

## Cerebral palsy overview

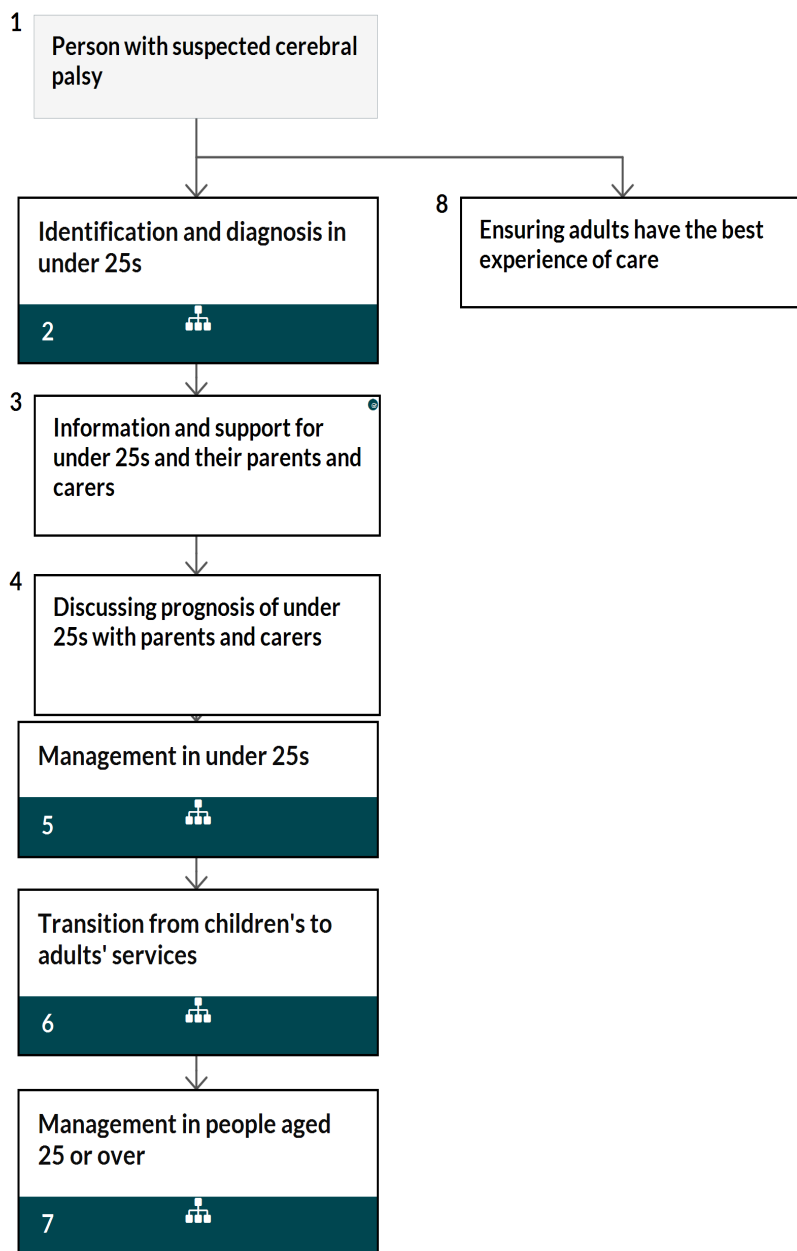
NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

<http://pathways.nice.org.uk/pathways/cerebral-palsy>

NICE Pathway last updated: 30 January 2020

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



## 1 Person with suspected cerebral palsy

No additional information

## 2 Identification and diagnosis in under 25s

See Cerebral palsy / Identifying and diagnosing cerebral palsy in under 25s

## 3 Information and support for under 25s and their parents and carers

Ensure that information and support focuses as much on the functional abilities of the child or young person with cerebral palsy as on any functional impairment.

Provide clear, timely and up-to-date information to parents or carers on the following topics:

- diagnosis (see [diagnosis](#))
- aetiology (see [assessing causes](#))
- prognosis (see [prognosis](#))
- expected developmental progress
- comorbidities (see [managing cerebral palsy in under 25s](#))
- availability of specialist equipment
- resources available and access to financial, respite, social care and other support for children and young people and their parents, carers and siblings (see also [recognising and addressing social care needs](#)).
- educational placement (including specialist preschool and early years settings)
- transition (see [transition from children to adult services](#)).

Ensure that clear information about the 'patient pathway' is shared with the child or young person and their parent or carers (for example, by providing them with copies of correspondence). Follow the principles in the recommendations in [enabling patients to actively participate in their care](#), in patient experience.

Provide information to the child or young person, and their parents or carers, on an ongoing basis. Adapt the communication methods and information resources to take account of the needs and understanding of the child or young person and their parents or carers. For example, think about using 1 or more of the following:

- oral explanations
- written information and leaflets
- mobile technology, including apps
- augmentative and alternative communication systems (see [speech, language and communication](#)).

Work with the child or young person and their parents and carers to develop and maintain a personal 'folder' in their preferred format (electronic or otherwise) containing relevant information that can be shared with their extended family and friends and used in health, social care, educational and transition settings. Information could include:

- early history
- motor subtype and limb involvement
- functional abilities
- interventions
- medication
- comorbidities
- preferred methods of communication
- any specialist equipment that is used or needed
- care plans
- emergency contact details.

Ensure that the child or young person and their parents or carers are provided with information, by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs:

- menstruation
- fertility
- contraception
- sex and sexuality
- parenting.

Provide information to the child or young person and their parents and carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) for children and young people with cerebral palsy, and how to access them.

Provide information about local support and advocacy groups to the child or young person and

their parents or carers.

NICE has written information for the public explaining its guidance on [cerebral palsy](#).

## Quality standards

The following quality statements are relevant to this part of the interactive flowchart.

### Cerebral palsy in children and young people

3. Information for parents and carers of children and young people with cerebral palsy
4. Personal folders for children and young people with cerebral palsy

## 4 Discussing prognosis of under 25s with parents and carers

### Walking and talking

Provide the following information to parents and carers about the prognosis for walking for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the possibility of difficulties with walking.
- If a child can sit at 2 years of age it is likely, but not certain, that they will be able to walk unaided by age 6.
- If a child cannot sit but can roll at 2 years of age, there is a possibility that they may be able to walk unaided by age 6.
- If a child cannot sit or roll at 2 years of age, they are unlikely to be able to walk unaided.

Recognise the following in relation to prognosis for speech development in a child with cerebral palsy, and discuss this with parents and carers as appropriate:

- Around 1 in 2 children with cerebral palsy have some difficulty with elements of communication (see [speech language and communication](#)).
- Around 1 in 3 children have difficulties with speech and language.
- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of difficulties with speech and language.
- Uncontrolled epilepsy may be associated with difficulties with all forms of communication, including speech.
- A child with bilateral spastic, dyskinetic or ataxic cerebral palsy is more likely to have

- difficulties with speech than a child with unilateral spastic cerebral palsy.

### Life expectancy

Provide the following information to parents and carers, as appropriate, about prognosis for life expectancy for a child with cerebral palsy:

- The more severe the child's physical, functional or cognitive impairment, the greater the likelihood of reduced life expectancy.
- There is an association between reduced life expectancy and the need for enteral tube feeding, but this reflects the severity of swallowing difficulties and is not because of the intervention.

### Use of MRI to determine prognosis

Do not rely on MRI alone for predicting prognosis in children with cerebral palsy.

Take account of the likely cause of cerebral palsy and the findings from MRI (if performed) when discussing prognosis with the child or young person and their parents or carers.

## 5 Management in under 25s

[See Cerebral palsy / Managing cerebral palsy in under 25s](#)

## 6 Transition from children's to adults' services

[See Cerebral palsy / Transition from children's to adults' services for young people with cerebral palsy](#)

## 7 Management in people aged 25 or over

[See Cerebral palsy / Managing cerebral palsy in people aged 25 or over](#)

## 8 Experience of care

Use these recommendations with NICE's recommendations on:

- [patient experience in adult NHS services](#)

- people's experience in adult social care services
- service user experience in adult mental health services.

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## 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.

## Glossary

### Anthropometric measurements

(body measurements that include weight, height, knee height, mid-upper arm circumference, waist circumference, head circumference and skinfold thickness measurements)

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### Child

(a person aged 11 years or younger)

### Supportive care

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

### Children

(people aged 11 years or younger)

### Transferring

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



**Walk unaided**

(the ability to walk independently in the community without the need for supportive devices such as a walking frame, tripod sticks or crutches)

**DXA**

(dual-energy X-ray absorptiometry)

**Young person**

(a person aged between 12 and 24 years of age)

**Young people**

(people aged between 12 and 24 years of age)

**Sources**

[Cerebral palsy in under 25s: assessment and management](#) (2017) NICE guideline NG62

**Your responsibility****Guidelines**

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

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to

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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.

### **Technology appraisals**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so 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.

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.

### **Medical technologies guidance, diagnostics guidance and interventional procedures guidance**

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with

the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance 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.