the costs considered will usually be  
23 from an NHS and personal social services (PSS) perspective, but further  
24 analyses may be conducted to consider wider social costs associated with the  
25 care of adults with cerebral palsy.

### 26 **3.5 Key issues and questions**

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



1 1 Management of abnormal muscle tone in adults aged 19 and over with  
2 cerebral palsy, including spasticity and associated movement disorders  
3 such as dystonia:

4 1.1 Which pharmacological treatments for spasticity (for example,  
5 enteral baclofen, tizanidine, diazepam, cannabinoids, botulinum toxin  
6 injections) are most effective for improving motor function, participation  
7 and quality of life in adults with cerebral palsy?

8 1.2 For which adults with cerebral palsy is implantation of an intrathecal  
9 baclofen pump more effective than other treatments for spasticity?

10 1.3 Which pharmacological treatments (for example, levodopa,  
11 anticholinergic drugs, botulinum toxin injections) are most effective for  
12 managing dystonia associated with spasticity in adults with cerebral  
13 palsy?

14 2 Assessing and monitoring for complications and comorbidities  
15 associated with cerebral palsy in adults over 25:

16 2.1 What is the most effective protocol for monitoring for the following  
17 disorders of bones and joints in adults with cerebral palsy?

- 18 – osteoarthritis
- 19 – osteoporosis (including osteopenia and osteomalacia)
- 20 – hip displacement
- 21 – spinal deformity, including scoliosis, kyphosis and lordosis
- 22 – cervical instability.

23 2.2 Which mental health assessment tools are clinically useful for adults  
24 with cerebral palsy?

25 2.3 What is the most effective protocol for monitoring for nutritional  
26 complications in adults with cerebral palsy?

27 3 Identifying and managing respiratory disorders associated with cerebral  
28 palsy in adults over 25, including assisted ventilation:

29 3.1 What is the most effective protocol for monitoring for respiratory  
30 health in adults with cerebral palsy?

31 3.2 Does assisted ventilation improve quality of life in adults with  
32 cerebral palsy who have a chronic respiratory disorder (including  
33 respiratory failure)?

- 1 3.3 Are prophylactic treatments (for example, antibiotics, chest  
2 physiotherapy, cough assistance) effective in preventing respiratory  
3 infections in adults with cerebral palsy?
- 4 4 Interventions that improve function and participation for adults over 25  
5 with cerebral palsy:
- 6 4.1 Which interventions (for example, vocational and independent living  
7 skills training) promote participation in adults with cerebral palsy?
- 8 4.2 Which interventions are effective for maintaining physical function in  
9 adults with cerebral palsy, for example:
- 10 – sporting activity  
11 – strengthening programmes or training  
12 – orthotics  
13 – Task-oriented upper limb training  
14 – orthopaedic surgery (including tendon lengthening and orthopaedic  
15 bony procedures in adulthood)?
- 16 4.3 What is the role of electronic assistive technology in promoting  
17 independence in adults with cerebral palsy?
- 18 4.4 Which interventions (for example augmentative and alternative  
19 communication systems) are effective in promoting effective  
20 communication for adults with cerebral palsy who have communication  
21 difficulties?
- 22 5 Identifying pain, such as musculoskeletal and gastrointestinal pain, in  
23 adults over 25 with cerebral palsy.
- 24 5.1 What is the most effective sequence of tests to identify causes of  
25 pain in an adult with cerebral palsy?
- 26 6 Configuration of services for adults over 25 with cerebral palsy
- 27 6.1 What are the necessary components (for example, an adult cerebral  
28 palsy multidisciplinary team [MDT], requisite skills for doctors with an  
29 interest in cerebral palsy in adults) in the network of care and support for  
30 adults with cerebral palsy?
- 31 6.2 What are the barriers to access to primary and secondary care for  
32 adults with cerebral palsy?
- 33

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

### 3 **3.6 Main outcomes**

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

- 6 • quality of life (both health- and social-related quality)
- 7 • functional independence (ability to carry out activities of daily living)
- 8 • pain
- 9 • psychological wellbeing
- 10 • participation
- 11 • frequency of falls
- 12 • hospital admission.

## 13 **4 NICE quality standards and NICE Pathways**

### 14 **4.1 NICE Pathways**

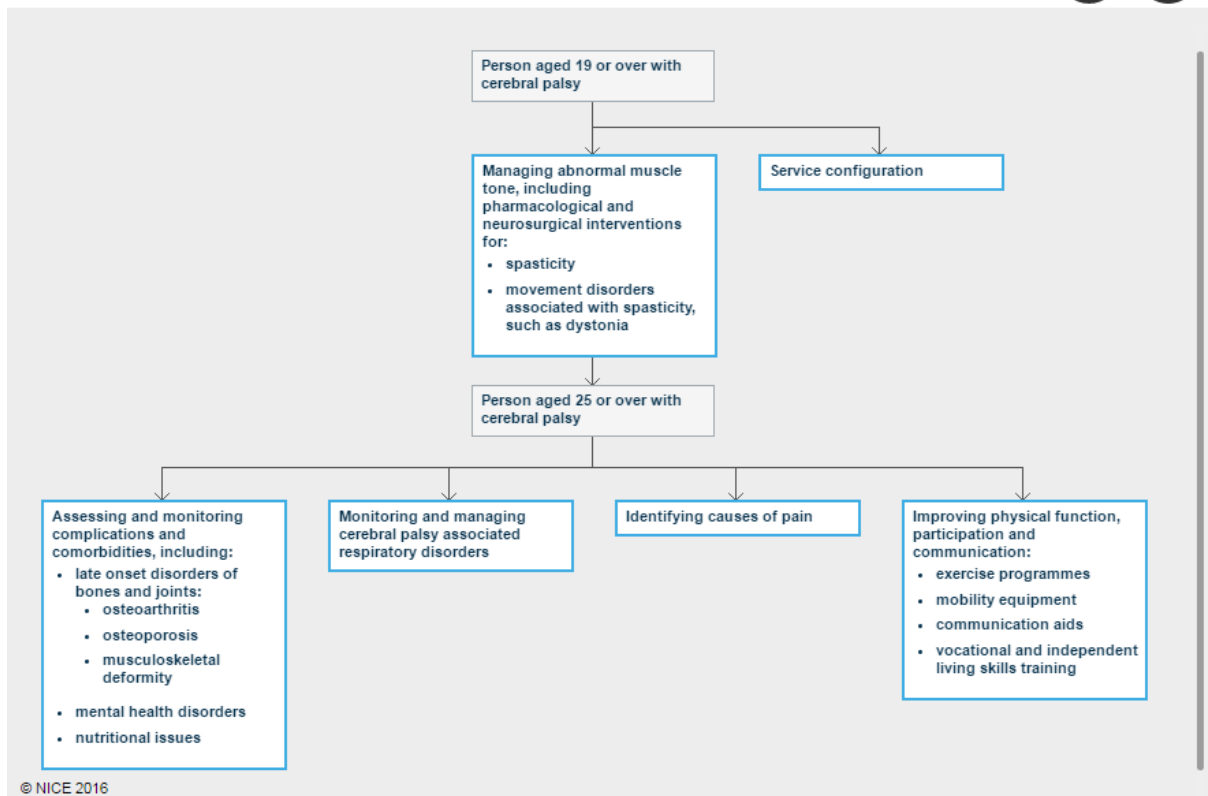
15 [NICE Pathways](#) bring together all NICE recommendations on a topic in an  
16 interactive flowchart.

17 When this guideline is published, the recommendations will be included in a  
18 pathway on cerebral palsy. This pathway will also include recommendations  
19 from the guideline on cerebral palsy in children and young people (publication  
20 expected January 2017). Links to other relevant guidance will also be included  
21 as appropriate.

22  
23 A pathway outline based on this scope only, showing the part of the pathway  
24 that will cover care for adults with cerebral palsy, is included below. It will be  
25 adapted and more detail added as the recommendations are written during  
26 guideline development.

27

## Cerebral palsy in adults overview

1  
23 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 29 November 2016 to 5 January 2017.

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.

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